

Chapter 2

Families of Adults with Autism Spectrum Disorders

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Overview and Introduction: Roles and Responsibilities of Parents

The roles and responsibilities of parents of children with autism shift as their children age and move from early childhood through the various developmental stages of life (Marcus, Kuncze, & Schopler, 2005). Although there are a variety of factors that influence the amount and type of involvement (e.g., the child's level of functioning, adaptive skills, stage of adulthood, degree of independence, availability of services), there are common threads across these and other factors.

Parents have commented on how they have to become more of a *supportive parent* and less of a *smothering parent* (*their own words*). By smothering, they are reflecting on a natural tendency to make decisions for their child, do for them what the child might be able to do for himself, and unintentionally impede the growth towards independence. Parents of adults realize that their role has to be a guide and facilitator, to help their adult child to self-advocate as much as possible. Parents are well aware of their diminishing strength and energy and the ability to be “on-call” 24/7 as well as the realization that others are inevitably going to have to assume supervisory or other supportive roles in the future. Helping the adult son or daughter learn to make decisions and choices, no matter how small, to effectively communicate his or her needs, and show good judgment becomes the focus for parents.

While following the path of increased independence, the adult with autism continues to need the parent as an advocate, a role most parents have had to play from the early years since diagnosis. The arena in which advocacy is required differs from the preadult years where the main advocacy takes place in the schools where services are mandated and the rules are clear. For parents who have been effective

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advocates in the schools and have spent years working with other parents to either develop programs or improve services for their child and others, the transition to advocacy for adults should be seamless. However, without entitlement the task is more challenging. Parents can no longer rely on the public education law of Individuals with Disabilities Education Act (IDEA) and usually the parent support groups they have been a part of have dissipated or their peer group dispersed, so they often may feel that they are back to “square one.” In addition, the complexities of the mental health, social security, vocational rehabilitation, and other agencies can be overwhelming. The uncertainty of public funds coupled with the bureaucratic challenges of the multiple systems can lead to discouragement and a kind of paralysis. At a time that most parents of typical adults can move on in their lives without worrying about their child, parents of adults with autism are essentially starting over and readjusting and shaping their advocacy skills to deal with new challenges.

Although parents of children with autism are encouraged to think about the future, more often than not serious planning gets postponed until their child becomes an adult. Issues such as estate planning (with special needs trusts), guardianship, and wills now have to be addressed. Even higher functioning adults who may appear to need less support require similar consideration with regard to long-term planning. Partial guardianship or other strategies for these individuals, especially concerning financial oversight, require careful decision-making by the parents.

Parents, unfortunately, often assume the role of “social outlet” or “social planner” for their adult child with autism who lacks natural peers and the desire to leave the house. Parents worry about their adult child not participating in social or recreational activities, so are forced to seek out appropriate community experiences, find a “peer buddy” or provide entertainment at home.

In the end, parents often have no choice but to accept these multiple roles at an age and time of life when they are entitled to taking care of themselves.

This chapter will review the many roles parents of adults play in their offspring’s life, the concerns they have for their child’s future, and the impact and stress these responsibilities cause for both parents and siblings. While intervention programs for families of adults with autism are rare, we will describe the model of services for families of adults provided by the TEACCH autism program in North Carolina.

Historical Context

The history of families of adults with autism somewhat parallels the history of families of children with autism in that the understanding of the nature and causes of autism has changed dramatically over approximately the last 50 years. Although it is now widely accepted that parents of children with autism should be supported and considered part of a treatment planning team, as recently as 40 years ago parents were viewed as part of their child’s problems (Schopler, 1971). Parents were largely blamed for the idiosyncratic and difficult behaviors seen in their children, whose

condition was considered an emotional disturbance, not the biologically based disorder that research and practice have shown today. As difficult as it was for parents to raise and cope with these challenging children, dealing with the added burden of blame and guilt was grossly unfair and harmful. Parents who were able to survive through sheer determination, courage, and single-mindedness of purpose still were scarred by their negative experiences with professionals. Others, who were unable to deal with a critical and markedly unhelpful professional community, gave up their struggle, placing their children in institutions. In some instances, parents were told early on to give their child up, partly because of the lack of available services and also because pediatricians and others failed to understand the parent perspective. Professionals today need to be aware of and appreciate what this earlier generation of parents went through and how the professionals of that era contributed to the stress of these parents. In the past decade, the rise in the diagnosis of forms of autism with fewer cognitive impairments, described as either high functioning autism (HFA) or Asperger's Syndrome, has coincided with identification of these cases in adulthood. Parents of these individuals have not had the benefit of an early diagnosis and support from the autism community and now are faced with the realization that their adult child with autism may require some degree of long-term support and services.

Focusing on the experience of families of adults, although the issue of causation of autism has been more or less resolved over the past 25 years, the interest and awareness of the needs of adults with autism has trailed behind those of children, especially young children. Compared to early childhood, relatively little has been written about autism in adulthood, beyond outcome studies (Howlin, Goode, Hutton, & Rutter, 2004), parental narratives (e.g., Park, 2001), and aspects of treatment and care (Howlin, 2004). More recently, autobiographies of high functioning persons with autism have become popular and have highlighted coping and adjustment problems in this subgroup (e.g., Tammet, 2006). What is known is that the problems of autism continue to some extent, that impairment in cognitive and social adaptation persists, and that the needs for long-range sheltered care and supervised employment pertain to the majority. The assistance that families require is consistent with that required during the preadult years, but the ability of most families to continue to take the initiative in procuring services can be compromised by their declining strength.

Historically, by adulthood most autistic individuals had been institutionalized; however, the recent efforts at deinstitutionalization is likely to all but eliminate that option, and the responsibility of the home and community to arrange for residential care and vocational opportunities has become more prevalent. Expertise in how to help adults with autism has been sorely lacking. Even where there are programs and services, the concern for parents and other family members is less than for families of young children. Ironically and sadly, many parents from earlier decades who struggled to be heard and advocated for services for their young children remain on the sidelines, while the newer generations of parents have seen the proliferation of programs for their children.

Concerns of Parents

Future planning. As soon as parents of a young child receive the diagnosis of an autism spectrum disorder (ASD), among the first questions they ask are “what will happen when my child becomes an adult?” “Will he/she be able to live independently?” “Go to college?” “Get a job?” “Will he/she get married?” Concerns for the future, with the parents throughout their child’s life, reemerge as their child goes through the developmental phases from childhood to adolescence and then again as they transition to becoming an adult.

As the child becomes an adolescent and then an adult, most parents of typically developing children find that their role changes from being the primary caretaker, educator, and financial supporter to having a more removed role in their child’s life. However, for parents of children with disabilities this change may not occur. In fact, for many families of adults with ASD, they may find that they are spending more time caring for children. In 1973, Kanner reported that the majority of 96 individuals who he first saw as children, and were now adults were highly dependent and living with their parents. More recent follow-up studies (Howlin et al., 2004) also show that parents in many instances continue to be the primary caregivers and/or main sources of support for their adult offspring. Mothers are more likely than fathers to be the caregiver with fathers helping with supervision rather than physical care or domestic tasks (Holmes & Carr, 1991). Limited support for caregivers coupled with limited opportunities for the family member with autism to socialize outside the family, be employed, or receive residential support adds to the burden of aging parents (Graetz, 2010).

Surveys of parents of adults indicate that their needs are quite varied (Eaves & Ho, 2008; Hare, Pratt, Burton, Bromley, & Emerson, 2004). The needs of parents of adults are generally comparable to those of parents caring for children with ASD (Bromley, Hare, Davison, & Emerson, 2004). The overriding concern for parents is about future planning including where they will live, where will they work or spend their days, and who will care for them when “I am no longer here.” As their children become young adults, parental dreams change from thinking about whether their child will go to college and get married to hoping that their child will have a happy and meaningful life. In addition to concerns about finding services and planning for the future, parents who are caring for their adults with ASD also need respite and breaks from the day-to-day responsibilities (Hare et al., 2004).

Guilt. When parents first get the diagnosis of autism or any other developmental disability, another frequent response of parents is that they feel guilt and worry that there is something they did or did not do that caused their child’s difficulty (Shea, 1993). It’s important to note that as their children grow up, this sense of guilt never totally disappears. In fact, at each new transition in development the parents once again have concerns that they are not doing everything they need to do to insure their child’s well-being and continued development (Morrell & Palmer, 2006; Van Bourgondien & Griffin, 2011). For parents of adults, the often heard message of the importance of early intervention and the often implied or sometimes directly stated

belief in a critical window for intervention during the preschool years can add to their sense of guilt and concern for their child's future. Many parents recognize that their adults with autism are in fact lifelong learners, yet the relatively limited information about adult issues and interventions adds to the parents of adult's sense of lack of support (Van Bourgondien & Griffin, 2011).

Guardianship. When adults with ASD reach 18 years of age, in the United States, parents no longer automatically have the legal right to make decisions for them regardless of the individual's level of intelligence or the ability to care for themselves. The parent needs to make a formal legal petition to be appointed the adult's guardian. Depending on the laws and statutes in the state, the parent or sibling or another responsible adult can be given full guardianship (usually involving financial, medical, and all decision making) or partial guardianship (responsible for some aspect of care such as health issues, but the adult maintains some rights, e.g., to vote). The decision to seek guardianship of their adult may seem clear cut for parents of individuals who clearly have an intellectual disability and autism. For parents of more able individuals on the spectrum, this decision is more complex. As parents try to respect their children's desire for adult status, they are also acutely aware of their children's vulnerability and problems with judgment. Unchecked credit card spending or other poor judgments regarding managing a budget put parents in the difficult dilemma of trying to protect their children while not taking all their rights and decision making away.

Transition planning. In the United States, the federal law IDEA requires that a transition plan be put in place by the time a student with an Individual Education Plan is 14 years of age. Unfortunately, not everyone has a meaningful transition plan developed, and the transition plan is only as good as the available community resources for individuals with ASD as they transition from school between 18 and 22 years of age. A 2008 online survey conducted by the University of Miami/Nova Southeastern University CARD program (Gerhardt & Lanier, 2011) of approximately 200 families of transition age and adults with ASD in Southern Florida found 67 % of families surveyed had no knowledge of available transition programs and settings. The majority (83 %) relied on family members as their primary source of transition planning.

Blacher, Kraemer, and Howell (2010) in a study of parents of 246 young adults (18–26 years of age) with a variety of learning and developmental disabilities found that parents of young adults with autism were significantly more worried about various aspects of transition than were parents of children with Down syndrome, cerebral palsy, or individuals with intellectual disabilities. This concern seems justified given the frequent lack of autism-specific information (Hare et al., 2004) and the results of outcome studies (Howlin et al., 2004) that show the majority of adults with ASD unable to do well in work, personal relationships or independent living. Almost 1/3 of families in a Canadian study (Eaves & Ho, 2008) reported lack of supports, work or an awkward transition to adult funding sources. Adding to the anxiety for parents is the movement from the educational entitlements available up to age 22 into the adult services world with no guarantee of services. At a time when

in most families of typically developing youngsters their children are leaving home and becoming more independent, for families with children with disabilities they may actually be spending more time with their adult children because of lack of services (Seltzer & Krauss, 1994). Shattuck, Wagner, Narendorf, Sterzing, and Hensley (2011) reported in a study of children with ASD leaving high school that most children lived with their parents (79 %) and most had a reduction in services as they left school. The odds of not receiving services were significantly higher for African American children and for youth from low income homes. For parents, the adult services world can be more confusing with the greater number of people involved, different agencies and amount of paperwork (Morrell & Palmer, 2006). Hare et al. (2004) cautions service providers that longstanding psychological distress together with social economic disadvantages not only reduce families capacity to provide care, but also affect the parent's ability to negotiate effectively with the service systems and to take and act on advice.

Clara Park (2001) in writing about her daughter's transition from childhood to becoming an adult titled her book "Exiting Nirvana" which is descriptive of Jesse's changes as well as the transition process itself. Coping with their "children's" development into "adults" presents families with new challenges in finding services, at the same time they experience the familiar guilt and fear that they may not be doing the right thing for their children (Van Bourgondien & Griffin, 2011). For some families their sense of guilt may also make them tenacious advocates for services as they are concerned about not doing everything possible to meet their adult's needs.

One of the most fundamental challenges of the transition process is what some parents refer to as "Letting go" (Morrell & Palmer, 2006). Regardless of whether it is a parent of a classic individual with autism and intellectual disabilities or the parent of a college bound individual with Asperger's Syndrome or HFA, the role of the parent changes and the adults with ASD take on a bigger role in advocating for themselves. Professionals working with adults, while still involving family members in some aspects of decision making, develop more direct relationships with the adult. In the ideal situation, the adolescent with autism has been involved in the Individualized Education Plan (IEP) process during high school so that they are taught how to identify their strengths and needs and to learn to ask others for the accommodations they needs.

Post secondary education. A growing number of children with autism especially those with Asperger's Syndrome or HFA are going on to attend community colleges or 4 year degree programs (VanBergeijk, Klin & Volkmar, 2008). For families, who have been actively involved in their children's education through public school and the IEP process, they are used to meeting with teachers and school officials to share information about their child's learning style and to advocate for accommodations and services. In post secondary education, this responsibility falls completely on the individual with ASD. The college student needs to be the person who contacts the college Disability Services program and to be able to talk with the professor about individual learning needs and accommodations. This change in responsibility for advocacy takes preparation for both the individual (young adult) with ASD and their parents (Palmer, 2006). In addition due to the student's difficulties in organizational

skills, interpersonal skills and general self care, families find themselves focusing more on how to help their children with the non-academic aspects of college living (Palmer, 2006) or else some college bound students continue to live at home with parental support in order to only change one aspect of their life at a time. For most typical students, it is often the indirect aspects of the college experience that prepares them for a job after graduation (Van Bergeijk et al., 2008). These skills include communication skills, work habits, team building, time management, and problem solving skills. Parents of individuals with ASD often have to recognize and then help their college bound children understand the difference between having a degree and having the skills needed to do a job.

Day services/employment. Parents hope that their child will have fulfilling work that is meaningful to them (Morrell & Palmer, 2006). Unfortunately, the data indicate that most adults with autism are either underemployed or unemployed (Gerhardt & Lanier, 2011; Howlin et al., 2004). In the 2008 CARD Center online survey (Gerhardt & Lanier, 2011) only 19 % of parents reported being familiar with agencies or professionals who can help with job development. Individuals with ASD and intellectual disabilities may be provided with day services in the form of a sheltered workshop or day program that may include some combination of work, volunteer, leisure activities or chores (Gerhardt & Lanier, 2011; Howlin et al., 2004; Saldana et al., 2009), though the availability of these services varies greatly upon the person's location and available funding sources. Lack of day services puts stress on families as parents end up staying home to care and supervise their adult offspring with the possible loss of income from the parents not being able to work (Hare et al., 2004; Saldana et al., 2009). In their study of 26 families of adults in England, Hare et al. (2004) found a significant positive correlation between formal support, family's weekly income, receipt of autism-specific day care and families' total satisfaction scores with day services.

Living situations. One of the top concerns of families is finding an appropriate living situation for their adults with ASD. Outcome studies have shown a wide range of variation in the number of individuals with autism who have left home to live independently, in a group home, or some supported living arrangement. A number of studies have shown that the majority of young adults continue to live at home with their parents. Shattuck et al. (2011) reported 79 % of adults with ASD aged 19–23 still lived at home with their parents in the few years after completing high school. The CARD program in their online survey found 85 % of adults still lived with their families. In a Spanish study, Saldana et al. (2009) reported 87 % of adults out of 74 lived with their families. In one of the few studies that showed a majority of adults with ASD leaving home, using data obtained from the State Mental Retardation Developmental Disabilities agencies in New York ($n=7,941$) and Massachusetts ($n=1,198$), Seltzer, Krauss, Orsmond, and Vestal (2000) reported that only 1/4 to 1/3 of the adults with ASD lived at home which was lower than those with other intellectual disabilities.

The reaction of mothers to the out-of-home placement of their adults with autism is very complex. Families who seek an out-of-home living situation for their adults, often experience anxiety and guilt about their decision. On the one hand, they worry

that no one will be able to care for their son or daughter as well as they do, at the same time they are afraid that their child's behavior will be so problematic that they won't be able to remain in the placement. The guilt feelings are often a result of feeling that as parents they should not be placing their son or daughter outside the home (Lehmann, 2009; Morrell & Palmer, 2006; Sullivan, 1997). There does not seem to be a single answer or a particular living situation which is right for all adults with ASD and their families. Kraus, Seltzer, and Jacobson (2005) compared maternal impressions of the positive and negative consequences of adults with autism living at home with their families versus placement in a residential setting. The main perceived benefits for the out-of-home placement were for the adult with ASD with fewer benefits for the family. For the adult with ASD, the mothers perceived more opportunities for learning and growth experiences in a residential program, but a greater likelihood of quality care and security in the family home. For other family members, having the adult with autism stay with the family provided the benefit of peace of mind for the parents and the enjoyment of their child's company. While out-of-home placements resulted in a calmer, more typical family life with less stress and more free time for the parents. Parental concerns about finding the right living situation are no doubt complicated by these competing benefits for the individual with autism and for their families. Some parents of adults have reported that they would never place their adult child with autism outside of their family home if they could guarantee that they would outlive their son or daughter. Since this is an unlikely outcome, many families pursue out-of-home placement in order to facilitate this process while they are still around to advocate for their offspring. The parental concerns for the future care of the individual with ASD continue no matter where the person lives.

Regardless of whether an adult with ASD lives at home or in a group home, supported living, or independent living situation, research and clinical experience suggest that they continue to be highly dependent on their parent's support (Howlin et al., 2004). This need for continued parental support crosses the entire spectrum of individuals with autism. In a Swedish study of individuals with Asperger's Syndrome and HFA, all of these more able adults, whether living at home or elsewhere, continued to be in need of their parent's support (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2007). In fact, people with ASD without intellectual disabilities may have greater difficulty qualifying for funding for living supports than individuals who have both ASD and intellectual disabilities when funding is based on the severity of the disability. Even when adults with autism live outside the family, their families especially their mothers have extensive contact and involvement in their care. Kraus et al. (2005) reported that 50 % of families visited their adult with autism at least weekly and an equal number of adults came weekly to visit at their mother's home. The role parents play in the life of their adult child who is living away from home can vary from social outlet to being an integral member of a treatment team. Many residential programs/group homes have Medicaid funding which requires an Individual Habilitation Plan (IHP) for their residents (Gerhardt & Lanier, 2011). These IHPs like the Individual Education Plan (IEP) for students are developed by a team and parents are instrumental members of these teams.

Issues for Parents That Cross Settings

In addition to the concerns about where will their adult children live and how will they spend their days, parents of adults have concerns that cross all aspects of their offspring's life.

Provider knowledge of autism. A frequently voiced concern among families about providers of adult services is the lack of knowledge about autism, the learning style of an individual with autism, and specific intervention techniques that will enable the individual with autism to be successful as an adult. Hare et al. (2004) reported significant positive correlations between receipt of autism-specific day care and families total satisfaction scores. While residential, work, and recreational programs for adults with disabilities are growing in many places, programs specifically designed for individuals with ASD or have staff training in understanding autism continue to be insufficient (Gerhardt & Lanier, 2011; Hare et al., 2004; Kraus et al., 2005; Van Bourgondien & Schopler, 1990). While many intervention programs for adults have required training programs for staff members, the core of these training programs are typically generic trainings on first aid, CPR, medication management, client rights, and confidentiality with less required training on specific intervention techniques related to autism. It is interesting to note that many families are not aware of specific intervention techniques that may be used for adults with autism (Hare et al., 2004). This is a sharp contrast to parents of young children who often request by name a specific intervention technique.

Parents continue to want the adults with autism to be actively engaged in learning new skills (Kraus et al., 2005; Morrell & Palmer, 2006; Van Bourgondien & Griffin, 2011). Speech and language interventions and other skill-building activities continued to be valued by parents of adults (Ellison, Clark, & Langford, 2005). Yet few adults appear to receive this intervention (Hare et al., 2004). Learning new skills or even maintaining the skills and the degree of independence acquired during school years require that adults be able to participate in activities outside their parent's home with staff members who understand the learning style of individuals with ASD.

Staff retention. Complicating the staff training issue is the issue of staff recruitment, retention, and ongoing supervision (Hare et al., 2004; Kraus et al., 2005). The turnover rate of staff members in programs that serve adults with disabilities has been reported to be as high as 50 % with ongoing staff vacancies of 10–11 % (Gerhardt & Lanier, 2011). Both families whose adult children are living at home and receiving support and families whose adults are living in a residential program are concerned about staff turnover and lack of consistency. The lack of consistency in caregivers creates difficulty for parents who rely on support within their home and for the individual with autism who seeks predictability. The frequent turnover also makes staff training critical yet in a way very ineffective. For the family, it always appears that they are starting at step one in interventions as the new staff member is getting to know the adult with ASD and his/her learning style and intervention programs. The progress for the person with autism seems to be determined more by the

staff's training and experience and less by the readiness level of the adult. The families find that they can never truly relax and feel certain that someone will be there for their son or daughter next month, let alone when the parent is no longer present. For families the turnover rate in staff members adds to their concerns about their adult's future. Many parents have had the experience of having worked with the same teacher, resource teacher, speech therapist, occupational therapist, psychologist, etc. for an extended period of time when their child was younger. Now that there is an adult with a lifetime ahead of them, this relatively shorter time frame for providers fuels concern for the future. Eaves and Ho (2008) found that when parents of adults report what has been most helpful to them over the years they mention specific people—family members (52 %) or individual teachers, social workers, etc. (50 %) and not a specific treatment approach or program. It is therefore not surprising that the lack of stability in care providers is an area of great concern to families.

Health and safety concerns. The protection and safety of their children with autism continues to be a high priority for families as their children become adults (Hare et al., 2004; Ivey, 2002). Within the home even if the behavioral difficulties of most children with ASD decrease with age, those who are aggressive as adults are bigger and stronger and harder to manage. Families can struggle to find the right balance between giving their adult increasing independence and responsibility while worrying about their ability to truly care for themselves and protect themselves from harmful behaviors from others. Parents of adults with autism with behavioral difficulties are more likely to give in to their children's demands compared to parents of adults with Down syndrome who can more readily say no to their children (Holmes & Carr, 1991). Another concern is that if being mistreated by another person, their son or daughter may not have the communication skills to tell others. For parents of more able adults, determining when they are truly ready to drive, live independently, or even navigate chat rooms on the Internet are areas of concern.

For the parents of the nonverbal adults, there is also the concern that other caregivers may not know when they are sick in order to seek medical attention (Kraus et al., 2005; Lehmann, 2009). Medical care in itself can be challenging for some families of adults with disabilities (Eaves & Ho, 2008; Hare et al., 2004). Most physicians who are trained to work with individuals with disabilities are pediatricians, pediatric neurologists, or child psychiatrists. It is much more challenging to find a provider for adults who also understand developmental disabilities or autism. Finding a gynecologist for a female with autism or a GI specialist for an adult with gastric distress can be difficult.

Social outlets. In examining what parents report as unmet needs, Eaves and Ho (2008), found that 75 % of 48 families reported a need for more social outlets whether that be in the form of a specific social program or a friend or support persons who could take their adults with ASD out to do things. Again, this lack of social outlets increases the time many adults with ASD spend with their parents or siblings, therefore decreasing the ability of family members to pursue their own

lives. With typical adolescents and adults, one way they assert their independence is in their desire to do things with someone outside of the family. It is harder for adults with autism to find these outlets.

Financial security and estate planning. A recurring theme in parents of adults support groups is the question about what resources will be there when I am gone to help support my child with a disability. Based on our clinical experience, there are families who try to assure their child's future by purchasing them an apartment/house that they can live in or possibly share with a roommate. Unfortunately, the bricks and mortar or capital expense of having a home is often the easiest part of developing a long-term living situation for the adults with ASD. Funding the supports the person needs, the ongoing operational costs is far more important and costly. Many families rely on state or federal funding through a combination of Medicaid, social security, and state dollars to pay for the supports and interventions their offspring require. These funding sources while supporting personnel costs and some room and board do not typically pay for all of the individual's clothing or leisure materials or activities. Many families continue to provide these material needs for their children. So families, who have some resources, plan for the day when they are gone by looking for how to establish trust funds or other financial arrangements that will leave some source for funds to supplement the care of their offspring with ASD without jeopardizing their eligibility for state or federal funding. Organizations and lawyers who specialize in estate planning are an important resource to families who are thinking of the future. Some advocacy organizations in addition to managing a trust will also agree to provide an advocate to make sure the individual with ASD's needs continue to be met.

Stress and Coping in Parents

The stress of being the parent of an individual with autism is associated with higher reported levels of depression, anxiety, and exhaustion than parents of typically developing children, other disabilities, or chronic illnesses such as cystic fibrosis (Abbeduto et al., 2004; Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Montes & Halterman, 2007; Seltzer et al., 2010). In addition, parents of a child or adolescent with a diagnosis of autism are more likely to report lower levels of perceived social support and hold less positive views of their child (e.g., Donovan, 1988, Koegel et al., 1992). Both symptom, severity and maladaptive behaviors in the child or adolescent with autism, have been identified as main contributors to maternal and family stress (Hastings et al., 2005; Lecavalier, Leone, & Wiltz, 2006). For example, elevated stress levels were shown to decrease in families without problem behaviors, but remain elevated in families where children, adolescents, or adults exhibited externalized behavior problems (e.g., Gray, 1994, Gray & Holden, 1992; Smith, Greenberg, & Seltzer, 2012). The daily health of mothers also appears at risk given increased reports of physical symptoms (e.g., head and

backaches, muscle discomfort, and fatigue) when compared to mothers of children without disabilities during childhood, adolescence, and adulthood (Smith, Seltzer, & Greenberg, 2012).

Parents of children, adolescents, and adults with autism also report an increased number of daily stressful events (e.g., Hastings, 2003; Smith et al., 2010). Specifically, mothers of adults with autism report engaging in arguments as well as avoiding arguments, stressful events in the workplace and at home, and stress from family members or friends more often than mothers of typically developing adults (Smith et al., 2010). Furthermore, mothers of adolescents and adults with autism experience lower positive affect, higher negative affect, more fatigue (almost triple the percentage of daily intrusions at work than mothers of children without a disability), more time engaged in child caring and maintaining the household, and less time spent in leisure activity (Smith et al., 2010). For some mothers, their child's transition to adolescence is associated with increased levels of behavioral disengagement (a form of emotion-focused coping where one reduces efforts to deal with stressors) and higher levels of anger than mothers of toddlers (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Among mothers, the use of poorer coping strategies during the adolescent years may be a sign of the typical stressors associated with parenting an adolescent but might also reflect an accumulation of stress from years of parenting a child with autism or an increasing sense of limited parenting control of a larger adolescent with autism than a small toddler (Smith et al., 2008).

In an unpublished study of mothers and fathers of adolescents and adults with moderate to severe autism, Reichle and Van Bourgondien (1995) found that both mothers ($n=36$) and fathers ($n=25$) reported high levels of stress related to parenting an adult with autism. Adults with autism who exhibited more maladaptive behavior were perceived as more stressful by both mothers and fathers. This increased stress was significantly related to depression and marital adjustment for mothers and fathers, though mothers reported significantly more depressive symptoms than fathers with 44 % of the mothers being at risk for depression.

The challenge of raising an adolescent or adult with autism is enhanced with the presence of siblings who themselves present with behavioral difficulties. There is increased risk of cognitive, social, linguistic, and psychiatric problems even among adult siblings of persons with autism in comparison to the general population (Piven et al., 1990), which increases the likelihood of difficulties surrounding family adjustment. When compared to mothers who have one adult child with a disability (i.e., autism), the mothers of multiple adult children with disabilities (where one has autism) report higher levels of depressive symptoms, higher anxiety, and poorer family functioning as evidenced by lower adaptability and cohesion among family members as they struggle to meet every individual's needs (Orsmond, Lin, & Seltzer, 2007).

Consistent with the subjective report of increased levels of stress by mothers of persons with autism, mothers also show physiological evidence of chronic stress. Cortisol is a hormone released in the body during times of acute stress with lower blood cortisol levels found among persons who experience chronic stress.

Seltzer et al. (2010) found lower daily levels of cortisol in mothers of adolescents and adults with autism. In addition, the authors found that mothers whose children had subclinical histories of behavior problems showed increased cortisol levels the morning following a day of multiple behavioral incidents while mothers of children with significant histories of behavioral issues did not. So families who have not had a history of dealing with behavioral difficulties with the corresponding chronic stress are more likely to show an acute stress reaction to specific behavior incidents in their adult children. While the reasons for lower cortisol levels in persons with chronic psychological stress are unknown, increased fatigue appears to be a negative consequence (Smith et al., 2010). Considering the relation between behavior problems in the individual with autism and maternal stress, direct intervention to reduce these behaviors may have positive benefits for the psychological and physical well-being of mothers.

The limitations associated with the behavioral characteristics of autism can greatly affect the day-to-day activities of the family. Behavioral difficulties and lack of flexibility in the individual with autism may limit the family's frequency of outings and the ability to partake in family vacations. Further, the additional needs of the person with autism necessitates greater intensity of caregiving and intervention resulting in less time for fun family activities, increased stress for mothers faced with decisions regarding whether or not to maintain employment, pursue activities outside the home, stress on the job of fathers, and overall stress between spouses (Gray, 1994; Hutton & Caron, 2005; Montes & Halterman, 2007).

Several factors have been reported in the literature that can buffer the stress associated with parenting an adult with autism. Psychoeducation plays a vital role in helping parents cope when they have a child with autism and is associated with decreased levels of depression among mothers (Bristol, Gallagher, & Holt, 1993). Continued psychoeducation is a beneficial pursuit for parents of adolescents and adults with autism as new challenges emerge with each stage of development. In addition, parents should encourage extended family members to participate in psychoeducation regarding the needs of persons with autism and to learn ways to support their relative with autism since lower levels of depression and anxiety are found among parents of children with autism who have family members who can provide assistance with care giving (Sharpley, Bitsika, & Efremidis, 1997). Finally, coping strategies can help parents adapt to the stress of parenting an individual with autism. Smith et al. (2008) compared the coping strategies of mothers of toddlers or adolescents with ASD and found that mothers of toddlers or adolescents with autism who more often engaged in problem-focused coping strategies (i.e., direct attempts to reduce the stressor) had a higher general well-being regardless of their child's level of symptomatology, when compared to mothers of who used more emotion-focused coping strategies (e.g., venting or denial).

Smith, Greenberg, Seltzer, 2012 assessed the contribution of social support to psychological well-being among mothers of an adolescent or adult with autism. Mothers who had a larger social network reported decreasing levels of depressive symptoms, higher levels of positive affect (e.g., vigor, friendliness, and elation), and

lower levels of negative affect (anxiety, anger, fatigue, and confusion) over an 18-month period. The quality of social support was also predictive of well-being among mothers. More specifically, mothers who received negative support (e.g., placing blame, criticism or excessive demands on the mother) were more likely to show increased rates of depression and negative affect as well as decreased rates of positive affect over time. Interestingly, positive emotional support (e.g., having a confidant or someone to talk to) was not predictive of psychological well-being suggesting that mothers will find most benefit from a social network with limited negative support.

Marital status is also associated with coping among parents of adults with autism. Lower rates of maternal depression are observed in families where spouses provide direct assistance with care as well as overt expressions of love and caring towards their wife (Bristol, Gallagher, & Schopler, 1988). There is mutual benefit for parents of persons with autism to provide support to one another, as depression among one parent is more likely to result in marital discord and reduced coping mechanisms. Outside the home, support groups offer the opportunity for sharing of information. In person meetings and electronic groups through email-lists and online networks are ways in which parents of children with autism are able to have contact with other parents and receive support. Support groups are particularly effective among mothers of adults with autism who more often than mothers of typically developing children offer and receive emotional support (Smith et al., 2010).

Siblings

In typically developing children, frequent positive sibling exchanges are associated with greater psychological well-being in the developing child. In general, interactions between siblings in early childhood are beneficial for cognitive, social, and emotional development. During adolescence, a period of development where individuals increasingly seek out social relationships outside of the nuclear family, siblings endorse decreased satisfaction with the sibling relationship. With the onset of adulthood, brothers and sisters report increased satisfaction and contact with their siblings (Cicirelli, 1994; Kim, McHale, Wayne Osgood, & Crouter, 2006; Scharf, Schulman, & Avigad-Spitz, 2005). The relationship between typically developing siblings has been extensively studied; however, very few studies have been conducted in order to investigate the interactions and quality of relationship between siblings when one has autism.

For a typically developing sibling, the influence of having a brother or sister with autism is associated with higher rates of behavioral and emotional concerns (Constantino et al., 2006; Fisman, Wolf, Elllison, & Freeman, 2000; Giallo & Gavidia-Payne, 2006; Hastings, 2003; Ross & Cuskelly, 2006) and fewer prosocial behaviors towards their sibling with autism in some studies (Hastings, 2003; Knott, Lewis, & Williams, 1995), and appropriate psychological and social-emotional adjustment in others (Hastings, 2007; Kaminsky & Dewey, 2002; Mates, 1990;

Verté, Roeyers, & Buyesse, 2003). Further, several studies report no adverse effects of having a sibling with autism (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Rodrigue, Geffken, & Morgan, 1993). Despite the communication, social, and behavioral challenges associated with a diagnosis of autism, some children who have a sibling with autism endorse both admiration for, and satisfaction with their brother or sister with autism (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003; Roeyers & Mycke, 1995). However, others report a lack of closeness and loneliness (Bägenholm & Gillberg, 1991), a limited number of interactions within the family and with their siblings in particular, and thoughts that their sibling with autism is a burden (Bägenholm & Gillberg, 1991; Knott et al., 1995) in comparison to the typical siblings of children with other disabilities. The inconsistencies across studies are thought to be due to differences in the methodology used such as reliance on indirect assessment of the social-emotional adjustment of the typical sibling through parent or teacher reports and small sample sizes. In addition, within some studies, children and young adults have been grouped in the same sample even though changes in the sibling relationship occur from childhood into adolescence and again during the transition from adolescence to adulthood.

Several factors have been identified that mediate the relationship between typically developing children and their sibling with autism. With regard to the family environment, increased levels of parental stress and marital discord were identified as indirect contributors to negative perceptions among typical siblings of the relationship they have with their siblings with autism (Benson & Karlof, 2008; Fisman et al., 1996), while increased size in the family unit improves acceptance and satisfaction with the brother or sister with autism given that the experience of stressors and responsibility is distributed among more family members. Finally, maternal depression can negatively affect the mental health of the typically developing sibling. The risk of maternal depression increases with the degree of impairment in the child with autism (e.g., Davis & Carter, 2008). In general, maternal depression has adverse consequences for children as exposure to the negative behaviors, cognitions, and affect of depression is associated with elevated risk to adjustment (Goodman & Gotlib, 1999). Shared genetic risk for depression between mothers and their children may also contribute to increased risk.

Although much of the literature focuses on the behavior and characteristics of the individual with autism, factors within the sibling of the individual with autism also influence sibling adjustment and psychological well-being. The siblings of persons with autism have greater genetic vulnerability for cognitive, social, linguistic, and learning difficulties than the general population (Ben-Yizhak et al., 2011; Gamliel, Yirmiya, Jaffe, Manor, & Sigman, 2009). In addition, siblings may also have subclinical manifestations of the communicative, social, and behavioral traits characteristic of persons with an autism spectrum diagnosis (e.g., broader autism phenotype; Bauminger & Yirmiya, 2001). Higher levels of broader autism phenotype predict poorer adjustment among siblings of the child with autism between the ages of 2 and 18 years (Meyer, Ingersoll, & Hambrick, 2011) and have been found to interact with negative life events to predict depression and anxiety among adolescent sisters of children with autism (Orsmond & Seltzer, 2009).

The early childhood experiences of siblings have consequences for the quality of interactions with their brother or sister with autism during adulthood; however, additional circumstances related to the transition to adult life continue to influence the sibling relationship. First, as the communication, social and behavioral challenges of autism have been shown to decrease in severity over the course of development (e.g., Seltzer et al., 2003), the likelihood that these changes are also associated with improvements in the sibling relationship increases (Orsmond, Kuo, & Seltzer, 2009). Nonetheless, the adaptive functioning or daily living skills of the brother or sister with autism may continue to influence the relationship as typical siblings of brothers or sisters with lower levels of functional independence report lower levels of closeness with their sibling (Orsmond & Seltzer, 2007). Second, during the transition to adulthood, individuals move away from their immediate family due to personal, educational, and professional pursuits. Within the literature, higher levels of education of the typically developing sibling as well as living at a distance from their sibling with autism have negative consequences for their perceptions of the sibling bond (Orsmond & Seltzer, 2007). Overall, siblings of adults with autism report less contact with their brother or sister, lower levels of positive affect in the relationship, and lower expectations for their sibling's future outcome in studies comparing the perceived quality of relationship between siblings among adults with a sibling with Down syndrome and those with a sibling with autism (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). These differences highlight the unique quality of the sibling relation for persons with autism.

An association between the frequency of sibling interactions in relation to the gender of siblings has also been assessed. Similar to the differences observed among children, Orsmond et al. (2009) found that the gender of both the typically developing sibling and brother or sister with autism has implications for the perceived quality of the sibling relationship in adults. Within the sibling dyads assessed, brothers of an adult sister with autism report the fewest shared interactions with sister's of a sister reporting the most shared interactions.

The trajectory of the sibling relationship may be improved by preventative measures including an emphasis on adaptive coping strategies and parental support that enhances the perceived quality of relationship between typically developing children and their brother or sister with autism. Researchers have contrasted the use of coping strategies among adolescents and adults. Problem-focused coping strategies involve the active seeing of solutions to problems or ways to reduce the effect of stressors versus emotion-focused coping strategies with which persons seeks to control or diminish the unwanted emotions associated with stressors. Adult siblings who employ the more adaptive problem-focused coping in which they determine ways to directly address the problem, rather than using avoidance, report a closer relationship with their brother or sister with autism (Orsmond & Seltzer, 2007). Among adolescents, support is provided by parents and friends. In the adult years, although significant others (e.g., partners or spouses) play the greatest role in helping the adult cope with stressors associated with their brother or sister with autism, parents continue to play a vital role (Orsmond et al., 2009). The quality of the

relationship between siblings and their adult brothers or sisters with autism is enhanced when parents are supportive (Orsmond et al., 2009).

Many young children, both anecdotally and empirically, report concerns that as adults they will shoulder the responsibility of caring for their sibling with autism when their parents are no longer able to do so. For adult siblings of individuals with autism, the necessity of maintaining their own personal and professional lives in addition to supporting their sibling with autism presents a challenge. However, increased sibling involvement is noted when the adult with autism has fewer behavioral challenges and when parents can support the relationship between siblings. Furthermore, although the frequency of interactions may decrease with the onset of adulthood, ratings of the quality of the sibling relationship do not (Orsmond & Seltzer, 2007). Even when adult siblings desire to have a role in their sibling's future, many do not want or are not able due to their own family's needs to take on all the roles and the intensity of involvement that their parents and especially their mother's play in their sibling's life. It is important for parents and siblings to talk directly and openly about the future needs of their family member with ASD and to decide which roles if any of the siblings can play.

Many parents are concerned about the impact on their typically developing children when living with a sibling with autism. Parents may find comfort in knowing that the majority of adults report that the relationship with their parents did not suffer as a result of having a sibling with autism, in fact, they state that having a sibling with autism had a positive effect on their relationship with their parents and with their mothers specifically (Orsmond & Seltzer, 2007).

Spouses of Individuals with ASD

As the population of higher functioning individuals with autism ages, a new area to consider will be the nature of the relationships and the stress and coping in spouses and children of adults with ASD. Today, older high functioning adults with autism are likely to have been diagnosed with autism as an adult. In fact, many individuals are referred as adults after a child of theirs has been diagnosed as having autism or Asperger's Syndrome. There is limited research on the spouses of individuals with ASD. With the increasing knowledge and identification of high functioning men and women, there is a growing awareness that a portion of adults with ASD do enter into long-term relationships with others (Howlin, 2003; Renty & Roeyers, 2006; Van Bourgondien & Powell, 2012). However, there is limited empirical data about the nature of these relationships. There are popular books that describe marital issues in couples where at least one partner is presumed to have autism. Some of these describe a single couple's experience (e.g., Newport & Newport, 2002), while another may describe a therapist's clinical practice where there is no diagnostic confirmation that a member of the couple does in fact have autism (Aston, 2003). Renty and Roeyers (2007) examined marital adaptation of 21 men with confirmed

diagnoses of ASD and their spouses. In all cases there was also a child with ASD in the household. The best predictor of positive adaptation for both spouses was informal support from the spouse, other family members, and friends. While the severity of ASD did not affect men with ASD's adaptation, it was inversely related to their spouses' marital adaptation. That is to say, the greater number of symptoms of ASD in the husband, the lower the wife's marital adaptation. Future studies will need to look more at the relationships of both women and men with ASD, and at the impact of having a parent with ASD on children.

Interventions for Families of Adults with ASD

There is limited research literature and very little written about interventions for families with adults with ASD. To provide a framework for future directions, we will describe the services for families of adults with autism provided by the TEACCH autism program at the University of North Carolina at Chapel Hill. The TEACCH autism program, established in 1972 by the North Carolina legislature and built upon the principle of partnering with families of individuals with autism (Schopler & Reichler, 1971), expanded its focus to include adults with autism in 1978. Including parents in the treatment process remained a core component with the adult population. In fact, the move to expand TEACCH services to address the needs of adults with autism was largely initiated by parents in the program whose children had aged into adolescence and adulthood. TEACCH shifted from its emphasis on childhood to the entire age spectrum while maintaining its commitment to the intervention principles of careful diagnosis and assessment, working with parents as co-therapists, community integration, practical information, and emotional support.

While many of the cases seen at TEACCH have received their ASD diagnoses as young children, in recent years with the expansion of the spectrum increasing numbers of adults are being referred for a diagnostic evaluation for autism or Asperger's Syndrome for the first time. Most cases have had previous diagnoses such as ADHD or any number of mental health-based conditions such as depression or an anxiety disorder. From the parent perspective (the focus of this chapter), their child, now an adult, has had a lifetime of behavioral, cognitive/learning and/or social/emotional problems with treatments based on these diagnoses. Yet, from their experience and point of view, the interventions and explanation have never quite captured the essence of their child's difficulties. Obtaining an accurate ASD diagnosis later in their adult child's life helps the family get redirected in what will hopefully be a more productive path. At the same time, parents understandably worry about the negative impact of prior misdiagnoses and the time perceived lost in treatment that did not address the core autism condition. On the other hand, most parents of adults receiving this diagnosis for the first time welcome the new information, especially

when coupled with appropriate services. They already have known that their child was not likely to live a normal life, so that expectation was abandoned well before ASD was considered. So having the correct diagnosis is viewed mainly as a new opportunity to help their adult child have a better future.

Parents are integral to the evaluation process, providing critical information about early history, a chronology of school performance and past interventions, and identifying areas of current and future concern. The adult with autism may or may not be a reliable source of information, adding even more value to the parent report. The interpretive conference is held either jointly with the adult and parents together with staff or concurrently in separate rooms, or can be a combination of both. The key to a successful conference is making sure everyone has an accurate understanding of the results and the meaning of the diagnosis as well as participating in and agreeing to a plan of action. Explaining the information in language (whether spoken or written) to the adult with ASD that makes sense requires knowledge and experience of the staff clinician. On occasion, the adult and parents may need more than one session to review the results because of the relatively complicated nature of the diagnosis (after years of operating under different assumptions), as well as the range of recommendations which takes time to process.

TEACCH provides a number of interventions, informational and support services that include parents as well as the adult with ASD. Consistent with the parents-as-co therapists' model originally developed by Eric Schopler for children, parents of adults are part of the team that focuses on the needs of the adult client. While one staff therapist is providing the adult with counseling on identified goals, another therapist meets with the parents helping with their issues of being a parent of an adult with ASD. Not every case is handled the same way; in some instances, parents meet less frequently than the adult client does. With young children in this model, parents are expected to carry out home teaching activities, teach self-help and other skills, whereas with adults, parents need to figure out where community supports can be found to provide direct service for their adult child. TEACCH's role tends to be consultative, using our knowledge of resources, navigating the family through the maze of agencies and potential opportunities and pitfalls.

There are two specialized programs which primarily serve adult clients, but involve parents. The Supported Employment program provides vocational assessments, helps the individual locate and acquire a job, and support clients in appropriate jobs, while including parents in the assessment process and remaining in contact after job placement, as needed. The Carolina Living and Learning Center is a residential-vocational program for 15 adults who function at a moderate-to-severe level of impairment. Close relationships with the parents are a high priority even though their adult children are no longer living at home.

Parents are offered support through the Parent Mentor program where the family of the newly diagnosed adult is matched with an experienced parent who has volunteered and trained to be a mentor. The Mentor, who has gone through similar life experiences, contacts the matched parent and offers to share his or her perspective,

guidance, and knowledge of resources. Like all parents of newly diagnosed children, having a peer to speak or meet with helps to offset the feeling of being alone and to validate their perceptions. For the Mentor, taking on this role is a way of “giving back” to the program as well as enhancing their sense of building community through helping others.

Support groups for parents of young children with autism are fairly common and a useful adjunct to other services. They are less common for parents of adults (as, frankly, are most services). TEACCH established such a support group close to 20 years ago in response to an unaddressed need. The Parents of Adults group meets monthly from September to June and has a topic for each session. Certain topics seem more relevant for parents whose children range in age from 18 to early 50s, for example, Estate Planning (future financial planning), Dealing with Difficult Behaviors, Finding Social Outlets for Your Adult Child with Autism, and Developing Independence.

The group structure and process involved a leader/facilitator and everyone is encouraged to speak. Members of the group have adult children with a wide range of autism, from severely intellectually impaired individuals with autism to high functioning individuals with autism. Some live in group homes or supervised apartments; others live at home. Most have jobs or work in a sheltered situation. Some of the parents have been actively involved in autism services in North Carolina since the late 1960s or early 1970s and continue to advocate for their adult child. Other parents have had a more recent diagnosis.

As with other support groups, parents attend this group for information and mutual support. Some of the information can be quite practical, such as getting the name of an attorney who can help with drawing up a will. For some parents, these meetings serve as a social opportunity, especially if their adult child continues to live at home and requires ongoing supervision. Family members, who have been parenting a child with autism for 30 or 40 years, continue to request updates on research that helps us better understand the nature of autism as well as the treatment approaches. Another benefit of this group has been the development of some services that were first discussed in the group. For example, a number of years ago the group was concerned about the lack of an appropriate day program specifically for adults with autism. Several meetings were devoted to this topic until some of the members raised the issue with the Autism Society of North Carolina. Eventually a task force was established and a program developed. Although the support group spent only a few hours on this topic, those discussions led to action and an important new service.

Parents of adolescents and adults with autism are always looking for more information that will help them better understand and to continue to guide their adult children. To meet this need, periodic workshops specifically for parents of adolescents and adults are offered on age relevant topics. Transitioning to life after school is over, sexuality, and self-determination are among the topics most requested by parents of adults.

Summary

In this chapter, we reviewed the concerns and roles of families of adults with ASDs, and the impact of the stress these responsibilities have on family members. In reviewing this information and working with families of adults, it is important to recognize that there are unique subgroups among the families of adults who carry different histories and experiences in relation to those who deliver services. Older parents whose children were first diagnosed at a time when parents were thought to be the cause of the disorder, first were blamed for the difficulties in their children and many went on to be the pioneers advocating for appropriate services for children when there were none. Many of these families were called upon once again to be pioneers and advocates for adult services as their children aged out of educational mandates. Another group are families whose children were viewed as having mental health disorders or carried no diagnosis at all as children, although they had clear difficulties both at home and at school, but, as autism has become more recognized and the spectrum expanded, they have been diagnosed as adults having ASD. This group has faced a different set of challenges and frustrations in finding services for their children. And then there are the parents of young adults whose children may have had early intervention services and relatively less difficulty throughout their child's life getting the supports and services their child needed. This group carries a different set of expectations and may actually experience a greater contrast between their previous experiences and the challenges of adult services.

Parents, siblings, and most likely spouses are affected by the long-term impact of having a family member on the autism spectrum. The research suggests that the role of families does not significantly diminish as the individual with ASD reaches adult status, and therefore issues related to stress and coping do not end or necessarily diminish. To address the needs of family members of adults, we need to start by providing quality vocational, residential, social, and recreational services for adults with autism. If funding levels decrease due to economic concerns and a push for "natural supports," those most affected are likely to be family members who experience an increase in their parenting responsibilities with age and not the expected decrease most parents experience. However, the research suggests that even when their adult with ASD does leave home, they clearly do not leave the family. Families of adults with autism continue to play a central role in supporting their son or daughter regardless of where they are on the spectrum and regardless of where they live or work. Interventions for adults with autism need to recognize the vital role that families can play in not just the transition to adult services, but in the long-term success of living and work settings. Parents of adults continue to know their children the best and as long as their health allows they are likely to be their best advocates.

Finally, family members of adults benefit from interventions and supports that are aimed at giving them both the information they need to problem solve about the issues they face as well as the support they need to positively cope with the stresses they face as a parent or sibling of someone with an ASD. As more models of adult

services are developed, the ones where professionals are sensitive to the value of family involvement and the needs of families are likely to be the most successful. With the increased awareness and services for individuals with ASD and their families, the next generation of families is more likely to have the supports they need to have a high quality of life for themselves and for their family member with autism.

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youth with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, 109, 237–254.
- Aston, M. (2003). *Asperger's in love*. London: Jessica Kingsley.
- Bägenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. *Journal of Mental Deficiency Research*, 35, 291–307.
- Bauminger, N., & Yirmaya, N. (2001). The functioning and well-being of siblings of children with autism: Behavioral-genetic and familial contributions. In J. A. Burack, T. Charman, N. Yirmiya, & P. R. Zelazo (Eds.), *The development of autism: Perspectives from theory and research* (pp. 61–80). Mahwah, NJ: Lawrence Erlbaum.
- Benson, P., & Karlof, K. (2008). Child, parent, and family predictors of later adjustment in siblings of children with autism. *Research in Autism Spectrum Disorders*, 2, 583–600.
- Ben-Yizhak, N., Yirmiya, N., Seidman, I., Alon, R., Lord, C., & Sigman, M. (2011). Pragmatic language and school related linguistic abilities in siblings of children with autism. *Journal of Autism and Developmental Disorders*, 41, 750–760.
- Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities*, 4, 3–16.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46, 722–730.
- Bristol, M. M., Gallagher, J. J., & Holt, K. D. (1993). Maternal depressive symptoms in autism: Response to psychoeducational intervention. *Rehabilitation Psychology*, 38, 3–10.
- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and non-disabled boys: Adaptation and spousal support. *Developmental Psychology*, 24, 441–451.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autism spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8, 409–423.
- Cederlund, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2007). Aspergers syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorder*, 38, 72–85.
- Cicirelli, V. G. (1994). The longest bond: The sibling life cycle. In L. L'Abate (Ed.), *Handbook of developmental family psychology and psychopathology* (pp. 44–59). New York: Wiley.
- Constantino, J. N., Lajonchere, C., Lutz, M., Gray, T., Abbacchi, A., McKenna, K., et al. (2006). Autistic social impairment in the siblings of children with pervasive developmental disorders. *American Journal of Psychiatry*, 163, 294–296.
- Davis, N., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278–1291.
- Donovan, A. M. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation*, 92, 502–509.

- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders and normal development. *Exceptionality*, 2, 97–110.
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 739–747.
- Ellison, D., Clark, C., & Langford, B. (2005). *Where are they now? Adult functioning in autism spectrum disorders*. Presentation at the international meeting for autism research, Boston, MA.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 1532–1541.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369–375.
- Gamliel, I., Yirmiya, N., Jaffe, D., Manor, O., & Sigman, M. (2009). Developmental trajectories in siblings of children with autism: Cognition and language from 4 months to 7 years. *Journal of Autism and Developmental Disorders*, 39, 1131–1144.
- Gerhardt, P. D., & Lanier, I. (2011). Addressing the needs of adolescent and adults with autism: A crises on the horizon. *Journal of Contemporary Psychotherapy*, 41, 37–45.
- Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, 50, 937–948.
- Goodman, S. H., & Gotlib, I. H. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review*, 106, 458–490.
- Graetz, J. E. (2010). Autism grows up: Opportunities for adults with autism. *Disability and Society*, 25, 33–47.
- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, 16, 275–300.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83–93.
- Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family caregivers supporting adults with autistic spectrum disorders. *Autism*, 8, 425–444.
- Hastings, R. P. (2003). Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33, 99–104.
- Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavioral problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37, 1485–1492.
- Hastings, R. P., Kovshoff, H., Ward, N. J., delgi Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35, 635–644.
- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome: Findings from a large-scale American survey. *Journal of Intellectual Disabilities Research*, 51, 1018–1029.
- Holmes, N., & Carr, J. (1991). The pattern of care in families of adults with a mental handicap: A comparison between families of autistic adults and Down syndrome adults. *Journal of Autism and Developmental Disabilities*, 21, 159–176.
- Howlin, P. (2003). Outcome in high functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 33, 3–13.
- Howlin, P. (2004). *Autism and Asperger syndrome: Preparing for adulthood* (2nd ed.), London: Routledge.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212–229.

- Hutton, A. M., & Caron, S. L. (2005). Experiences of families of children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, 20, 180–189.
- Ivey, J. (2002). A comparison of teacher and parental expectations for children with autism. *Dissertation Abstracts International*, 93, 2198.
- Kaminsky, L., & Dewey, D. (2001). Sibling relationships of children with autism. *Journal of Autism and Developmental Disorders*, 31, 399–410.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 43, 225–232.
- Kanner, L. (1973). *Childhood psychosis: Initial studies and new insights*. New York: Winston/Wiley.
- Kim, J. Y., McHale, S. M., Wayne Osgood, D., & Crouter, A. C. (2006). Longitudinal course and family correlates of sibling relationships from childhood through adolescence. *Child Development*, 77, 1746–1761.
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interactions of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry*, 13, 965–976.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., et al. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22, 205–216.
- Kraus, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, 49, 111–124.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172–183.
- Lehmann, A. L. (2009). *The accidental teacher: Life lessons from my silent son*. Ann Arbor, MI: The University of Michigan Press.
- Marcus, L., Kuncle, L., & Schopler, E. (2005). Working with families. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 1055–1086). Hoboken, NJ: Wiley.
- Mates, T. E. (1990). Siblings of autistic children: Their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders*, 20, 545–553.
- Meyer, K., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 1413–1420.
- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, 119, 1040–1046.
- Morrell, M. D., & Palmer, A. (2006). *Parents across the autism spectrum: Unexpected lessons we have learned*. Philadelphia: Jessica Kingsley.
- Newport, J., & Newport, M. (2002). *Autism-Asperger's & sexuality*. Arlington, TX: Future Horizons.
- Orsmond, G. I., Kuo, H. Y., & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and well-being in adolescence and adulthood. *Autism: The International Journal of Research and Practice*, 13, 59–80.
- Orsmond, G. I., Lin, L., & Seltzer, M. M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities. *Intellectual and Developmental Disabilities*, 45, 257–270.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adults lives. *Journal of Intellectual Disability Research*, 51, 682–696.
- Orsmond, G. I., & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, 39, 1053–1065.
- Palmer, A. (2006). *Realizing the college dream with autism or Asperger syndrome: A parent guide to student success*. Philadelphia: Jessica Kingsley.
- Park, C. C. (2001). *Existing Nirvana: A daughter's life with autism*. Boston: Little, Brown.

- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45, 855–865.
- Piven, J., Gayle, J., Chase, G. A., Fink, B., Landa, R., Wzorek, M. M., et al. (1990). A family history of neuropsychiatric disorders in the adult siblings of autistic individuals. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 177–183.
- Reichle, N. C., & Van Bourgondien, M. E. (1995). *Maternal and paternal coping of families of adolescents and adults with autism*. Unpublished manuscript, TEACCH program, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA.
- Renty, J., & Roeyers, H. (2006). Quality of life in high functioning adults with autism spectrum disorders: The predictive value of disability and support characteristics. *Autism*, 10, 511–524.
- Renty, J., & Roeyers, H. (2007). Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Journal of Autism and Developmental Disorders*, 37, 1247–1255.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383–394.
- Rodrigue, J. R., Geffken, G. R., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23, 665–674.
- Roeyers, H., & Mycke, K. (1995). Siblings of a child with autism, with mental retardation and with normal development. *Child: Care, Health, Development*, 2, 305–319.
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, 31, 77–86.
- Saldana, D., Alvarez, R. M., Lobaton, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009). Objective and subjective quality of life in adults with autism spectrum disorders in Southern Spain. *Autism*, 113, 303–316.
- Scharf, M., Schulman, S., & Avigad-Spitz, L. (2005). Sibling relationships in emerging adulthood and adolescence. *Journal of Adolescent Research*, 20, 64–90.
- Schopler, E. (1971). Parents of psychotic children as scapegoats. *Journal of Contemporary Psychology*, 4, 17–22.
- Schopler, E., & Reichler, R. J. (1971). Parents as cotherapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia*, 1, 87–102.
- Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., et al. (2010). Marital cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, 40, 457–469.
- Seltzer, M. M., & Krauss, M. W. (1994). Aging parents with co-resident adults children: The impact of lifelong caregiving. In M. M. Seltzer, M. W. Krauss, & M. P. Janicki (Eds.), *Life course perspectives on adulthood and old age* (pp. 3–18). Washington, DC: The American Association of Mental Retardation Monograph Series.
- Seltzer, M. M., Krauss, M. W., Orsmond, G. I., & Vestal, C. (2000). Families of adolescents and adults with autism. Uncharted Territory. In L. M. Glidden (Ed.), *International review of research on mental retardation* (Vol. 23, pp. 267–294). San Diego, CA: Academic Press.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33, 565–581.
- Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 19–28.
- Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatric & Adolescent Medicine*, 165, 141–146.

- Shea, V. (1993). Interpreting results to parents of preschool children. In E. Schopler, M. E. Van Bourgondien, & M. Bristol (Eds.), *Preschool issues in autism* (pp. 185–198). New York: Plenum Press.
- Smith, L. E., Greenberg, J. S., & Seltzer, M. M. (2012). Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 1818–1826.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism of Developmental Disorders*, 40, 167–178.
- Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal on Autism and Developmental Disorders*, 42, 1836–1846.
- Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 37, 876–889.
- Sullivan, R. (1997). When your son/daughter leaves home: Heartbreak? Relief? Or both? *Newsletter of Autism Services Center*, Winter, 2.
- Tammet, D. (2006). *Born on a blue day: Inside the extraordinary mind of an autistic savant*. New York: Free Press: A Division of Simon & Schuster, Inc.
- VanBergeijk, E., Klin, A., Volkmar, F. (2008). Supporting more able student on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38, 1359–1370.
- Van Bourgondien, M. E., & Griffin, L. (2011). *Top ten things parents want professionals to know*. Presentation at the Annual Leo Croghan conference, Raleigh, NC.
- Van Bourgondien, M. E., & Powell, P. (2012). *Social relationships and sexuality*. Poster presentation at the International Meeting for Autism Research, Toronto, Canada.
- Van Bourgondien, M. E., & Schopler, E. (1990). Critical issues in the residential care of people with autism. *Journal of Autism and Developmental Disorders*, 20, 391–399.
- Verté, S., Roeyers, H., & Buyesse, A. (2003). Behavioral problems, social competence, and self-concept in siblings of children with autism. *Child: Care, Health, & Development*, 29, 193–205.

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