

Quality of Life in Families with a Transition Aged Young Adult on the Autism Spectrum

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## Abstract

### Quality of Life in Families with Transition Aged Young Adults on the Autism Spectrum

Barbara B. Demchick

The purpose of this study was to describe family quality of life (FQOL) from the perspective of families with youth on the autism spectrum at or nearing the age of transition from school to adulthood. A qualitative phenomenology approach was used. Participants included ten families made up of six mothers, two fathers, and two grandmothers. The primary form of data collection was two in- depth interviews. Observations and field notes supplemented interview data, and previously administered Maryland Autism Services Surveys (MASS) were examined to contribute to the triangulation of the data. Trustworthiness of the data was enhanced by the presence of a second researcher during data collection and analysis, peer debriefing, and member checking. Another purpose of this study was to explore sensory processing in these transition aged youth, and to investigate the influence of sensory processing difficulties on family life. This was explored through the interviews, and through administration of the Adolescent/ Adult Sensory Profile, which was filled out by the family members. Results of the qualitative study revealed three themes that describe FQOL from the participants' perspectives: changes associated with puberty and associated disorders that

manifest or worsen during puberty affect autism and challenge quality of life; occupations are influenced and restricted when there is a family member on the autism spectrum; and the onus of responsibility for transition falls on the family. The investigation into sensory processing in young adults revealed the existence of difficulties in sensory processing, with trends noted in the types of difficulties seen in these young adults. Sensory processing influenced FQOL, with families modifying activities to accommodate their young adult's sensory needs. Implications of these results for the study of occupation and for the practice of occupational therapy are discussed.

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## Chapter 1:

### Problem Statement

#### Introduction

Leaving high school can be an exciting time for young people as they transition to the new challenges of work, postsecondary education, and independent living. However, the transition from school to adulthood can be difficult for individuals with disabilities. For youth with autism spectrum disorders (ASDs), this is especially true, because postsecondary and employment opportunities for these transitioning students have been limited (Schall & Wehman, 2008).

**Autism characteristics and prevalence.** Autism spectrum disorders are a group of developmental disabilities characterized by impaired social interaction, a restricted repertoire of activities and interests and impaired communication (American Psychiatric Association [APA], 2000). ASDs can affect any individual and family, they occur across all races and economic lines, and are seen more in males approximately four times as often as females (Centers for Disease Control and Prevention [CDC], 2010). The symptoms of ASDs typically are present before age 3 years and often are accompanied by difficulties in cognitive functioning, learning, attention, behavior, and sensory processing. The latter is of particular concern to occupational therapists, as sensory processing falls within the occupational therapy domain of practice (American Occupational Therapy Association [AOTA], 2008). Abnormalities in sensory processing have been widely reported in those with autism, although most research has been done with young children (Dunn, 2001; Tomcheck & Dunn, 2007; Watling, Deitz, & White, 2001). Additionally, some researchers have suggested that there is a link between the sensory processing

problems that a person with autism experiences and difficulties in managing daily life (Dunn, 2001; Kern et al., 2006), although most of these studies likewise have been with children.

The term spectrum disorder is used to indicate that ASDs encompass a range of behaviorally defined conditions, which are diagnosed through clinical observation of development. These conditions, as articulated in the Diagnostic and Statistical Manual IV-Text Revision (APA, 2000) include autistic disorder (i.e., autism), Asperger disorder, and pervasive developmental disorder--not otherwise specified (PDD-NOS). Those with Asperger disorder generally are felt to have fewer diagnostic symptoms of ASDs compared with autism, especially in communication. However, it is important to note that these included diagnoses will be eliminated and subsumed under the broader diagnosis of Autism Spectrum Disorder with the proposed DSM V diagnostic criteria, due to be published in 2013 (APA, 2010). For this reason, the term autism spectrum disorder (ASD) will be used in the singular form. The issues associated with ASD are permanent and continue into adulthood and create "life-long challenges" for the individual (Hendricks & Wehman, 2009, p.77). Because ASD is a spectrum disorder individual presentation and severity varies, as do individual needs. However, most individuals with ASD need support and services to maximize their productivity and level of independence. Services that people with ASD require during transition and throughout adulthood include but are not limited to services for vocational training, housing, postsecondary education, and community involvement (Hendricks & Wehman, 2009).

The prevalence of autism spectrum disorder, once thought to be rare, has risen considerably in the last 20 years (Anderson, 2010). Prevalence was estimated to be 1 in

2000 in the 1980's, and had risen to 2.5 per 1,000 by 1994 (Rutter, 2005). More recent estimates placed the incidence of ASD at 6-7 per 1,000, which is consistent with the 1 in 150 figure cited by the Centers for Disease Control(CDC) in 2007. Autism is now estimated to occur in approximately 11.3 per 1,000 or 1 in 88 children, based on a the most recent surveillance study by the Centers of Disease Control, Autism Developmental Disabilities Monitoring System [ADDM] (CDC, 2012). Prevalence estimates vary according to state, and Maryland's prevalence is slightly above the national average, at 12.4 per 1,000 (CDC, 2012).

Although improved diagnosis and broader defined criteria account for some of the increase, a true increase in the risk for a child to develop ASD cannot be ruled out (CDC, 2010, CDC 2012). While the reasons behind this increase are not fully clear, what is clear is that there are an increasing number of individuals being diagnosed with autism than ever before, and as a result, there is a steadily growing population of young adults on the autism spectrum (Organization for Autism Research [OAR], 2009). Those diagnosed in the 1990s are already reaching the age of transition from the educational system. Based on current trends, the number of adults is only going to increase.

It is important to recognize that CDC ADDM prevalence estimates have been determined based upon the numbers of 8 year olds counted (CDC, 2010, CDC, 2012). There is no firm estimate on the number of adults. In 2007, The Autism Society of America predicted, based on the Census Bureau population and the 2007 CDC report, that there soon would be roughly 1,495,264 adults with autism living in the United States (Christ Sullivan, 2007). Even though this is an outdated estimate in view of the increase in prevalence according to the most recent CDC report, it does signify that there are a

large number of individuals that are reaching adulthood and will reach adulthood in the coming years.

**Adult transition.** This increase in prevalence has led to the need for greater services and supports for transition aged young adults on the autism spectrum. Yet, program development, funding and research on program effectiveness have been focused on children. As of this writing, once a young person leaves the public school service delivery system, where services and supports are mandated according to the Individuals with Disabilities Education Act [IDEA], the need for service far exceeds service availability. Few therapeutic interventions are in place for young adults on the autism spectrum, and insufficient service provision and multidisciplinary support are reported (Moxon & Gates, 2001; OAR, 2009). This suggests the need to regard ASD as a public health concern, and to place an emphasis on examining resources available to adults with this disorder. Additionally, there has been limited evaluation of the effectiveness of the services that are available for those young adults.

It is significant to note that surveys suggest that as many as 50 % of individuals diagnosed on the autism spectrum have normal intelligence, and are not intellectually disabled (Fombonne, 2003). This is supported by the most recent CDC reports, where the rate of those functioning at the higher end of the spectrum showed the largest increase in incidence (CDC, 2010; CDC, 2012). Although young people with ASD demonstrate significant and limiting interpersonal deficits, some may possess cognitive abilities similar to neurotypical or even intellectually gifted individuals (Barnhill, Hagiwara, Myles, & Simpson, 2000). In spite of this, studies suggest that the majority of these transition aged young adults live at home with parents, siblings, or other relatives and

have a low rate of employment or higher education when compared with same age typical peers (Easter Seals, 2008; Eaves & Ho, 2008; Howlin, 2000, ). The rate of employment is even lower than the rate of employment for those with other developmental disabilities (OAR, 2009). Even young adults who have been successful in secondary school have limited success in college and employment (Hendricks & Wehman, 2009). Many argue that reasons for these limited outcomes have more to do with the failure to provide needed supports and services rather than the challenges associated with ASD itself (Eaves and Ho, 2008, Graetz, 2010; OAR, 2009 ). For these reasons, it is important to more closely examine studies of adults on the autism spectrum to try to ascertain what contributes to positive outcomes and quality of life of individuals and their families.

**Family issues.** Clearly, limited adult outcomes for those on the autism spectrum, create additional obligations for their families. In the absence of standard societal mechanisms for appropriate assessment and treatment, families must personally shoulder many of the responsibilities associated with securing appropriate services for their children (Lord & Bishop,2010; OAR, 2009). Survey research suggests that parents know little about helping their children with ASD transition to the adult world. The University of Miami/Nova Southeastern University Center for Autism Related Disorders [CARD] (2008) conducted an on-line survey of approximately 200 families of transition-age and adult constituents with ASD in southern Florida. The results indicate that 67% of families surveyed had no knowledge of available transition programs and settings and 83% relied on family members as their primary source of transition planning assistance (CARD, 2008). This is concerning, especially considering that transition planning is mandated to be part of a student's Individualized Education Program (IEP) through the Individuals

with Disabilities Education Act [ IDEA ] (US Department of Education, [USDE] 2004), beginning no later than his or her 16th birthday. Under IDEA, transition planning requires the development of measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and independent living skills (USDE, 2004). Transition, according to IDEA, also means coordination with the adult service delivery system before leaving secondary school, which is rarely done in practice (OAR, 2009). Thus, it appears that for many young people with ASD and their families, the intended impact of IDEA's transition mandate has failed to materialize, leaving large numbers of adults with ASD without the skills necessary to meet the demands of life postsecondary school, and their families to try to fill in the gap. This limits these young adults' ability to be productive members of society.

Without adequate supports, many families take on responsibilities for managing their young adult son or daughter's life, long after these responsibilities end in families of typical young adults. This is a source of stress for many caregivers and family members, which may contribute to decreased health and well-being (Abbeduto, Seltzer, & Shattuck, 2004; Lee, Harrington, Louie, & Newschaffer 2009). Survey research reports that concern over their child's long term independence and personal quality of life is much greater among families with children on the autism spectrum of all ages than parents of children without disabilities (Easter Seals, 2008; Graetz, 2010; OAR, 2009). The time of transition from school to community is particularly stressful for caregivers, with families having concerns about their young adult's opportunities for employment, residential living, and socialization. Additionally, parents and caregivers find that they must advocate on behalf of their children long into adulthood. Some research suggests

that parents with higher education and socioeconomic status have stronger advocacy skills and are better able to secure the available services on behalf of their children. A parent who is not well equipped to navigate the system, based on limited means and education often finds securing services especially difficult (Anderson, 2010, Bhasin & Schendel, 2007; van Meter et al., 2010).

There are also financial burdens associated with raising a child, and later a young adult on the autism spectrum. Current costs of ASD reflect care giving provisions in adulthood, and lost income in individuals with ASD and their families. (Lord & Bishop, 2010). When compared with typical families, families of children with autism report being significantly more afraid that their child will not have sufficient financial support after the parent dies, the cost of caring for the child will drain the family's current and future financial resources, and the cost of raising their child with autism will have a financial impact on other siblings (Easter Seals, 2008). Their concerns are justified as, compared to families with typically developing children, there is an estimated additional cost of 3-5 million dollars necessary to care for an individual with ASD over the course of his or her lifetime (Lord & Bishop, 2010). Additionally, many families of a young adult with autism live on a single income, and incur debt as the demands of supporting their child, even as he or she reaches adulthood, preclude both parents working full time (Eskow, Pinelis & Summers, 2011; Lord & Bishop, 2010). The family member with autism clearly impacts family functioning and quality of life of the family unit.

### **Quality of Life**

Quality of life is a measure of satisfaction with one's life. While there are many definitions of quality of life, it is generally agreed that quality of life occurs when a

person has opportunity to pursue and achieve goals in the home, in the community, and at work (Schalock, 2000). It is also generally agreed that the quality of life of individuals is related to those around them, which points to the need to look at families when examining quality of life.

Family quality of life (FQOL), an extension of individual quality of life, is a dynamic sense of well-being of the whole family. When the quality of life of a family is satisfactory, each member is likely to be emotionally healthier, and participate in activities at home and at work (Zuna, Summers, Turnbull, Hu, & Xu, 2011). For a family to experience quality of life, its members must have the opportunity to pursue goals in all areas of life (Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003). It would follow then, when the family includes a person with a disability, that person's quality of life would affect the quality of life of the entire family.

When the family includes a person with a developmental or intellectual disability, such as a young adult on the autism spectrum, it is imperative to use a support paradigm when addressing quality of life. This means that for quality of life to occur, the environment needs to be reinforced with various opportunities and resources (Brown & Brown, 2005). Unfortunately, as already stated, the need for appropriate services continues to exceed available resources, especially for transition aged youth. In the state of Maryland, families seeking services through the two agencies designated as access points for adult services, the Developmental Disabilities Administration [DDA] and the Division of Rehabilitation Services [DORS], are often met with restricted eligibility requirements, lengthy waiting lists and limited funding ( Division of Rehabilitation Services [DORS], 2010). It would follow, then, that this inadequacy of the adult service

delivery system resources can limit both the individual and family members' abilities to participate in desired activities and occupations and would impact quality of life of the entire family.

### **Purpose Statement**

While quality of life in families living with autism has been a topic of study in recent years, the focus of these studies has largely been with families with younger children. Transition is a very challenging and complicated process for young adults with ASD and their families (Eaves & Ho, 2006; Hendricks & Wehman, 2009; OAR, 2009), and there have been far fewer studies exploring families with young adult children in this stage of life. Even fewer of these studies examine participation in desired occupations and activities in families with a young adult child with ASD.

The purpose of this study which was part of an on- going multiphase study at Towson University was to examine the phenomenon of FQOL among families of transition aged young adults with autism. This study used a phenomenological approach to explore issues and to gain an understanding of family needs and concerns from the perspectives of parents and caregivers of transition aged youth. It explored the young adult's and the family's abilities to engage in meaningful activities and occupations. Understanding the perspective of the family is important. As we learn what enhances the young adult with autism and the family's quality of life, including the ability to participate in desired activities and occupations within the community, the more we can influence the professionals and policy makers who provide services to those on the autism spectrum and their families.

Additionally, this study included a small pilot study exploring sensory processing in the transition age youth on the autism spectrum. The impact of sensory processing on family quality of life in families with transition aged youth has not been systematically studied. It is important to understand whether supports that mediate the effects of sensory processing difficulties might enhance a transition aged youth's ability to participate in occupations and activities, and thereby affect the well being of the family.

### **Occupation Based Theoretical Perspective**

**PEO Model.** In addition to quality of life, the Person-Environment-Occupation [PEO] model (Law, 1996) of occupational therapy is the theoretical perspective that was used to guide this study. PEO reflects the complex interactions between the person and the environment in which individuals carry out activities and occupations that are meaningful to them. The model is conceptualized as the person, his or her environments, and occupations interacting dynamically over time. The person is the individual who possesses numerous roles and performance components. The environment in which an individual participates in an activity or occupation, has the potential to enable or hinder an individual's ability to carry out occupations and activities. The environment is conceptualized broadly according to PEO. It includes cultural, physical, social, and institutional factors, and can impact a person, family, or community. Occupation is defined as an activity or task in which a person engages. An occupation is chosen for the meaning it has to the individual or group of individuals. The transaction between the person, environment and occupation results in occupational performance, which is the outcome of the model, whereby the individual is engaged in meaningful and purposeful activities within an environment (Strong, et al., 1999).

The three components of the PEO model, person, environment, and occupation, change over time, resulting in various degrees of occupational performance (Law et al., 1996). This allows the model to consider developmental changes throughout the life span. When looking at the transition aged adult with autism, one can see that a reduction in supports and services from those provided in the school system would impact the PEO interaction, and as a result, could result in a decline in occupational performance. Additionally, the PEO model is flexible enough to not only view the individual with autism in the context of his or her family and the supports and services he or she receives, but also allows us to view the family in the context of having a young adult child on the autism spectrum (Law et al., 1996).

The PEO model was developed to examine complex occupational performance issues (Strong et al., 1999). It was therefore well suited to guide this study, as it is clear from outcome studies that young adults with ASD lack optimal occupational performance (Graetz, 2010; Howlin, 2000; OAR, 2009). It was also very well suited to examining quality of life, because, quality of life is considered to be an outcome of the person, environment, occupation transaction. According to PEO, “the quality of a person’s experience, with regard to level of satisfaction and functioning, is the outcome of the fit between the person-environment-occupation transaction” (Strong, et al., 1999, p. 124). Related to this, quality of life is also considered an outcome of occupational therapy (AOTA, 2008). Moreover, both PEO and family quality of life point to the importance of environment as having the capacity to support or hinder occupational performance. Turnbull, Summers, Lee, and Kyzar (2007), who have studied family quality of life extensively, emphasize the importance of using a support paradigm when discussing

quality of life with families who have a member with an intellectual or developmental disability, which places emphasis on infusing accommodations and supports into various contexts. This is consistent with PEO.

**Social and occupational justice.** Additionally, this study was guided by firm beliefs in social and occupational justice. Social justice includes political, educational, legal, economic, social and other human rights of people (Bruner, 2008). Social justice encompasses equality, empowerment, fairness in the relationship between people and the government, equal opportunity, and equal access to resources (Braveman & Bass-Haugen, 2009). According to principles of social justice, everyone is entitled to be able to meet his or her basic needs for income, shelter, and other necessities. Everyone is also entitled to self-respect and equal citizenship, which demand more than a meeting of basic needs—but demand opportunities and life chances (Braveman & Bass-Haugen).

Occupational justice is a similar construct which addresses the inequities that arise when participation in occupations is “barred, confined, restricted, segregated, prohibited, undeveloped, disrupted, alienated, marginalized, exploited, excluded, or otherwise restricted” (Townsend & Wilcock, 2004 p.77). This is what can and does happen when young adults with ASD have limited opportunities to pursue occupations and activities within their communities. It also happens when family members are unable to participate in activities and occupations that are meaningful to them, because of care demands of their adult children with ASD. Central to the concept of occupational justice is the provision of resources to meet the differing occupational needs of people and populations (Wilcock, 2006). Both social and occupational justice are consistent with PEO and quality of life approaches, which emphasize the allocation of resources to meet

needs. They provide an appropriate lens to examine quality of life in transition aged youth and their families, and remind us of the importance of participation in occupation to health and well-being.

### **Summary**

The incidence of ASD has increased dramatically in the last decade, leading to a growing number of adults with an autism diagnosis. As ASD is a permanent developmental disorder, those with ASD often have challenges that continue into adulthood. Given the heterogeneity of the spectrum disorder, adolescents and adults with ASD continue to need a variety of services and supports to meet their needs, although in many communities, demand far exceeds the supply of these services (Hendricks & Wehman, 2009; OAR, 2009). In the absence of standard societal mechanisms to pay for appropriate assessment and treatment, families often shoulder many of responsibilities and costs associated with securing appropriate services for their children (Lord and Bishop, 2010). This impacts occupational performance, and the quality of life of the entire family unit.

Although there has been a growing body of literature written about young adults with ASD, there still is a limited amount of evidence based literature looking at young adults at age of transition to adulthood and their families, especially from an occupational lens. The current study applied PEO and FQOL models to explore the needs of transition-age youth with ASD and their families. The following chapter reviews the literature that is related the factors influencing FQOL for these young adults and their families.

## **Chapter 2:**

### **Literature Review**

#### **Introduction**

It is generally accepted that an unprecedented number of those with ASD are reaching adulthood (OAR, 2009). While autism is an individual diagnosis, the impairments in social interaction, communication, and behavior that characterize it may have a profound effect on the family unit, exceeding the impact of other disabilities (Brown, MacAdam- Crisp, Wang, and Iarocci, 2006; Eskow, Pinelis, & Summers, 2011; Lee et al., 2008). Transition to adulthood represents a significant challenge for individuals on the autism spectrum and their families.

It is therefore important to closely examine studies of transition age young adults on the autism spectrum and their families to try to ascertain what contributes to positive outcomes and quality of life. As an increasing number of youngsters with ASD reach later adolescence and adulthood, it is essential to understand what contributes to a positive quality of life for them and their families so that ultimately services can be developed that provide support to those on the autism spectrum and their families and communities.

This literature review begins with a cursory examination of the characteristics of young adults on the autism spectrum, including a discussion on sensory processing. This is followed by a brief review of the legislation and funding relevant to transition age youth and adults with ASD. Next, the construct of family quality of life is explored, which is followed by a discussion of factors that significantly affect the quality of life of young adults with ASD. These include higher education, employment, social

relationships, choice, self- determination and self advocacy, and community living.

Following this, there is a discourse on the ramifications of having a transition age young adult with ASD on family members. Specifically, transition and the family, caregiver burden, and siblings are discussed. The effect of the person, environment, and occupation transaction on occupational performance is discussed throughout.

### **Characteristics**

Autism is a developmental disorder that is ordinarily diagnosed in early childhood. However, the impairments associated with it generally persist throughout the life time, and pose ongoing challenges for the individual and his or her family (Howlin et al., 2004; Seltzer et al., 2003). Most studies of the characteristics of ASD have examined children. The body of literature examining adolescents and young adults with ASD is comparatively small (Schall & McDonough, 2011, Seltzer et al., 2003). Understanding the life course pattern of ASD is essential for understanding the impact of autism on the family and society, and ultimately for developing appropriate interventions and systems of support.

Research suggests that individuals with ASD are at increased risk for health problems, when compared with people in the general population. This risk increases as individuals get older (Kring, Greenberg, & Seltzer, 2010). Physical health may be compromised, particularly in adolescents and adults with autism (Barnhill et al., 2007). Gastro- intestinal problems have been specifically noted in the literature (Kring et al., 2010). Kring et al.(2010), in their longitudinal study with a large community based sample of adolescents and adults with ASD, report that those who have health problems

are more likely to experience subsequent behavior problems, which can be problematic for their families.

Epilepsy is also reported in the literature, and it is associated with decreased adaptive functioning in adolescents and adults with ASD (Danielsson, Gillberg, Billstedt, Gillberg, & Olsson, 2005; Mourisden, Rich, & Isager, 2011). Recent studies suggest that about one third of children with autism (Danielson et al., 2005; Mourisden et al., 2011) have been diagnosed with epilepsy some time in their lifetime. Researchers have concluded that epilepsy is a co-morbid condition associated with ASD (Mourisden et al., 2011)

Studies show that a majority of individuals with both autism and epilepsy have decreased social and cognitive functional abilities in adulthood. For instance, in a study by Smith and Matson (2010a), one hundred participants, all with an intellectual disability (ID) were matched and compared across four equal groups comprising 25 participants with ID alone, 25 participants with epilepsy, 25 participants with ASD, and 25 participants with combined ASD and epilepsy. When controlling for age, gender, race, level of intellectual disability, and hearing and visual impairments, significant differences were found among the four groups. Individuals with both ASD and epilepsy were found to have more impaired social skills than the ID only group, or groups containing either epilepsy or autism alone. These researchers also examined behavioral differences among these same groups in another research study, and findings were similar, in that adults with ID and both ASD and epilepsy had significantly more aggression and stereotypic behaviors than in the other groupings (Smith & Matson, 2010b). Adults with both autism and epilepsy in Danielsson et al.'s (2005) study had more severe cognitive impairment

than did adults with autism and no epilepsy. These studies support previous literature in which epilepsy is shown to be to be a negative prognostic factor for the outcome of autism (Nordin & Gilberg & 1998).

Even in the absence of complicating factors such as epilepsy, the literature suggests that most individuals with ASD demonstrate uneven cognitive skills (Aspy & Grossman, 2011). At least 10% of young people with ASD have been estimated to have savant characteristics, demonstrating exceptional skill in a particular area, a characteristic that continues into adolescence and adulthood (Hill & Frith, 2003). Executive function has been found to be impaired, even in those with normal intelligence, as has the ability to infer the mental state of others, commonly referred to as theory of mind (Ozonoff, Pennington, & Rodgers, 1991). Additional cognitive differences seen in young adults with ASD include poor problem solving, limited organizational skills, and distractibility (Aspy & Grossman, 2011).

Similarly, social and behavioral issues are seen in adults with ASD, even in the absence of co-morbid diagnoses. According to Shattuck et al. (2007), who studied 241 adolescents and adults with ASD over a 4 ½ year period, the lack of friendships is the most frequently seen social characteristic in this age group. The lack of friendships has likewise been reported in multiple studies (Howlin, Good, Hutton, & Rutter, 2004; Matson, Wilkins, & Ancona, 2008; Orsmond, Krauss, & Seltzer, 2004; Seltzer et al., 2003). Repetitive patterns of behavior are also common in young adults with ASD, although they may look different in those that are higher functioning on the autism spectrum. Preoccupation with areas of interest may be seen in those on the higher end of

the spectrum, whereas repetitive behaviors in those with intellectual disabilities may include body movements such as rocking or finger flicking (Aspy & Grossman, 2011).

Autism and severe intellectual disability put the individual at greater risk for developing challenging behaviors such as aggression and self-injurious behavior (Hill & Furniss, 2006). Matson, Wilkins, and Ancona (2008), in their study of 57 adults with autism and severe intellectual disability matched by age, gender, and verbal ability with the same number of controls with a diagnosis of severe ID without autism, found that there were significant impairments in social interaction and restricted or repetitive behaviors and interests in the autism group compared to the group with ID alone.

**Autism in adults.** Seltzer, Shattuck, Abbeduto, & Greenberg (2004) in their systematic review of 25 studies on characteristics of adults with ASD performed between 1971 and 2004, concluded that despite variability in diagnostic practices, and differences in design, sample, and measures of these studies, the evidence suggests that symptoms of autism lessen to some degree during adolescence and young adulthood. However, not all adolescents and young adults show improvement, and even with improvement, impairments can remain severe. In this group of researchers' original research, Seltzer et al. (2003) found that many communication abilities improved in adolescence and adulthood, and that 70% of those individuals in their sample of 405 adolescents and adults developed some functional communication skills by the time they reached adulthood. According to the already discussed Shattuck et al. (2007) study, at these stages of life, there are greater impairments in nonverbal communication and social reciprocity than in verbal communication.

Characteristics of autism, such as limited development of language or other forms of social communication, continue through adolescence and adulthood. Though the literature reports that adolescents and transition aged young adults with autism may improve in some skill areas, the rate that they improve does not sufficiently accommodate the increasing demands placed upon them as they grow older. Studies that follow children with autism into adulthood demonstrate that the impairment in language continues to limit functional skills (Howlin, 2003; Howlin, Mahwood & Rutter, 2000; Seltzer et al., 2003; Seltzer et al., 2004) and is “central to the disorder and might underlie many other areas of dysfunction” (Howlin, et al., 2000, p. 572).

Not only are those with ASD less able to understand verbal and non verbal expressions in others due to limitations in language, but also they have difficulty understanding and managing their emotions (Aspy & Grossman, 2011). This contributes to decreased emotional well being, which, as will be discussed, impacts family quality of life. As already suggested, when under stress, children on the autism spectrum of all ages are at greater risk of rage and tantrums (Myles and Southwick, 2005). Also, many studies suggest that those with ASD have higher rates of depression, anxiety, and social anxiety than those without ASD (Ghaziuddin, Ghaziuddin, & Greden, 2002; McPheeter, Davis, Navarre, & Scott, 2011; Sterling, Dawson, Estes, & Greenson, 2008).

In their study of 34 adults with autism, Gillot & Standen (2007) found that these young adults were three times more anxious than a comparison group, and showed significantly higher scores in measures of panic, agoraphobia, and separation anxiety. The autism group also reported more stress, particularly concerning the ability to cope with change. Similarly, Bradley, Ames, & Bolton (2011) interviewed caregivers of 36

adolescents aged 14-20 with intellectual disability and autism, and the same number of controls matched for age and IQ but without autism, to examine the incidence of psychiatric disorders. Data analyses revealed significantly elevated levels of stereotypic behaviors and compulsions in the ASD group. Further, the authors also found increased numbers of fears and phobias in the ASD group as well as significantly increased anxiety. The primary author of this study reported similar results in an earlier study with 12 young adults with severe intellectual disability and autism, and a matched group without autism (Bradley, Summers, Wood, & Bryson, 2004).

**Sensory processing.** Although not considered a defining symptom of ASD, unusual sensory processing has long been reported. Most research examining sensory processing has been with children, and in fact, in this population sensory differences have been found in the majority of children ( Baraneck, David, Poe, Stone, & Watson, 2006; Rogers, Hepburn & Wehner, 2003; Watling, Deitz, & White, 2001; ). For instance, Tomcheck and Dunn (2007) found in a sample of 283 young children with ASD, that 95% demonstrated significant sensory processing difficulties. Sensory differences have been described in multiple senses, and include hypersensitivity, hyposensitivity, and general sensory overload (O'Neill & Jones, 1997).

The Sensory Profile (Dunn, 1999) has been widely used to examine sensory processing, and to differentiate children with autism from children with other diagnoses and typically developing children. Rogers, Hepburn, and Wehner (2003), who used the Sensory Profile to measure sensory responsiveness, showed through correlational analyses that neither overall developmental level nor IQ of the child was related to sensory reactivity. However, they did find that abnormal sensory reactivity had a

significant relationship to overall adaptive behavior as measured by the Vineland Adaptive Behavior Scales. Examination of sensory processing in adolescents and adults has been much less plentiful, and the influence of sensory processing on adaptive skills and occupational performance has not been as systematically studied.

Kern et al. (2006) used the Sensory Profile to examine 104 children and adults ages 3-56, and age and gender matched typical peers with ASD, and like the studies examining children alone, found differences in sensory processing in the ASD population. Those with autism had abnormal auditory, visual, touch, and oral sensory processing that was significantly different from controls. However, lower levels of abnormal sensory processing were found in the adults than the children except for over-responsivity to touch, which did not improve with age. This might indicate the possibility that those with ASD can develop effective compensatory sensory strategies as they get older, although this cannot be concluded. In another study by these same researchers, correlation between the sensory profile results and the severity of autism as measured by the Childhood Autism Rating Scale [CARS] (Schopler Reichler, & Renner, 1994) suggests that sensory dysfunction in autism may relate to the severity of autistic symptoms in children, although this is not the case in adults (Kern et al., 2007).

Leekam, Nieto, Libby, Wing, & Gould (2007), in a study of 200 children and adults with ASD, using The Diagnostic Interview for Social and Communication Disorders [DISCO] (Wing, Leekam, Libby, Gould, & Larcombe, 2002), an assessment that examines characteristics of autism, found that over 90 percent of those with ASD showed significant sensory processing difficulties. Abnormal sensory processing was found in all ages, and in individuals that were labeled as both high and low functioning,

based on their IQs. The domains of touch and smell/taste that distinguished autism and non-autism groups in their studies with children (Leekam et al., 2007) did not change with age or IQ, although other sensory domains such as vision appeared better at older ages. While the great majority of individuals with autism had symptoms in more than one sensory domain, these researchers found that younger low-functioning people were affected by more types of sensory processing difficulties than older and higher functioning individuals.

Crane, Goddard, & Pring (2009) exclusively examined sensory processing in adults with ASD, in their study with 18 adults aged 18-65, and the same number of age, gender, and IQ matched comparison participants. They used the Adolescent/ Adult Sensory Profile (Brown & Dunn, 2002), which is based on the already mentioned Sensory Profile. The Adolescent/Adult Sensory Profile can be filled out by a caretaker, but was designed to be used as a self report measure, which was done in the Crane et al. study. Results indicated that, consistent with studies with children and those with both children and adults, 94.4 percent of the ASD sample demonstrated sensory processing difficulties in at least one of the four sensory quadrants measured. These quadrants include low registration, or responding slowly or not noticing sensory stimuli; sensation seeking, or actively pursuing sensory stimulation; sensory sensitivity, or experiencing discomfort in response to sensory stimuli; and sensory avoiding, or engaging in behavior to reduce exposure to sensory stimulation. Specifically, they found that the ASD group showed higher scores in the low registration, sensory sensitivity, and sensation avoidance quadrants, but scored lower than the comparison group in the sensation seeking quadrant. The authors also concluded that there were significant within group variations in sensory

processing among those with ASD, suggesting that those with ASD might have very different, yet similarly severe deficits in sensory processing. Also consistent with the previously mentioned Kern et al. (2007) study, no significant correlations were observed between the levels of autistic traits and levels of sensory processing. However this study must be interpreted with caution not only due to its small sample size, but also because all of the participants with ASD were very high functioning and had IQs that were in the above average range (Crane et al., 2009).

While these studies support the existence of sensory processing difficulties in autism that persist into adulthood, they do not examine the relationship between sensory processing and the self regulation difficulties seen in individuals with ASD nor do they look at the effect of sensory processing on daily living for the young person with ASD or for the family. Only one single case study was found that appeared to address any of this in transition age young adults with ASD. Schoener, Kinnealy, & Koenig (2008) discuss a single case study, in which a young man, previously classified as intellectually disabled, expressed, once he learned to communicate through typing, that interventions to enhance sensory function improved his ability to move, communicate, and interact. While this study is certainly not generalizable, it does suggest that disordered sensory processing might be related to the defining characteristics of ASD and may point to the need to consider interventions that address sensory processing for young adults on the autism spectrum. This study also suggests that there is a link between the sensory processing problems that a person with autism experiences and difficulties in managing daily life. However, Schoener et al. did not seek to understand how the sensory and daily life

difficulties affected the family unit. To date, the literature has not examined whether sensory processing difficulties in young adults affect family quality of life at all.

Understanding the problems that are unique to this population of adolescents and young adults with ASD and to this time of life will help individuals, families, schools, and support agencies develop the types of plans and services that can truly support the transition to adulthood (Geller & Greenberg, 2010). The fact that characteristics of autism can continue to change in adolescence and adulthood, further reinforces the need for services for transition age youth with ASD and their families (Shattuck et al., 2007). Therefore, it is essential to examine the services that are legislated and funded for this population.

### **Legislation and Funding**

A comprehensive review of legislation and funding is beyond the scope of this paper. However, it is important to examine the legislation that impacts the services that those with ASD receive, especially considering that quality of life, when addressing individuals with disabilities is dependent on the “congruence of public policy and behavior” (Schalock, 2000, p. 118). Further, it is important to review legislation and funding in Maryland in order to understand the context of the experiences reported by the participants in this study. While still in school, adolescents receive services through the Individuals with Disabilities Act (IDEA), which is mandated by law. IDEA is essentially an entitlement program. The law says that every person who meets certain criteria is entitled to receive such services, and they cannot be turned down. A diagnosis of ASD meets these criteria. This is in stark contrast to the laws governing young adults once they have aged out of the school system.

**IDEA transition requirements.** IDEA mandates that students with disabilities are entitled to a free and appropriate public education in the least restrictive environment possible, and that supports and resources are to be made available so this can be carried out. It also dictates that transition planning be in place to effectively prepare students with special needs, including those with ASD, for post-graduation education, vocational training, employment and community living. Transition planning is required to be part of a student's Individualized Education Program (IEP) beginning no later than his or her 16th birthday (United States Department of Education [USDE], 2004).

Under IDEA, transition planning requires the development of measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and independent living skills (USDE, 2004). The goal in educating students with disabilities is supposed to be to help them become productive members of society as adults; however, often schools fail to direct these students into meaningful employment opportunities that are appropriate for their strengths and achievements (Hendricks & Wehman, 2009). Supportive pre-vocational activities, including learning about appropriate work behaviors and supported volunteer and internship experiences, should be included as part of the transition process, however these are not consistently provided (Geller & Greenberg, 2010). Other barriers to transition planning include lack of knowledge of resources and funding and eligibility requirements (Geller & Greenberg, 2010). Individuals are no longer covered under IDEA after the year of their 21<sup>st</sup> birthday, even if transition goals have not been fully addressed and met. (OAR, 2009; Geller & Greenberg, 2010).

**Relevant laws supporting adult services.** There are no federal laws or regulations specifically designed to provide for vocational and employment assistance to adolescents and adults with ASD. These specific concerns are generally subsumed under the laws that provide personal and systemic protection for individuals with disabilities. Included in the relevant disability legislation, in addition to the already mentioned IDEA, are the Vocational Rehabilitation Act of 1973 (VRA), the Ticket to Work Incentives and Improvement Act of 1999, and the Americans with Disabilities Act (ADA). The Olmstead decision and Medicaid Health and Community Based Waivers are also relevant.

The Vocational Rehabilitation Act of 1973 (VRA), and specifically section 504 of the VRA is an anti-discrimination law that provides equal access for individuals with disabilities to any program, service or activity receiving financial assistance from the federal government. The VRA also provides money for time-limited job training and employment assistance at the state level. In 1986, Congress amended the VRA to include language on the importance of transition and transition services. However, many people with autism have not been successful in getting VRA services, which is due in part to outdated concerns regarding their ability to remain employed following the cessation of the time-limited supports (Revell & Miller, 2009) authorized under the VRA.

The Ticket to Work and Work Incentives Improvement Act of 1999 provides specific financial resources in support of adults with disabilities. It is an employment program for individuals with disabilities who are already receiving Social Security benefits (Revell & Miller, 2009). The goal of the program is to increase opportunities and choices for adults to obtain specific employment-related services from both public and

private providers. Through this program, the individual may secure employment-related services through an approved agency. Services offered include job readiness and work skills assessment, career counseling, employment placement, internships and apprenticeships, job coaching, or transportation. Related to this, in 2006, the Social Security Administration (SSA) established the Work Incentives Planning and Assistance (WIPA) program to help address the need for effective benefits planning. Work Incentives are programs under SSA that allow individuals with disabilities to remain employed without the loss of medical benefits (Revell & Miller, 2009).

The Americans with Disabilities Act (ADA) promotes community access and participation by people with disabilities of all ages. The ADA prohibits discrimination against individuals with disabilities in the areas of employment, transportation, public accommodations, public services and telecommunications. The ADA also makes it unlawful for employers to discriminate against potentially qualified employees on the basis of a disability. Under the ADA, employers are required provide reasonable accommodations to workers who are able, with such accommodations, to perform the essential functions of the job. The impact of ADA on the employment of individuals with autism has not yet been tested (OAR, 2009).

**Home and community based services (HCBS) waiver supports.** In 1999, the US Supreme Court issued a ruling in the case of *Olmstead v. L.C.*, which affirmed the right of people with disabilities to receive public benefits and services in the most integrated setting most appropriate to their needs. This means that services need to be delivered within the community whenever appropriate. The Court ruled that failing to do so is a violation of the ADA (Kaiser Family Foundation, 2004). The *Olmstead* decision

has been used to support the provision of Medicaid Home and Community Based Services (HCBS) Waivers, which support service provision in the community. HCBS waivers have generally been used to provide funding for those with developmental disabilities, including autism, in order to support community-based services to individuals with disabilities who otherwise would require institutional care. HCBS waivers provide an alternative to the provision of comprehensive long-term care services in institutional settings, and are funded jointly by the state and federal governments.

Certain provisions of the Social Security Act are waived when providing HCBS waivers. The section regarding equal access, or state wideness, as phrased in the Social Security Act, is waived, so that states can target waivers to particular areas of the state where the need is greatest. Also, the section regarding comparability of services is waived, so that states can make waiver services available to people at risk of institutionalization, like those with autism, without being required to make them available to the whole Medicaid population. Lastly, regulations regarding income and resources are waived. This allows states to provide Medicaid to people in the community who would otherwise be ineligible due to income and resources of a parent or spouse (Center for Medicare and Medicaid Services [CMS], 2011). The State Medicaid Agency has the ultimate responsibility for a HCBS waiver program, although it may delegate the daily operation of a program to another entity. In the case of the Maryland Medicaid Autism Waiver, that entity is the Maryland State Department of Education [MSDE] (CMS, 2011).

**HCBS waiver services in Maryland.** The Maryland Medicaid Autism Waiver is a HCBS waiver available to children and adolescents with autism, until the end of the

school year in which they turn 21. Like other Health and Community Based Services waivers, there are a limited number of recipients funded for the waiver. There are approximately 900 autism waiver slots in the state, and MSDE maintains a large registry or waiting list, consisting of approximately 3,000 individuals (Eskow, Pineles, & Summers, 2011). Although the Maryland Medicaid Autism Waiver does not serve adults with ASD, it is relevant to this discussion. First, transition services are among the waiver services provided to the individual with ASD (MSDE, 2010). Additionally, as is clearly explained in chapter three, participants for the current study were obtained from MSDE from those families who were recipients of the autism waiver or on the autism waiver registry.

Additional Health and Community Waiver Services are available to adults with developmental disabilities, including those with autism, although they are not specific to those with ASD. One such waiver in Maryland is the Community Pathways Waiver, which includes residential and supported employment services. Additionally, it covers family and individual support services for eligible individuals. Community Pathways serves nearly 9,000 people of all ages with developmental and intellectual disabilities in Maryland (Developmental Disabilities Administration [DDA], 2010).

HCBS waiver funds are generally used to fund programs and services and are not provided to the person or to the family directly. However, some states, including Maryland, do have HCBS waivers in which people with ASD and other developmental disabilities are given funding to purchase the services and services that they need in order to live and work in their communities. This waiver in Maryland is called the New

Directions Waiver. The New Directions Waiver is limited to only 100 people with developmental disabilities (DDA, 2010).

**State agencies.** Most community based services to adults with ASD are funded through two state administered agencies which receive federal funding: Vocational Rehabilitation (VR), or Developmental Disabilities (DD) (OAR, 2009). In Maryland, VR services are administered through the State Department of Education Division Of Rehabilitation Services (DORS), and DD services are administered through the Developmental Disabilities Administration (DDA). State Vocational Rehabilitation agencies offer time limited job training, employment support, counseling, education, and other services deemed necessary to prepare an individual to work. Developmental Disabilities agencies, on the other hand, assume an ongoing need for intervention. DD agencies generally provide more long term services including supported employment, day programming, residential services, and case management. The already mentioned adult waivers are administered through DDA (DDA, 2010). Eligibility for services provided by both Vocational Rehabilitation and Developmental Disabilities funding varies on a state by state basis, with some states limiting eligibility to those with an IQ less than 70 (OAR, 2009). The restriction in eligibility limits this as a source of funding to many people with ASD. The state of Maryland maintains a long waiting list for services, with those with the most severe needs taking priority (DORS, 2009). However, DDA does offer low intensity support services (LISS), which may be granted to an individual with developmental disabilities, no matter what their priority status. LISS services are provided on a first come first served basis, and offer up to \$3000 per year to

provide for the needs of a child with a developmental disability within the home or an adult with a developmental disability within the community (DDA, 2011).

Although there are laws and services available to assist individuals with disabilities after they transition from secondary school, they are not afforded to all those who need them. Individuals with ASD and their families often struggle with multiple aspects of life (OAR, 2009; Geller & Greenberg, 2010). Once they leave the public school system, due to a shortage of services and programs, especially regarding employment and community living, young adults with ASD become less visible to general public and more dependent on their family caregivers (Graetz, 2010). For these reasons, the construct of quality of life needs to be examined.

### **Quality of Life**

Quality of life is a broad multidimensional construct that is not universally defined. It is believed to be a measure of general satisfaction with one's life, however its true meaning is difficult to ascertain because of its highly individual subjective nature. When referring to individuals with intellectual disabilities quality of life occurs when a person's basic needs are satisfied and “. . . he or she has the same opportunity as anyone else to pursue and achieve goals in the major settings of home, community and work” (Schalock, 2000, p 118). While dimensions of quality of life of individuals with developmental and intellectual disabilities, including autism, have been examined in the literature (Graetz, 2010; Renty & Royer, 2006; Verdugo, Schalock, Keith, & Stancliffe, 2005; Wehmeyer & Schalock, 2001), it is generally agreed that the quality of life of individuals is related to those around them, which is why it is important to look at families when examining quality of life.

**Family quality of life.** For this reason, the construct of family quality of life (FQOL) has been advanced. The involvement of families is a natural extension to the examination of individual quality of life for “family quality of life addresses the impact of individual quality of life on the family- the interaction and reverberation of individual members as they produce the aggregate of family quality of life” (Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003, p.319). While there are several definitions of family quality of life, Zuna et al. (2011) emphasize, based on their review of the literature, that the essence of family quality of life reflects the belief that the family as a whole is responsible for meeting the individual needs of each of its family members. FQOL, therefore, examines the entire family and the experiences that the members have as individuals as well as the unit, defining meaning and purpose for all members of the family. Family quality of life addresses many of the ways autism affects families, and is therefore an important outcome to examine in families with children of all ages with ASD. However, thus far, research has been done predominantly with families with children, rather than young adults with disabilities.

There are various domains that define family quality of life in families with individuals with a disability. Poston, Turnbull, Park, Mannan, Marquis and Wang (2003) conducted a qualitative grounded theory inquiry to investigate family quality of life and identified 10 domains: advocacy, health, productivity, emotional well-being, physical environment, social well-being, daily family life, family interaction, financial well-being and parenting. In the process of developing a tool to measure FQOL, Park et al. (2003) indicated refinement of the ten domains was needed. By consolidating the original ten domains, the number of domains was subsequently reduced. Further analyses resulted in

these five domains of family quality of life: family interaction, parenting, emotional well-being, physical/material well-being, and disability related support (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). These domains reflect both the individual and family unit aspects of FQOL, as family interaction and parenting are family oriented domains, whereas physical/material well being and emotional well being are individual oriented domains (Zuna et al., 2011).

Since quality of life of individuals within the family, including the transition aged young adult with autism, is intricately connected to FQOL as a whole, individual outcomes regarding the young adult with autism are viewed within this context throughout this paper. This view is consistent with Zuna et al. (2011), who emphasize the importance of strengthening the link between the family and individual quality of life. Looking at the family as a unit contributes to more effective supportive services and overall improved long term outcomes for the family member with a disability (Hoffman et al., 2006; Park et al, 2003; Smith-Bird & Turnbull, 2005; Schalock, 2000; Summers, Hoffman, Marquis, Turnbull, Poston,& Nelson, 2005). This connection between individual and family quality of life becomes more essential to examine as more and more families with individuals with intellectual and developmental disabilities are providing ongoing care and support to adult children within the community (Brown et al., 2003).

Zuna et al. (2011) emphasize that services and supports that may be available to a person with a disability impact both the family unit and the individual members. This is reflected in the domain of disability related support. Consistent with this domain, Turnbull, Lee, and Kyzar (2007) and Brown and Brown (2005) consider the practical

implications of the ideas behind a quality of life approach for both individuals and families at the levels of community, policy and management. They argue that for individuals with disabilities and their families, the environment must be reinforced with various opportunities and resources in order to attain quality of life (Brown & Brown, 2005). These supports are not only for the individual. Families need to be the beneficiaries of services as well, as not only are families affected by the disability of their family member, but also family support may be critical to effective outcomes for the family member with a disability (Zuna et al., 2011).

**Disability related support, quality of life, and autism.** The critical need for services as well as the interconnectedness of disability related support and quality of life are supported in research where findings demonstrate insufficient disability related services for children as well as adults with disabilities (Brown, Anand, Fung, Isaacs, & Baum, 2003; Eskow et al., 2011; Graetz, 2010; Renty & Royers, 2006). For instance, Renty and Royers (2006) found in their study with 58 young adults on the autism spectrum that a discrepancy between needed and received formal support was strongly associated with their quality of life. Adults with a high level of quality of life on the Quality of Life Questionnaire (Shallock & Keith, 1993) reported less formal support discrepancy compared to their counterparts who reported a lower quality of life. Based on a linear regression analysis, the authors concluded that quality of life of these individuals is most strongly associated with an unmet formal support need regarding accommodations, interpersonal relationships, daytime activities and ASD-specific information. They also concluded that perceived informal support is significantly related to quality of life. While study participants were likely higher functioning than those with

ASD in the families in the current study, it is notable that the majority of young adults in Renty and Royers' (2006) study sample lived with their parents, whom they perceived as "ready to provide support and aid if needed" (p.519). This points to the connection between support, the individual, and the family. This study also points to a good person environment fit, which is relevant to the person- environment- occupation model that is guiding the current study.

A more explicit linkage between support, the individual with autism and the family unit is illustrated in Brown et al.'s (2003) mixed methods study with 34 families with sons and daughters of all ages with intellectual disabilities including autism. Participating family members indicated that, although some services were available for their children with intellectual disabilities and their families, existing services did not sufficiently meet their family needs. Out of the 34 participant families, 14 families were dissatisfied and three families were very dissatisfied with services. This lack of effective disability related support influenced the quality of life of the whole family in many participants. Additionally, five of these families reported having very few financially affordable services available to them, indicating a financial burden associated with securing disability related support, which is reflective of the physical/material well-being domain of FQOL. While this study illustrates the relationship between support, the individual and the family, it also points to the interrelatedness of FQOL domains in FQOL research.

The ability of supports and services to enhance quality of life of families is also seen in Eskow et al.'s (2011) study of families with a member of the autism spectrum. In their survey study using the Maryland Autism Services Survey (MASS) with 229 families

with children and adolescents receiving services through the Maryland Medicaid Autism Waiver, and 632 families of children and adolescents of all ages on the Waiver registry or waiting list, those receiving waiver services reported an overall higher quality of life than those families with children and youth on the waiver registry. The emotional well-being domain of family quality of life was significantly higher in the group receiving waiver services than in the registry group although emotional well-being was lower in both groups than the other FQOL domains. Also, in this study, the majority of the respondents reported that having a child on the autism spectrum affected their own employment status, and employment status was improved in many of those receiving waiver services. This, too, has implications for the physical/material well-being domain of family quality of life as well as disability related support, and additionally reflects the interaction between person, environment, and occupation. It demonstrates a connection between programming, supports, and services provided to children up to age 21 with ASD, and FQOL as reported by the parents. Moreover, some of the services provided through the autism waiver support parents directly as well as the son or daughter with ASD. One must consider whether needs of the caretaker are being met when he or she has to make adjustments to employment status to engage in additional child care.

In another survey study of 143 caregivers of adults on the autism spectrum in the Midwestern U.S, seventy-two percent of respondents either disagreed or strongly disagreed when asked if services in their state were adequate for families supporting an adult with ASD. While many felt services were lacking, more than half felt that the use of the available support services had improved their family's quality of life (Graetz, 2010). Respondents caring for a family member with significant intellectual impairment

were especially dissatisfied with services in the state. This research points to importance of disability related support in enhancing quality of life of the family. This research also has implications for the current study, as most participants in the present study had sons and daughters who are also intellectually disabled.

As already suggested, even with disability related supports, many young adults with ASD remain highly dependent on their families following transition from secondary school. In order to fully appreciate the quality of life of families with an adult with ASD, it is important to examine postsecondary outcomes, which in typical transition age young adults, involve continuing education, employment, and community living skills. Opportunities in these areas have been limited for transition age adults with ASD, with young adults' needs in these areas not consistently met. (Graetz, 2010; Howlin et al., 2004; OAR, 2009). This has significant implications for FQOL. Continuing education and employment are relevant from a person- environment- occupation (PEO) perspective, as both represent areas of occupational performance that are usually important to transition aged youth.

### **Participation of Adults with ASD in Adult Community Life**

**Higher education.** Higher education is a typical occupation of transition aged young adults, however for families that have a young adult with ASD, a college degree may not be a likely outcome or, even a transition related goal (Camarena & Sarigiani, 2009). As will be discussed in chapter 3, due to the sampling methods, families who participated in the current study do not have children for whom college is a viable option. However, it is important to note, that many of those on the autism spectrum are intellectually capable of university level education, but require a range of academic and

supportive accommodations in order for them to be successful (Glennon, 2001). Thus, planning for college and attending college or other education programs, can indeed have implications for the study of FQOL in families with a son or daughter with autism. For instance, in a qualitative study with 21 high school aged adolescents and parents using semi-structured interviews, Camarena and Sarigiani (2009) found that parents had concerns related to uncertainties about their son or daughter's future college experiences regarding academics, social challenges, and obtaining services. Similarly, in a single case study by Silberberg (2010), a father of a college student with high functioning autism discussed the challenges of having a son on the autism spectrum in college and how his own week day routines revolve around helping his son with ASD successfully meet the demands of college, such as homework.

According to Roberts (2009), factors to be considered during transition planning from high school to post secondary education for students with ASD, are current academic achievement, self advocacy abilities, and time management skills. Another consideration must be the current accommodations and needs for which the adolescent is eligible while obtaining post- secondary education This is relevant to the exploration of sensory processing, since the accommodations that may be needed by those with ASD, may involve adjustments to the physical environment such as modification of overhead lighting and room alterations that reduce distracting background noise (Roberson & Ne'eman, 2008) that are not the typical accommodations provided in college (Sharp, Johnson, Izzo, and Murray 2005).

The nature of ASD can create unique challenges for individuals with ASD facing post secondary education. Through their review of the literature regarding ASD and post

secondary education, VanBergeijk, Klin, and Volkmar (2008) explored the challenges often faced by individuals with ASD. They found that dorm life can be one hindrance for these individuals, due to their difficulty with social skills. Organization of both self and time can also be major issues, as individuals with autism may not have the necessary skills to manage note taking, planning study time, or managing large projects. Due to the difficulties in the adult service system, obtaining appropriate services to assist with these needs can be an issue as well (Van Bergeijk et al., 2008). This can affect FQOL of the whole family unit.

Hart, Grigal and Weir (2010) identify dual or concurrent enrollment options for individuals with ASD and intellectual disabilities in their review of post secondary education outcomes, in which students take community college courses during their high school years to help ease the transition into college classes. Hart et al. also suggest auditing classes to allow a student to learn the information and skills without grades, and/or living at home and commuting to school. These alternatives can allow the families of the individual to be more involved and remove the challenges of dorm life (Hart et al., 2010). The young man in Silberberg's (2010) already cited case study lived at home, where he was able to receive additional living support. His father acknowledged that he assisted his son by doing things as making his lunch, which allowed his son with ASD to devote his energies to school tasks. Parents in Camarena and Sargiani's (2009) study felt that trade schools and community college programs might provide their children with alternatives to a traditional college education, to prepare their sons and daughters for employment.

**Employment.** Employment is considered a typical task of transition aged youth, with some working while attending school, and others going directly to the work force following secondary school. Employment is often a primary aspiration for those with ASD as they enter their postsecondary years, whether directly from high school or following postsecondary education (Hendricks, 2010). While employment provides a transition aged young adult with ASD opportunities to pursue and achieve goals in the areas of work and community, it is also essential to the physical/material well-being domain of family quality of life (Summers et al., 2005). Studies suggest that the development of work behaviors and employment may enhance quality of life and independence in adults on the autism spectrum (Garcia Villamisar, Wehman, & Navarro, 2002; Graetz, 2010; Persson, 2000), as well as reduce reliance on government support programs (Jarbrink, McCrone, Fombonne, Zandan, & Knapp, 2007).

Despite this, the impairments of individuals with ASD make obtaining and maintaining a job difficult, even for those with normal intelligence (Geller & Greenberg, 2010). Some of the characteristics associated with ASD that may be obstacles to employment include impairments in verbal and non- verbal communication, social relationship difficulties, improper social behaviors, heightened or reduced responses to the sensory stimulation, difficulty with executive functioning, and difficulty with changes in routine (Hendricks, 2010; Keel, Mesibov, & Woods, 1997;Muller, Schuler, Burton, & Yates, 2003). Even people with ASD who have managed to achieve a high level of education and have recognized qualifications for certain positions still have job status and levels of employment that are lower than those without the diagnosis (Eaves and Ho, 2008; Howlin,, 2000; Howlin et al., 2004;Mawhood & Howlin, 1999). Employment

status is even lower for those without such qualifications. Many need to rely on their families to find a job (Howlin, 2000). In the 2006 survey of 200 families with transition age youth and adults with autism through the University of Miami/Nova Southeastern University Center for Autism Related Disorders [CARD], 74% of adults with ASD reported that they wanted to work but they were unemployed. Similarly, Howlin et al. (2004) found in their follow up study with 68 adults on the autism spectrum that less than one third of them were in some form of employment, and that the majority remained dependent on their families for support, affecting family quality of life.

The rate of employment for those with ASD is lower than with any other disability group (Hendricks, 2010), with many reporting volunteer experience as their only form of employment (Eaves and Ho, 2008; Hendricks & Wehman, 2009). Even when employed, young adults on the autism spectrum tend to work fewer hours and make less money. They are also likely to be employed in more menial and less satisfying jobs than their typically developing counterparts (Eaves & Ho, 2008; Howlin and Mahwood, 1999, Jeness-Coussens, Magill-Evans, & Koning, 2006). This creates a poor financial situation for individuals with ASD, requiring them to rely on family members or societal programs for financial assistance (Cimera & Cowan, 2009).

Although little is known on how to best support people with ASD in achieving and sustaining employment, there are a few studies that demonstrate the value of such endeavors. Hillier et al. (2007) examined nine young adults with autism spectrum disorders, as they participated in a two year vocational support program consisting of pre-employment support, job matching, and continued job coaching in the post employment period. Participants had recently completed high school, had a mean age of 22, and were

not intellectually disabled. Additionally, employers and coworkers were offered information regarding ASD and how to interact with each participant in a way to maximize performance in the workplace. The researchers examined employment rate and level of income, as well as hours worked, and self-report questionnaires at various intervals after job placement. Results indicated a significant increase in employment levels and work hours. Seven participants of eight remaining in the program (after one left due to family relocation) retained the original job placement. Participants were rated highly by their supervisors, and demonstrated job satisfaction. This study suggests employment related disability supports can contribute to quality of life, however results must be examined with caution in view of the small sample size. It is also important to recognize that even with all the supports received, young adults were only working an average of 17 hours per week. Another interest to the current study is that job accommodations provided included those to enhance sensory regulation.

Hagner & Coony (2005) interviewed supervisors of 14 successfully employed individuals with autism, who were identified through community rehabilitation service provider groups. The researchers used semi-structured interviews as well as workplace observations in order to explore the supervisors' practices as well as their perceptions of their employees with autism. Qualitative analysis revealed that supervisors rated their employees with ASD highly, and that accommodation strategies were associated with successful job performance. These studies demonstrate the importance of reinforcing the environment with supports to ensure successful occupational performance.

Muller et al. (2003) explored perspectives on strategies for improving vocational placement and job retention services for individuals on the autism spectrum. Using semi-

structured individual interviews with 18 adults over age 18 with ASD without intellectual disabilities, they asked participants to describe positive and negative aspects of their vocational experiences, to identify obstacles to successful employment, and to recommend vocational supports. Qualitative analysis of interview transcripts revealed that participants had difficulty coordinating the job search process and difficulty acclimating to new job routines, once securing a position. They reported difficulty with communication, and most frequently mentioned an inability to master the social demands of the workplace as obstacles to work success. As in the previously mentioned studies, participants believed that infusing the work environment with supports enhanced vocational success. Participants also discussed the importance of autism awareness training for those who work with people with ASD, which points out that effective disability related supports may be provided to individuals other than the one with the disability to enhance outcomes.

While none of these already mentioned research endeavors examined FQOL specifically, Billstedt, Gillberg and Gillberg (2011) found in their study of caretakers of 108 young adults with ASD, that many parents expressed worry over their adult children not having meaningful employment. Additionally, parents expressed concern not only over the fact that their sons and daughters didn't have meaningful work, but also that they did not have "meaningful daily activity" (p.17). This suggests an overall concern about productivity of these young adults, not just paid work, and relates to the concept of engagement in occupation in the PEO model.

Graetz et al. (2010) also examined caregiver concerns regarding their loved one with ASD's employment. Caregivers expressed worry about a lack of job opportunities,

and fears about future employment once the caregiver was no longer able to care for the family member. They also had concern about a lack of support. Graetz et al. also found, based on parent report, that the functioning level of the family member with ASD was associated with his or her employment opportunities, with those who are higher functioning demonstrating more employment opportunities, and those who are lower functioning, less. Likewise, Hendricks (2010) found that cognitive functioning deficits and behavioral difficulties are additional challenges to obtaining employment. This has implications for the current study, as participating families have sons and daughters who have cognitive and behavioral disorders.

The little information that exists on adults with ASD at lower functioning levels also suggests positive outcomes are possible from supportive employment. In a study of 44 adults with autism, Garcia- Villamisar (2007) found that those in a supported employment program showed gains in cognitive performance compared to those who were unemployed. In an earlier study, Garcia-Villamisar et al. (2002) examined adults with autism, 26 of whom were in a sheltered workshop program, and 21 of whom after attending the sheltered workshop, were placed in supported employment in the community. Participants were evaluated before splitting the group in two, and after the supported employment group was in the community for 30 months. Results suggested that those who were moved to community supported employment, showed excellent results in their program and their score on the Childhood Autism Rating Scale[CARS] (Shopler, Reichler, & Renner, 1994) remained stable over the period, compared to the sheltered employment group, who showed a deterioration in function and an increase in autistic characteristics according to the CARS during that period. The authors also

reported increased quality of life in the supported employment group. This suggests that the type of program and support make a difference and reinforce the relationship between occupational performance and quality of life. Lastly, an older study showed that adults with autism and challenging behaviors can be productive in the work setting, and their behaviors can be successfully managed (Smith, Belcher, & Juhrs, 1986). This also has implications for quality of life of the family unit.

**Friendships, Social Relationships, and Leisure.** Interpersonal relationships and friendships are contributors to quality of life (Wehmeyer & Schalock, 2001), and may be limited in those with disabilities. Reduced friendships are reported in outcome studies examining young adults with ASD ( Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008;Howlin, 2000, Shattuck et al., 2007) and caregivers report concern over restricted social opportunities in their adult children (Eaves and Ho, 2008; Graetz, 2010, Jokinen & Brown, 2005).

It is particularly important to explore personal relationships with those on the autism spectrum, since the social challenges presented by this population have been well documented, and have already been discussed in the context of higher education and employment. In their study of 235 adolescents and adults with ASD, Orsmond, Krauss, & Seltzer (2004) found that in addition to having limited friendships and peer relationships, those with ASD demonstrated limited participation in social and recreational activities. Those adolescents and young adults with less impaired social interaction skills were more likely to participate in recreational activities in this study. This is consistent with the work of Van Naarden, Braun, Yeargin-Allsop, and Lollar (2006), who emphasize that leisure activities not only occur in a person's unobligated time but also frequently reflect

social interaction. Although they did not specifically study ASD, their questionnaire research with 490 young adults with developmental disabilities showed that those with intellectual disabilities with coexisting impairments engage in fewer social and group leisure activities than those with other disabilities. These findings are particularly noteworthy in view of Billstedt et al.'s (2011) research. They found in their study of 108 adults with ASD with a mean age of 24 whom they followed since childhood that regular participation in recreational activities was significantly associated with quality of life as perceived by their caregivers, staff, and through the researchers' observations.

Howlin et al. (2004) found that only 15 to 20 percent of 68 young adults with ASD with IQs greater than 50 had friendships with shared enjoyment. This is consistent with Shattuck et al.'s (2007) previously mentioned finding that a lack of friendship was the most invariable characteristic of adults with ASD. In an earlier study Howlin (2000) reported that in adults with ASD, social contacts often result from special interests and skills rather than friendships, which she proposes may limit social support. Additionally, Tantam (2000) proposes that the routines and private preoccupations in which many young adults with ASD engage, may leave them isolated. These ideas are supported by Jennes-Coussens et al.'s (2006) study based on questionnaires and interviews that reported that leisure activities in 12 transition age young men with ASD were most likely to consist of individual endeavors such as playing video games, surfing the internet, watching television, and reading, whereas those without autism were more likely to engage in sports and physical activities for leisure. These findings may have health as well as social implications, and may impact FQOL.

Muller, Schuller, and Yates (2008) examined the perspectives of 18 adults with ASD regarding social challenges and supports. Participants were asked to describe their social experiences, and to recommend supports and strategies needed to help them with their social interactions. Data were collected through semi-structured interviews. Results revealed that participants reported often feeling isolated. They noted that as both children and adults they couldn't figure out how to join others, and similar to previously mentioned studies (Howlin, 2000; Shattuck et al., 2007), many told of having no real friendships. They reported having difficulty initiating social interactions and described a variety of communication challenges that hindered social participation. These participants, who were not intellectually impaired, reported that they longed for social connectedness, suggesting that their needs in this arena were unmet, which has implications for FQOL. Older studies suggest that disability related supports may enhance social skills for those with ASD (Howlin & Yates, 1999), however more research is needed in this area to see if social supports can contribute to family quality of life.

Issues of sexuality are particularly difficult for young adults with ASD.

A young adult with ASD may need to be explicitly taught what is appropriate to say to a person he finds attractive, and may need concrete and explicit sexual education. Stokes, Newton, & Kaur (2007), based on their study of 25 adolescents and adults with ASD and 38 typical adolescents and adults, contend that individuals with ASD are more likely to engage in inappropriate behaviors when interested in somebody of the opposite sex. This can contribute to social difficulties and be a source of stress and concern for their families, which may affect FQOL.

**Choice, self– determination, and self advocacy.** Individual choice is a fundamental principle of quality of life and on interventions based on quality of life principles (Brown & Brown, 2005.) Choice is related to the developmental skills of the individual, and needs to be seen in the contexts of needs, goals, activities, place, and personnel, when concerning those with developmental disabilities. It is also essential to note that when individuals are unable to effectively communicate, which is often seen in individuals with ASD, choices can be overlooked (Brown & Brown, 2005). This is related to the emotional well- being domain of FQOL.

The importance of choice is reflected in studies where people with disabilities, including those on the autism spectrum, are asked about what they feel is important to them and what supports they needed. In Fresher-Samways, Roush, Choi, Derosier, & Steel's's (2003) qualitative examination of perceived quality of life in 12 adults with both developmental and acquired disabilities, the topic of choice was identified as an important theme. Participants reported negative reactions to external attempts to control what they do and positive reactions to having choice. Similarly, in a qualitative study using focus groups with five adults with cognitive disabilities and four individuals with autism, all who had a history of problem behavior, participants expressed the need for decision making and personal freedom. They felt that a lack of choice and personal freedom contributed to their behavioral challenges (Ruef & Turnbull, 2002).

Choice is also consistent with the concept of self- determination. While many definitions are included in the literature, it is generally agreed that self-determination is the capacity to choose, and to act on the basis of those choices (Wehmeyer & Schalock, 2001). Self determined individuals act according to their own preferences, interests, and

abilities, and are free of undue influence. They have self-awareness, and possess skills necessary to achieve their desired outcomes (Wehmeyer & Schalock, 2001).

Most people without disabilities develop self-determination in childhood and adolescence, as they gain greater responsibilities and freedom from their parents and teachers, however, this does not happen as easily for those on the autism spectrum. Therefore, many students with disabilities transition to adulthood with limited skills in self-determination, and as a result they lack self-advocacy, or the ability to navigate the challenges they face (Field & Hoffman, 1999). Theoretically, the Individuals with Disabilities Education Act [IDEA] (US Department of Education, 2004), includes opportunities for adolescents to become actively involved in planning for the post high school transition by age 16, however, many young people still lack skills in self-determination and self-advocacy upon leaving high school (Webb, Patterson, & Syverut, 2008).

It is generally accepted among professionals working with transition aged youth that people who are self-directed are more likely to have the initiative to be successful, have ambition, and have a reasonable work ethic (Camarena & Sargiani, 2009; Murray, 2003; Wehmeyer & Schwartz, 1997). As a result they do better in life than those who do not. Murray (2003) refers to self-determination as a protective factor that can distinguish between resilient high risk youth, and those high risk youth who do not experience positive outcomes. There is not a lot of research evidence, however what does exist provides support to this idea. The most convincing evidence comes from an older study by Wehmeyer & Schwartz (1997), who measured the self-determination of 80 high school youth diagnosed with mild intellectual disability or learning disabilities, and

classified them as high or low in self-determination. One year after these students left high school, they and their families were contacted to determine status in several areas, including living arrangements, current and past employment situations, postsecondary education status, and community integration outcomes. This information was analyzed, controlling for level of intelligence and type of disability. Results showed that as a group, the self-determined youth were doing better than their peers one year out of school. Members of the high self-determination group were more likely to live outside the family home and be employed for pay.

In a survey study of 208 college students, by Hennesy, Roessler, Cook, Unger, and Rumrill (2006), participants emphasized the importance of college bound students with disabilities becoming self-advocates. However, in their study with adolescents and their parents, Camarena & Sargiani (2009) found that many of the participating adolescents lacked awareness of their disability and underestimated the level of academic and social challenges that they faced ahead, leaving the authors to question whether they possessed the necessary self-determination and self-advocacy skills to be successful in college. Self-determination in those with more significant disabilities is even more inadequate, based on the limited evidence available. Carter, Owens Trainer, Sun, & Swedeen (2009) reported that students with severe intellectual and developmental disabilities display restricted knowledge about self-determination and how to perform the necessary behaviors to achieve self-determination. Furthermore, they determined that teachers perceive the greatest difficulties in students with disabilities as identifying and expressing their own needs, interests, and abilities to set expectations and goals (Carter et al., 2009).

Systematic study of autism and self-determination is virtually non-existent. Held, Thoma & Thomas (2004) engaged in a participatory action research study with one transition age young man with autism. Following instruction in developing goals and encouragement to participate actively in his education during secondary school, this young man transitioned from school with a job and an apartment in the community with a roommate. Hillman (2010) reported in her single qualitative case study with a mother with a young adult with ASD the complicated process by which the mother and her family encouraged the development of self-determination in her son. Hillman concluded that this mother's fostering of her son's abilities to make his own choices and decisions was evident in the way that she parented her son as he grew older, and the way she and other family members interacted with him. Thus, in this family, self-determination reflected several domains of family quality of life. Clearly, further research is needed to examine self-determination and young adults on the autism spectrum and family quality of life.

Field and Hoffman (1999) emphasize that family involvement is essential to the development and practice of self-determination, as self-determination skills are influenced by the type of role models available to the individual. They maintain that since parents often engage in advocacy efforts on behalf of their children, the concrete advocacy skills that they model can help their children with autism and other disabilities in acquiring these skills. Similarly, they point out that interactions between parents and their children may provide opportunities and reinforcement for the development of these skills as was seen in the Hillman et al. (2010) case study. However, in a survey study of parents' attitudes about their school aged children with ASD, due to safety concerns

about their children, parents tended to be overprotective, thereby limiting their youngsters' independent skill development and self-determination behaviors (Ivey, 2004). While professionals recognize that there are relationships between self-determination, family involvement, and support, research about the nature of these relationships is particularly lacking.

Self-determination requires not only that people with disabilities develop resources, but that society respond (Held, Thoma & Thomas, 2004). This is recognized by those states that have Medicaid Home and Community Based self-determination waivers, such as the New Directions Waiver in Maryland. As mentioned under legislation, in this type of waiver, money flows directly to the individuals with developmental disabilities to direct their funding, and can be used for housing, supported employment, and other supports (DDA, 2009), and encourages recipients to take an active role in decision making.

**Community living and housing.** -Physical/material well-being is a domain of FQOL (Summers et al., 2006). An indicator of physical/material well-being is housing. Even among those with strong cognitive skills, many young adults with ASD continue to live with their parents, siblings, or another family member (Billstedt et al., 2011, CARD, 2008; OAR, 2009). Outcome studies such as Howlin et al. (2004) concur that the majority of adults with autism live with their families, although a few are successful in living alone. In Howlin et al.'s (2004) follow up study of 68 adults on the autism spectrum with an IQ above 50, less than 5 % lived independently.

Carmarena and Sargani (2009) reported that parents of adolescents with ASD consider their children's ability to live independently a major concern. Concerns about

their children being able to take care of themselves were also expressed by parents of adolescents with ASD in Lee, Harrington, Louie & Newschaffer's (2008) study. These studies are consistent with large scale survey research among 1,652 parents of youngsters with ASD and 917 parents of typically developing youngsters, which reported a much greater concern among parents of youngsters with ASD about long term independent living (Easter Seals, 2008). This reinforces the importance of examining FQOL.

While there are several housing options that exist for young adults with disabilities including those on the autism spectrum, the shift has been away from individuals living in large group situations, to supported living in a more independent environment (Targett & Smith, 2009) This is largely the result of efforts among the disability community to increase self- determination and choice to meet people's needs within a preferred setting. Many people with ASD will require support to enhance their independence in living. Some may require services for a limited amount of time while others may need such services throughout their lives. In either case, the absence of such services can have significant, long lasting negative consequences for individuals and their families. For instance, in Graetz's (2010) study of caretakers of adults with ASD, the majority of responses reflected concerns about the lack of available residential services for their adult children.

These concerns are justified, because there are significant shortages of residential services for adults with autism and other developmental disabilities, according to the National Association of Providers of Residential Services (OAR, 2009). Most states have lengthy waiting lists for residential services (DDA, 2010). This is especially distressing, because research suggests that living outside the family home is beneficial to those with

ASD. Krauss, Seltzer and Jacobson (2005) found that mothers of young adults with autism whose children live away from home in a variety of living settings report greater benefits for their children, whereas mothers of whose grown children with ASDs live with them, report negative consequences for their sons and daughters, including social isolation and complacency. This has implications for FQOL research, especially because, as reported by Graetz (2010), when adult children live at home with supports that are perceived by the family as inadequate and needs that are unmet, other family members, especially parents, may be limited in their ability to pursue activities of choice.

**Instrumental activities of daily living.** It is also important to note that successful community living not only includes housing but also a number of specific skills linked to instrumental activities of daily living and home safety, for which support might be needed. People with ASD may require assistance in daily living activities and continued care long into adulthood (Blacher, Kraemer, & Howell, 2010). A study by Matson, Dempsey, & Fodstad (2009) showed that many with ASD have significant difficulties with adaptive skills such as dressing, bathing, hygiene, grooming, and meal preparation. Data were taken from staff people working with adults residing in developmental centers in this study, and those on the autism spectrum were more significantly impaired in these daily activities than those with intellectual disabilities alone.

However, increased independence can be taught when proper support is offered. Persson (2000) studied seven men with autism and varying degrees of intellectual disability who had a history of institutionalization and were living in two group homes. Using a structured teaching approach, these men were instructed in skills of daily living over a 2 ½ year period by residential staff who were blind to the study. All men showed

steady increases in independence throughout the period. In a similar study, Van Bourgondien, Reichle, & Schopler,(2003) found in their examination of young adults with autism and moderate to severe intellectual disabilities, that those in a residential program also using a structured teaching approach, showed improvements in adaptive skills and behaviors that were significantly greater than improvements seen in control participants living in other residential programs. This reinforces that even when person factors are significantly limiting, environmental supports can enhance one's ability to engage in occupations, pointing to the applicability of the PEO model. However, one must consider that if families are the ones providing this instruction in the absence of adequate supports and services, it may limit, rather than enhance overall FQOL (Graetz, 2010).

Financial management and community mobility are other areas that need to be examined with transition aged young adults with autism. The development of financial management, which is a part of the FQOL domain of physical /material well- being, begins in childhood and extends into adulthood, as an individual learns to navigate the financial challenges encountered in daily life as well as those necessary to achieve long-term financial independence. Because individuals with ASD are often uneven in achieving aspects of maturity that occur more predictably for typically developing youth, parents may avoid exposing their children to some of the small opportunities for managing money on a daily basis that typically developing children receive. Handling small amounts of money, taking part in banking activities, and having an after-school job in high school can all be steps toward having a more mature concept of financial management. These experiences are often lacking in those on the autism spectrum (Geller

and Greenberg, 2010). Despite the importance of financial management on reducing dependence on family and support services, financial management has not been systematically studied in transition aged youth with ASD or their families. However, financial management of their sons and daughters is a concern of parents of those with ASD (Easter Seals, 2008).

Young adults may also need support to move about the community, whether using public transportation or riding in a car (Datlow-Smith & Targett, 2009). Although public transportation systems need to be accessible according to the Americans with Disabilities Act (ADA), little attention is paid to the accommodations that might be necessary for those with ASD (OAR, 2009). Public transportation can be confusing and may require extensive training in order to manage navigation independently. In Graetz's (2010) study, nearly half of the parents responded that their young adult son or daughter lacked access to public transportation.

Driving is another form of community mobility, which is difficult for many with ASD. Specific research evidence in this area is extremely limited. Farley et al. (2009) reported in their twenty year outcome study of 41 individuals with ASD that only a small percentage of individuals with ASD are able to drive independently. They suggest that for individuals who are unable to utilize public transportation to or to secure a driver's license, family or social services staff become the only options to get them from place to place. They conclude that lack of transportation drastically decreases independence and makes participation in employment and leisure opportunities difficult. Their study is consistent with a single case study by Silberberg (2010), in which a parent of a young adult with ASD discussed how happy he was that his son had learned to drive, because it

reduced the young man's dependence upon his family, although he emphasized that getting his son to do so had been a challenging process.

Sheppard, Ropar, Underwood, & Van Loon (2009) showed that a group of 23 high functioning young adults with ASD demonstrated difficulty identifying driving hazards involving people, as compared to a group of 21 typical controls, when viewing video clips. There was no difference between the two groups in identifying driving hazards in which the participants were looking at cars, with no visible people. Although both the ASD group and the comparison group participants were non-drivers, the authors concluded that the difficulty those with ASD had in interpreting what they called social hazards, could make driving a particularly challenging task for them, which may account for some of the reasons so many do not drive. They also suggested that individuals with ASD may be less aware of the potentially dangerous nature of their own actions when they are pedestrians, which makes community safety a potential issue.

In addition to the above, many with ASD have a lack of general safety awareness. They may not know how to avoid or deal effectively with potentially dangerous situations, such as getting lost, as they move about within the community. There isn't a lot of information on this topic, however parents are concerned for the safety of their transition aged children with ASD (Graetz, 2010), which may affect FQOL.

### **Family Issues**

**Transition and the family.** As stated earlier in this discourse, the quality of life of individuals with autism is related to those around them, and having a family member with autism affects the quality of life of the rest of the family. The difficulties and stressors facing families raising young children on the autism spectrum have been

documented (Brown et al., 2006; Gray, 2002; Trapagnier, 1999; Werner Degrace, 2004), however family challenges when raising young adult children with ASD have not been as well researched. Literature investigating families with a young adult member with a developmental disability does exist and although more and more work is being done examining the challenges associated with transition, the number of studies examining families with transition age young adults specifically with ASD remains relatively small.

The period of transition of youngsters with disabilities from mandated services under the Individuals with Disabilities Education Act (IDEA )to the adult services world, where there are no entitlement services may be difficult for parents (Krauss Seltzer & Jacobson, 2005). In contrast to families of typically developing youth who expect less day to day involvement with their children as they move to the next stage of their lives, these families anticipate an increased level of responsibility for developing and supporting the options available to their children as they work to secure services that they believe their youngsters need, but are no longer required, to be given (Krauss, Seltzer, & Jacobson, 2005) Therefore, the parenting domain of family quality of life is clearly different than in families with typically developing young adults, where day to day responsibilities of parenting dramatically lessen at transition age.

Kraemer and Blacher (2001) studied parents of children with severe intellectual disabilities transitioning from the public school system, and found that parents play an important role in transition planning with school administrators as well as adult services providers on behalf of their youngsters. Similarly, van Ingen and Moore (2010) examined parents of young adults in a day habilitation program and found that involved parents worked to transition their children with a” fervent effort” (p.540) and were very

deliberate with tasks. The authors reported that even after some parents had helped transition children out of the family home, during their adult child's subsequent transitions in the adult years to other homes or day programs, they remained present to educate staff. The findings of both these studies are consistent with the already cited work of Field and Hoffman (1999), who emphasize the importance of parental involvement in determining and supporting the options available to their youngsters with ASD as they enter adulthood.

These studies suggest that parental advocacy is an essential role for parents as their son or daughter transitions into adulthood. This is particularly true for parents of children with ASD. According to the Organization for Autism Research (OAR, 2009), for parents "new stressors and challenges may appear as their child enters the transition years" (p.14), such as unfamiliarity with the adult system of services and supports or potential inability of this system to meet the needs of their adult child, creating a significant need for parental advocacy (OAR, 2009). Specifically with the ASD population, continued advocacy is necessary throughout the transition years because supports and services are limited for this population and adult outcomes are often poor (Brown et al., 2003; Eaves & Ho, 2008, Graetz, 2010; Howlin et al., 2004).

Brown et al. (2003) found that 25 out of 34 families in their study with a child or adult with a disability, including autism, participated in advocacy activities. Some parents reported that "if they did not take the time to actively seek out and advocate for support services, no one else would" (Brown et al., 2003, p.218). Similarly, Hetherington et al. (2006) found in their qualitative study of 15-20 year olds with ASD and other developmental disabilities and their families, that parents consistently demonstrated their

involvement through the use of advocacy skills. They described how tiring it is to constantly “battle” (p.167) with the school district. At this point in the students’ lives, the researchers described parents as fatigued by years of effort to communicate effectively with the schools. As a group, parents expressed frustration with the lack of communication and information from the schools. They also had concerns over their interactions with school personnel.

Neece, Kraemer, and Blacher’s (2009) research with 128 transition age young adults with intellectual disabilities including autism, and their families, found that parents who were satisfied with their child’s transition reported higher family well-being, a term that is consistent with family quality of life. More specifically these researchers found that families who were satisfied with their involvement in the transition process, reported higher well- being. An additional relevant finding in this study is that families with a son or daughter with problem behaviors were less likely to be satisfied with their child’s educational program and transition process, or their own involvement in transition. This has implications for the FQOL in families of transition aged youth with ASD, as many young adults with ASD are likely to have such behaviors.

This study also suggests that there is a relationship between what service providers do and how satisfied parents feel during transition (Neece et al., 2009). This is consistent with research that found that families report more satisfaction with the transition process when they have personalized and less bureaucratic relationships with school personnel (Hetherington et al., 2006). Although advocacy and parent professional partnerships have not been as systematically examined in families with transition aged young adults as they have in families with younger children (Blue-Banning et al., 2004;

Stoner et al., 2005; Wang et al., 2004), it appears that quality of a child's educational program, related transition planning, and parental- school partnerships during transition affect parental advocacy roles and family quality of life. The young adult's program is a critical piece of the broader family environment. When the program does not meet parents' expectations, the family system is affected, which as suggested earlier, may indeed occur in families with a young adult child on the autism spectrum. Also consistent with literature on families with a child with a disability (Stoner et al., 2005; Wang et al., 2004), these studies suggest that although advocacy on behalf of their adult children can be a source of stress and frustration, parental advocacy on behalf of their young adult child can also be satisfying (Hetherington, et al., 2006; Neece et al., 2009; van Ingen & Moore, 2010).

Yet, as important as parental involvement is, many parents lack the information they need. In Hetherington et al.'s (2006) study, many parents felt that they didn't have the knowledge to effectively support their children's transition to adult life. Similarly, Hare et al. (2004), in their study with 26 caregivers of adults with autism, reported that the majority lacked knowledge about services available. These studies are consistent with the University of Miami / Nova Southeastern University Center for Autism and Related Services (CARD) survey with parents of transition age youth and young adults with ASD, which reported that 67% of families lacked knowledge of transition programs and settings, 83 % relied on family members to help with transition planning, and 78% were unfamiliar with agencies and professionals that could assist them with job development (CARD, 2008). A lack of information and resources can contribute to stress in families and, and can affect FQOL.

**Caregiving demands and stress.** Parents with adolescents and young adults with autism report stress regarding their youngsters, which may contribute to decreased emotional well-being, which is a family quality of life domain. In addition to stressors regarding transition, as already discussed, survey research reveals that parents are concerned about their child's ability to live independently and maintain a positive quality of life (Easter Seals, 2008). Additionally, according to the Easter Seals Living with Autism Survey, parents also are worried about their child's ability to be financially secure, especially if something should happen to them (Easter Seals, 2008), which reflects the connection between the physical/ material well-being and emotional well-being domains of FQOL. They also have concerns over their child's well-being and their child's learning difficulties (Lee et al., 2008). Additionally, parents have stress with reconciling what is realistic for their children as opposed to what they aspire for them to achieve (Camarena & Sargiani, 2009).

In addition to these stressors, parents with adolescents and young adults with autism may experience increased care giving demands ( Lee, et al., 2008) which can also affect overall emotional well-being. Smith et al. (2010) found that in comparison with a nationally representative sample of mothers of children without disabilities, mothers of adolescent and adult children with ASD spent significantly more time providing childcare and doing chores, and less time in leisure activities. This indicates that having an adolescent or adult child with ASD may affect a caregiver's ability to engage in desired occupations. Since engagement in desired occupations is essential to healthy adaptation and a source happiness in daily life (Yerxa, 1998), it would seem that an inability to complete desired activities could be a contributor to decreased well-being and quality of

life. Smith et al.(2010) concluded that mothers of adolescents and adults with ASD reported significantly lower levels of positive affect and higher levels of negative affect on a daily basis, which influences the emotional well- being domain of family quality of life.

Some research suggests that in addition to stress, mothers also may experience more depression (Abbeduto, Seltzer, & Shattuck, 2004, Barker et al., 2010 Lounds et al., 2007) when compared with parents of young people with other disabilities. For instance, Abbeduto, Seltzer, & Shattuck (2004) examined mothers of adolescents and young adults with Down syndrome, fragile X syndrome, and autism, and looked at psychological well- being, depressive symptoms, and pessimism. They found that mothers of adolescents and young adults with autism had higher levels of pessimism, more distant relationships with the affected adolescent, and higher levels of depressive symptoms compared with the groups with Down syndrome and fragile X. The authors felt these differences were due to the types of caregiver challenges that these mothers faced. Additionally, those adolescents and young adults who had more behavioral symptoms had mothers with more pessimism and greater depressive symptoms. Kring et al. (2010) suggest that health problems, which are frequently seen in adolescents and young adults with autism, can contribute to maladaptive behavior, and therefore impact maternal burden. All of these results are in accordance with studies of family quality of life children of families with children with disabilities, where respondents with a child with ASD report lower enjoyment of life (Brown et al., 2006; Gray, 2002; Hastings, 2003; Trapagnier, 1999; Werner Degrace, 2004).

In spite of the challenges of caring for an adolescent or adult with ASD, some research indicates that there is considerable heterogeneity in the actual toll that care giving takes on the well-being of mothers ( Lounds et al., 2007; Orsmond et al., 2006). Whereas care giving can wear down some mothers, other mothers show a pattern of adaptation and either maintain or show gains in well-being ( Lounds et al., 2007; Orsmond et al., 2006). Orsmond et al. (2006) examined the mother child relationship among 202 adolescents and adults with autism living at home and their mothers, and found that in spite of care giving demands, most parents reported a positive relationship with their son or daughter. Characteristics of the son or daughter with autism, such as less maladaptive behavior, less social impairment, and lower levels of pessimism in the mother were predictive of a positive mother child relationship. Similarly, Greenberg et al. (2004) found that mothers of young people with autism who have a lot of optimism, have better psychological well- being. Therefore, it appears that characteristics of the young adult as well as characteristics in the mother influence emotional well- being and as a result FQOL.

Lounds et al. (2007) examined 140 mothers with adolescents and young adults over a 4 ½ year period, to explore patterns of maternal adaptation by examining the conditions under which parenting an adolescent or young adult with autism was experienced positively. Their results showed a decline in anxiety and improvement in mother child relationship quality over time for the majority of the participants, and an increase in overall well- being. The authors suggested that this was likely associated with an improvement in behavior and other core features of autism in their children. Surprisingly, Lounds et al. also found a reduction in maternal anxiety after their young

adult children exited secondary school. However this must be interpreted cautiously, since the vast majority of young adults in their study were engaged in productive adult activities, which is not always the case (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010 ; Graetz, 2010). Lounds et al. (2007) acknowledged that a subgroup of mothers continued to experience significant anxiety and depressive symptoms as their sons and daughters grew into adulthood, but did not articulate any trends that contributed to these results.

Similarly, Barker, et al. (2010) investigated depressive symptoms and anxiety in mothers of adolescent and adult children with ASD over a 10 year period in a sample of 379 mothers. They found that during this time, maternal depressive symptoms remained fairly stable, while anxiety level lessened. However, there was evidence to indicate elevated levels of depression and anxiety in a subgroup of mothers whose son or daughter had significant behavioral problems or who had smaller support networks and more stressful life events. Taken collectively, these studies suggest that although maternal emotional well-being may be compromised when there is a child with ASD, adjustments and positive affect are possible as both the child and the mother mature and when appropriate supports and coping strategies are in place. These studies also indicate a complex link between the family quality of life domains of parenting and emotional well-being, when it comes to parenting a young adult with ASD.

Research evidence regarding fathers is virtually non-existent. Abbeduto et al. (2004) contend that family research focuses on mothers because even today with changing gender roles, mothers still assume primary care giving roles and are therefore most subject to the challenges associated with their son or daughter's disability. This is

consistent with Ivey (2004), who reported that mothers of adolescents have more stress than fathers because they are the ones most involved with the day to day management. What limited research includes fathers supports these claims. Allik, Larson & Smedje (2006) found that in their study with children and adolescents that mothers but not fathers reported an impaired health related quality of life, and that there was a relationship between maternal well- being, but not paternal well-being, and child characteristics. However, in contrast, Hartley et al.'s(2011) study with 91 married mothers and fathers of adolescents and adults with ASD, found that fathers' parenting experiences were more strongly impacted by child characteristics than were mothers' parenting experiences. Additionally, their study results emphasize the connection between the marital relationship and parenting experiences, as parents of both genders who reported higher marital satisfaction also reported feeling less burdened by their adolescent or adult sons or daughters with ASD than those with less marital satisfaction. Marital satisfaction was associated with feelings of closeness in the father child relationship. Clearly, further research is needed in this area, although this study suggests the possibility that a good marital relationship might mediate the strains of parenting when there is an adult child with ASD, contributing to emotional well-being and FQOL. This is significant when one considers that some studies suggest that divorce rates may be high among families with a member with autism (National Center for Autism Research and Education, 2008, as cited by Dillenburger et al., 2010).

**Siblings.** Few studies have systematically examined siblings of adult children on the autism spectrum, and the effect on FQOL. Allgood's (2010) qualitative dissertation research of young adult siblings of those on the higher end of the autism spectrum

suggests that having a sibling on the spectrum impacts the social relationships as well as vocational choices in the neurotypical sibling. Results also suggest that some neurotypical siblings report assuming a parenting role with their siblings.

Hodapp and Urbano (2007) used a questionnaire to compare 176 siblings of adults with autism with 284 siblings of adults with Down syndrome. Siblings with brothers or sisters with Down syndrome showed closer and warmer sibling relationships along with slightly lower levels of depressive symptoms and more contacts with siblings than siblings of adults with autism. Siblings of adults with Down syndrome tended to see their brother or sister more often than siblings of adults with autism. However, consistent with other family studies, lower levels of behavioral problems were associated with closer sibling relationships in both groups.

Similarly, Orsmond and Seltzer (2007) compared adult siblings of those with ASD with adult siblings of adults with Down Syndrome, as part of a large longitudinal study. They revealed that siblings of adults with ASD had less contact with their brother or sister, reported lower levels of positive affect in the relationship, and felt more pessimistic about their brother or sister's future. These siblings were more likely to report that their relationships with their parents had been affected by the sibling with autism. For siblings of adults with ASD, a closer sibling relationship was observed when the sibling lived closer to the brother or sister with ASD, and when his or her brother or sister with ASD had higher levels of functional independence.

A more recent study examined 56 adolescent siblings in addition to 142 adult siblings of those with ASD, and their findings appeared more positive (Orsmond, Kuo, & Seltzer, 2009). Overall, both groups reported positive affect, and neither group showed

depressive symptoms. Adolescents engaged in more shared activities with their brother or sister with ASD than did adult siblings, and reported more positive affect in their sibling relationship when their sibling with ASD had fewer behavior problems. Adolescent siblings reported greater social support from parents and friends than did adults. The importance of social support for adolescent siblings was also related to family size. Adolescents from larger families reported greater positive affect in their sibling relationship. As older studies have suggested, in larger families, the care giving responsibility can be more easily shared, therefore enabling the sibling to find more satisfaction in the relationship with his or her brother or sister with ASD (Howlin, 1988). Even though adolescents reported greater support from their parents than did adults in the Orsmond, Kuo & Seltzer (2009) study, a positive association between parental support and positive affect in the sibling relationship was seen in adults. For adults, more shared activities were observed when the sibling with ASD was younger in age and had fewer behavior problems.

Although having a brother or sister with an ASD can be a major stressor for siblings of any age, these findings suggest that positive adjustment and coping is possible. This is consistent with Pilowsky, Yirmiya, Doppelt, Gross- Tsur, and Shalev's (2007) study of children and adolescent siblings of youngsters on the autism spectrum, where the majority of sibling participants were considered to be well adjusted. Family characteristics such as size, gender, and age of the child also impacted a sibling's relationship with his or her brother or sister with ASD in Pillowsky et al.'s study. While these family characteristics cannot be changed, interventions that focus on sibling coping and parental support could be helpful disability related supports. Orsmond, Kuo, and

Seltzer's (2009) research particularly shows that parents may play a role in siblings' perceived relationship quality with their brother or sister with an ASD, even in adulthood. More research examining how adult children with ASD affect the family interaction domain of family quality of life is indicated.

### **Summary**

ASD affects as many as 1 in 88 individuals (CDC, 2012). The incidence of ASD has increased dramatically in the last decade, leading to a growing number of adults with an autism diagnosis (OAR, 2009). Autism is a permanent developmental disorder, and as such, those with ASD often have challenges that continue into adulthood. Yet, there are no mandated supports and services for these young adults once they transition from the school system at age 21, leaving many without access to needed programming (Dillenburger et al., 2010; OAR, 2009). Because of this, parents and other family members may find themselves facing new challenges as a son or daughter transitions to the post school world, and face concerns about an uncertain future. Often care giving burden increases at the time when it would normally decrease in the life span. It is clear that the quality of life of the whole family is affected.

While individuals with autism may make academic, language, or social gains throughout adolescence and into adulthood (Seltzer, 2004; Shattuck et al., 2007), based on existing outcome studies, it is clear that many adults with autism will not achieve independence from their families (Billstedt et al., 2011; Graetz, 2010; Howlin et al., 2004). In view of current long-term outcomes for these young adults and the stress associated with caring for a transition aged son or daughter with autism, effective transition planning for both the young adult and the family has increasing importance

(Kraemer, Blacher, & Howell, 2010). Yet, it appears that transition planning falls short of its intended mandate, at least for some, which is to prepare the adult and family for adulthood (Geller & Greenberg, 2010; OAR, 2009).

It is evident that more research is needed to explore the quality of life of individuals with ASD and their families during this age of transition from school to young adulthood. Existing research has shown that for many individuals with developmental disabilities, the transition process is challenging and affects the entire family across multiple domains. As with studies of younger children, (Brown et al., 2006), the challenges on the family associated with a young adult with ASD appear to exceed those of other disabilities. A qualitative exploration of FQOL of families with a transition aged young adult with ASD can enhance the knowledge of how ASD impacts the overall quality of life of the family, and may potentially inform the planning of supports and services that will best meet the needs of the young adults and their families. By thoroughly exploring FQOL more can be learned from the perspectives of the family.

For instance, one area in which existing research is virtually nonexistent is in exploring the occurrence of sensory processing difficulties and their effects on a young adult's daily functioning as well as on the quality of life of the family unit. While research has established that sensory processing may be impaired in adolescents and young adults on the autism spectrum, as well as children (Dunn, 2000; Kern, 2006; Kern, 2007), how this influences family quality of life has not been systematically examined in families of young adults. Given that effective interventions exist that can affect sensory processing in a positive direction, it is important to begin to understand how sensory

processing difficulties may affect young adults with ASD and their families, even on a very small scale.

Many of those with ASD can integrate successfully into their communities and work competitively; however, it is essential that the transition into adulthood be supported to ensure success. Given the heterogeneity of the spectrum disorder, adolescents and adults with ASD and their families will continue to need a variety of services and supports to meet their needs, although in many communities, demand far exceeds the supply of these services (Graetz, 2010; Hendricks & Wehman, 2009; OAR, 2009). When supports and services are provided, family quality of life improves as do successful outcomes. Individuals with ASD deserve to have access to the same things that people not on the autism spectrum have, such as a home, an education, a job, community integration, and relationships, and with the right support, this is achievable. Their families also have the right to pursue activities and occupations of choice.

Although more and more literature is being written about transition aged young adults with ASD, there still is a limited amount of evidence-based literature, especially concerning quality of life of the family. Aspects of quality of life, such as caregiving burden, have been examined however the holistic construct of quality of life has been far less frequently studied. Additionally, the research that does exist does not examine adults with ASD and their families using an occupation based perspective. This perspective is valuable, as the quality of a person's experience in terms of satisfaction and functioning has to do with the person, environment occupation transaction (Strong et al., 1999). Both internal changes or person factors, and external changes, including supports, services, and policy changes, have the potential to influence the daily life experiences of both the

young adult with ASD and the entire family, and enhance occupational performance (Strong et al., 1999). It is also important to recognize, that while the unit of exploration of this current study is the family, given the large numbers of families of young adults with autism, and the even larger numbers of families of children with autism rapidly approaching adulthood, understanding the issues surrounding transition aged youth with ASD and their families becomes a major societal issue, making the need for this understanding even more imperative.

## Research Questions

To examine the phenomenon of FQOL among families of transition aged young adults with autism:

1. How do families with a transition aged individual with autism describe their family quality of life (FQoL)?
  - a. Past FQoL?
  - b. Current FQoL?
  - c. Future FQoL?
2. What factors do family members perceive as contributing to family quality of life?
3. What factors do families perceive as hindering family quality of life?
4. How do family members of a young adult with autism describe daily occupations and roles of family members?
5. How do family members of a young adult with autism describe the support and services they receive?
  - a. What are additional services to enhance support and productivity?

To explore sensory processing of young adults with ASD and the impact of sensory processing on FQOL:

6. How has sensory processing of the young adult with ASD impacted the family's ability to perform daily occupations and activities ?
  - a. In the past?
  - b. Presently?

## **Chapter 3:**

### **Methodology**

#### **Introduction**

As the prevalence of autism spectrum disorder has risen in the past several years, the number of those with ASD reaching adulthood has also increased (OAR, 2009). The communication, behavioral and social impairments that characterize ASD persist into adulthood, and continue to deeply affect the family unit (Brown et al., 2006; Eskow, Pinelis, & Summers, 2011). The transition to adulthood creates ongoing challenges for those with ASD and their families, and is only beginning to be investigated systematically. Therefore, this study sought to investigate quality of life for young adults with ASD and their families. Further, the contribution of sensory processing difficulties to behavior in young adults with ASD, and the effect of these on the family, have not been examined in the existing literature, and therefore warranted further exploration.

As part of an ongoing, multi- phase effort investigating family quality of life at Towson University, this study focused on examining family quality of life (FQOL) in families with sons, grandsons, and daughters with autism spectrum disorder between the ages of 18 and 24 years. It also piloted an exploration of sensory processing and family quality of life. This chapter (a) provides the rationale and goals of the study, (b) identifies sampling procedures, along with introducing the study sample, (c) describes data collection and instrumentation, (d) explains methods of data analysis, (e) discusses the role of the researcher, (f) clarifies ethical considerations, and (g) reviews the trustworthiness of the data.

## **Research Design and Rationale**

This study qualitatively explored the phenomenon of FQOL for families with a son, grandson, or daughter with ASD. Qualitative research methods were used for this study due to the complex nature of FQOL. Qualitative research is typically applied when a reflective understanding of a complex issue is desired (Creswell, 2009), and is used to understand phenomena “in terms of the meanings people bring to them” (Denzin & Lincoln, 2005, p.3). Qualitative research is holistic in that it attempts to provide a contextual understanding of the complex interrelationships that affect behavior (Jones & Nicol, 2003). To that end, qualitative research means going in to the field or real world to get close enough to the people and circumstances there to gain an understanding of what is happening (Patton, 2002). As will be described, in this study, in depth interviews and observations of families with a transition aged young adult took place.

This study used a qualitative phenomenological approach. A phenomenological study describes the meaning of the lived experiences for several individuals about a concept or phenomenon, which in this study is family quality of life when there is a transition aged son or daughter with ASD. A phenomenological study focuses on “descriptions of what people experience and how it is they experience what they experience” (Patton, 2002, p. 107). In phenomenology, researchers look for the invariant structure, or the central underlying meaning of the experience or phenomenon, and emphasize that experiences contain both outward appearance and inward consciousness based on memory, image and meaning (Creswell, 2007). Phenomenology is concerned with wholeness, examining a phenomenon from different angles, and describes experiences in vivid and accurate terms (Moustakas, 1994). A phenomenological

approach to the study of quality of life enhances the knowledge base of occupational therapy and occupational science by providing insight into the lived experiences and occupations of families with a transition aged young adult with ASD.

### **Participants**

The population for this current study was families with transition age young adults between 18 and 24 years old, with a diagnosis of autism spectrum disorder. As this was part of a multi- phase study, participants were selected from a group of participants who participated in a previous phase of this ongoing research. This prior phase consisted of a large scale survey study.

In 2008, the Maryland Autism Survey Study (MASS), which is described later in this chapter, was sent through the Maryland State Department of Education (MSDE) to all families with a child up to age 21 on the Maryland Medicaid Autism Waiver or on the waiver registry (wait list), which consisted of 3,021 families. There were 861 families who completed and returned the MASS in 2008, a 28.8% response rate (Eskow et al., 2011). Those who completed the initial survey and agreed to be contacted again, 489 families, were sent another MASS in 2011. The current participants were selected from those who returned the second survey, who said they were interested in participating in future studies, and who have a family member with ASD at transition age. While 27 families met these selection criteria, ten of these families were included in this phenomenological study. According to Creswell (2007), phenomenology studies are typically performed with up to 10 participants, although phenomenological studies may have between 5 and 25 participants. The sample size of 10 was selected based on the researcher's expectation that this number would provide reasonable coverage of the

phenomenon of family quality of life under study. The design was flexible enough to allow for alteration of that number as fieldwork unfolded, should it have been necessary. However, in qualitative research, sample selection to the point of redundancy is recommended (Patton, 2002), which was indeed achieved with 10 participants.

The first five participants selected were chosen based on the age of the young adult with autism. Those with the oldest young adult children were contacted via e-mail, using an e-mail script (See appendix B). If there was no response via e-mail, participants were contacted via telephone by the researcher. The purpose of selecting the families with the oldest children first was that these families had already experienced the process of transitioning from secondary school or were actively in the process of navigating this transition, and therefore would be able to share their perceptions about transition. One of the five families with the oldest children did not respond to the researcher's request, and therefore, the family with the next oldest child was contacted. Families having an adult child with a co-occurring additional disability not associated with ASD (e.g. blindness) were excluded. Choosing participants based on them meeting specified criteria is consistent with a qualitative phenomenological approach. Sampling is aimed at providing insight about a phenomenon, not at empirical generalization from a sample to the population (Patton, 2002).

The person who filled out the survey was the one contacted. That person served as the participant for the study and determined whether any other family members would also participate, including the adult with ASD if desired. Two of the initial five participants, who were mothers of transition aged young adults, chose to have their spouses, who were their children's fathers, participate with them. One mother, who was

in the initial group of five, chose to have her son on the autism spectrum participate. This was the only family who had the adult child with ASD participate, however, five additional young adults, although not participants in interviews, were present during at least part of data collection.

The rest of the study participants were not chosen in advance, but rather were selected from those who met the study criteria, following initial data analysis from the first five participants. This is consistent with qualitative phenomenology research, as naturalistic inquiry designs cannot typically be completely specified in advance (Patton, 2002). It is not unusual for a qualitative naturalistic design, which includes sampling to emerge as data collection unfolds, as such designs need to remain flexible enough to explore whatever the phenomenon under study offers for inquiry (Patton, 2002). Opportunistic emergent sampling (Patton, 2002) was therefore used to select the remaining cases. By definition, opportunistic emergent sampling takes advantage of whatever unfolds as it unfolds, and allows cases to be selected based on initial data collection and analysis. Being open to following wherever the data leads is a strength of qualitative strategies (Patton, 2002).

In this current study, based on initial data collection and analysis, additional participants continued to be selected based on the age of the young adult child. They also were selected based on waiver status, as the researcher sought a similar number of participants from waiver and registry groups. The investigator also sought participants who were fathers of young adults on the autism spectrum, as there was limited father input among the first five participants. Additionally, the investigator sought families of young adults identified as having co-occurring conditions associated with autism, and

parents of females, based on initial examination of the data from the first five participants. Parents in differing geographic regions in the state, and of different incomes, were also sought.

Families were ranked according to these factors, and were asked to participate based on ranking. If a family did not respond to multiple efforts to be contacted by e mail and telephone, the next participant on the list was selected. The family with one of the oldest children who did not respond to the initial request to participate as one of the initial five participants, did agree to participate later. She was a custodial grandparent of an adult child on the autism spectrum. Another family who was chosen to participate based on the process just described turned out to be a non- custodial grandparent of the young adult with ASD, with extensive experience with autism as she was the parent of a middle aged autistic adult, and a founder of an organization that provides services to those on the autism spectrum. It was decided to include her as a participant, as although she was clearly different from the other participants, as it was felt that this participant would be information rich, and would provide insight into quality of life for families with a transition aged young adult with ASD. Including participants who are unusual in some way is consistent with Patton's (2002) idea of extreme case sampling. Patton (2002) emphasizes the value of including such cases. Overall, participants included six mothers, with two of them having their husbands participate in some of the data collection. Participants also included two grandmothers, and two fathers. Demographic information for participants is further described in the following chapter.

In the current study, as is typical of qualitative research, sampling was designed to yield an in depth understanding, and therefore was not designed to be representative of

the population at large. However, it is noteworthy that the demographics of the families with children with ASD of all ages who filled out the MASS in 2008, from which this study sample was drawn, were consistent with the existing demographics in the state of Maryland (Demchick, 2010). Highest representation came from the Maryland counties with the highest numbers of children with autism. Male to female ratio of those with autism, was in agreement with the male to female ratio in the state. Also, socioeconomic status and ethnic make up the of the waiver registry group were congruent with that of the state, with the income of the registry group, consistent with the median income in the state as measured by the US Census Bureau (2010). The income level and level of parent education were significantly higher in the waiver sample than the registry sample (K. Eskow, personal communication, January 2009), which is consistent with existing studies that suggest families with greater resources are more likely to seek out services (Anderson, 2010, van Meter et al., 2010). The final group of participants in this current study had a higher income than is average for the state and was not ethnically diverse.

### **Setting**

In order to maintain authenticity to each family experience of quality of life, data collection occurred at naturalistic locations designated by the families. In most cases, this was the family home, however three families preferred to meet at local restaurants. These natural environments permitted open and free interaction between the family members and researcher. Gathering information by talking to people and seeing them in a natural context is a hallmark of qualitative research strategies (Creswell, 2009).

## Procedures

The current study had already been approved by the Towson University Institutional Review Board (IRB), prior to its inception, as it was part of a multiphase study of FQOL for families with children and young adults with ASD. (See appendix A). Modifications to the IRB were submitted to allow for the exploration of sensory processing, which was part of the current study, and had not been examined in previous FQOL studies at Towson University.

Initial introductions between the investigator and participants took place via email, or by telephone if there was no response to the e mail within a week. (See appendix B for e mail script). During this initial interaction, the investigator outlined the structure of the study, summarized methods of data collection, and sought permission to audio tape interviews. A time frame for the study was identified at this time. All participants were informed of their right to confidentiality. Participants were also informed of their right to terminate their participation at any point in the investigation.

Participants engaged in two interviews. Prior to beginning the first interview, the participant filled out the informed consent forms, and gave permission for audiotaping the interviews as well as permission for the researcher to view the previously administered 2011 MASS survey. (See appendix C). The first interview was an unstructured open ended interview featuring general questions about FQOL. Additionally, participants were asked to show photographs of family members to guide the discussion. Even participants who met at a restaurant brought pictures to the meeting. This researcher was accompanied by a co- researcher, who was a graduate student in occupational therapy or a recent graduate of the occupational therapy program at Towson

University, and was familiar with the study of FQOL. Researchers also made observations of the participant's behaviors, apparent moods, reactions to questions, and any other noteworthy factors, and take notes during the interview. The physical environment and interactions between the participant and other family members (if available) were also observed. Additionally, after completing the interview, both researcher and co-researcher wrote field notes, which are defined as written notes acquired through observation and/or interview data (Huberman & Miles, 2002). Field notes contained the descriptions of what was observed, as well as the observer's own feelings, reactions to the experience, and reflections about the meaning (Patton, 2002). At the end of this interview, the researcher left the family with the Adolescent/ Adult Sensory Profile (Brown & Dunn, 2002), in a stamped return envelope to be mailed back to the researcher. (See appendix G). The first interview took an average of 1 ½ to 2 ½ hours.

In between interviews, the interview was transcribed. Transcriptions were either completed by a professional transcriptionist, an occupational therapy graduate student, or by the primary researcher. Transcriptions, observations, and notes aided in the development of semi structured questions that were asked during the second interview, as questions in the second interview were based on the information gathered from the first. During the second interview, the primary researcher verified findings from the first interview and clarified anything that might have been confusing from the first interview. The researcher also offered the participant a transcript of the first interview for review. One participant wanted a transcript, and an audio copy of the recorded interview. The other participants verified the findings from the first interview through conversation.

During the second interview, the researcher also asked semi-structured questions to explore issues related to sensory processing in the young adult with ASD and how that affected FQOL. She used information obtained from the returned Adolescent/ Adult Sensory Profile to guide questions. The second interview lasted an average of 45 minutes to 1 hour. As with the first interview, observations and notes were written during the interview, and field notes were completed after the interview, although only the primary researcher conducted this interview. However, for four participants, the second interview was completed by phone, limiting the observations and field notes to what could be ascertained through voice. A professional transcriptionist transcribed the second interviews.

### **Data Collection and Instruments**

This study employed several concurrent methods of data collection. Multiple sources of data were used because no single data source can be trusted to provide a comprehensive perspective of the phenomenon of family quality of life in families with a transition aged young adult under study. By using a variety of sources, the researcher validated and cross checked findings, which is the process of triangulation (Patton, 2002).

As is typical in qualitative phenomenological research, the primary source of data collection was in- depth interviewing (Creswell, 2009). The purpose of interviewing was to allow the researcher to enter another person's perspective. Qualitative interviewing assumes that the perspective of the interviewee is meaningful (Patton, 2002). In this study, two interviews were carried out, using open ended questions. Interviews captured direct quotations about participants' perspectives and experiences (Patton, 2002). For the first interview, a general interview guide to collecting qualitative data through open

ended questions was employed. (See appendix D). This approach outlined a set of questions to be explored with each participant, which served as a basic checklist to make sure all relevant topics were covered (Patton, 2002). The interview guide provided questions within which the interviewer could explore, probe, and ask questions that best provided insights on family quality of life in families with a transition aged young adult with ASD. The interview guide was the same for all participants for the first interview. For the second interview, the guiding questions for each participant were unique for that participant, as questions were based on the information obtained during the prior interview. This approach permitted flexibility in the interview process. (See appendix D for sample second interview questions).

A second source of data collection was observation. To understand the complexities of many situations, direct observation of the phenomenon of interest is valuable (Patton, 2002). Through direct observations of the physical environment, interactions between the participant and other family members when possible, and apparent moods and reactions of the participant, the researcher was able to understand the context in which people interact, which is important to developing a holistic perspective. The observations also allowed the interviewer to learn about things that the participant might not have brought up in an interview. Additionally, direct observation also allowed the researchers to move beyond the perceptions of the participant. By detailing observations, the researcher was able to develop a more comprehensive view of the setting (Patton, 2002). Both the primary researcher and a co-investigator engaged in direct observation during the first interview, and both documented descriptions of what was observed as well as personal reflections (See appendix E).

Qualitative research also allows for the examination of documents such as photographs as a data source. Families were asked to share photographs in this study. Photographs can be valuable, not only because of what can be learned by looking at them directly, but also as a stimulus to ask questions through the interview (Patton, 2002).

A qualitative inquiry does not preclude the use of quantitative data (Yin, 2009). Participants were asked to fill out The Adolescent/Adult Sensory Profile (Brown & Dunn, 2002) on their son or daughter with autism or in conjunction with their young adult. The Sensory Profile was used to understand the sensory processing of the young adult with autism. The Adolescent/ Adult Sensory Profile is a self- reporting questionnaire which measures responses to sensory events in everyday life. There are 60 items in the profile. Individuals complete the questionnaire by reporting how frequently they, or someone in their care, respond in the way described by each item using a five point Likert scale (almost never, seldom, occasionally, frequently, almost always). The Adolescent/ Adult Sensory Profile yields four scores which correspond to the four quadrants of sensory processing proposed in Dunn's model of sensory processing, i.e., sensation seeking, sensation avoiding, sensory sensitivity and low registration. Using national samples of 950 adolescents and adults, the authors calculated scores which indicate when performance is significantly different from peers' responses, which indicates difficulty with sensory processing (Brown & Dunn, 2002).

Psychometric properties of the Adolescent/ Adult Sensory Profile have been examined, and for item reliability, the sensory sensitivity subscale yielded a coefficient alpha value of .81, with alpha values of .77 for the sensation avoiding subscale, .82 for the low registration subscale, and .79 for the sensation seeking subscale. Construct

validity was assessed by determining whether a strong preference for a sensory processing pattern resulted in different physiological response patterns as measured by skin conductance studies. There were a significant differences in responsivity across the four groups: sensory sensitivity, sensation avoiding, low registration, and sensation seeking,  $F(3, 17) = 8.38, p = .001$  (Brown Tollefson, Dunn, Cromwell, & Fillion, 2001). In the current study the Adolescent/ Adult Sensory Profiles of each young adult were used to guide second interview questions. The measure was also scored for all but one young adult, whose parent was unable to answer enough questions to get a valid score.

While not administered as part of this study, the already returned 2011 MASS, a tool adapted from the *Beach Center Family Quality of Life Scale and the Family-Professional Partnership Scale*, was examined by this researcher with permission from the participants. This survey was developed to evaluate the satisfaction and quality of life of families of individuals receiving the Maryland Medicaid Autism Waiver services or on the Autism Waiver registry (Eskow et al., 2011). Eskow (2010) reported, in a National institute on Health grant application:

The MASS survey utilizes a combination of Likert scaled and open- ended questions, which address the following areas: Background Information, Symptom Severity, Child Health, Service Utilization, Service Decision Making, Partnership, Family Quality of Life, Employment, Child's Progress and General Information. The Partnership and Family Quality of Life (FQOL) sections were taken with permission from the Beach Center Family- Professional Partnership and Family Quality of Life Survey. Various sections of the tool are still under development (service utilization, service decision making and employment); however, the child

health section includes questions from the National Survey of Children with Special Health Needs (NSCSHN). The Beach Center Family- Professional Partnership and FQOL scales have published validity and reliability information. The FQOL scale was developed through an initial qualitative study (Poston et al., 2003) and field tested in two national studies to establish the primary factors of psychometric characteristics of the final measure (Hoffman, Marquis, Poston, Summers, & Poston, 2006). The Family Quality of Life Scale contains 25 items with an overall Chronbach's alpha of 0.88. Complete psychometric characteristics including convergent validity and reliability are described in Hoffman et al. (2006). The Partnership Scale was developed and validated using a qualitative, grounded theory approach involving focus groups and individual interview to identify factors families and professional considered critical to effective partnerships (Blue- Banning, Summers, Frankland, Nelson, and Beegle, 2004). Items generated through the qualitative study were submitted to two national field tests (Summers et al., 2005). Chronbach's alpha for satisfaction ratings on the 18-item scale was 0.96; 0.94 for the Child- Focused items and 0.92 for the Family- Focused items. The fit statistics for the Child- Focused factor were  $X^2(27) = 47$ ,  $p < .001$ , CFI = .97, RMSEA = .07. For the Family- Focused factor, the statistics were  $X^2(27) = 61$ ,  $p < .001$ , CFI = .90, RMSEA = .08

Many of the items contained in the MASS sections are not validated at the time of writing. These items have been piloted by the 2008 and 2011 surveys, but psychometric properties of the MASS have not yet been established (K. Eskow, personal communication, April, 2011). However, the reliability and validity established for the

FQOL and Partnership sections do extend to the MASS. The MASS results were used descriptively in the present study.

### **Data Analysis**

Phenomenological analysis seeks to elucidate the meaning, structure, and essence of the lived experience for a group of people (Patton, 2002), who in this study were families of transition aged young adults on the autism spectrum. Qualitative analysis involves inductive reasoning, whereby the researcher discovers patterns, themes, and categories in the data. In this study, the researcher examined each piece of data individually and constructed meaning by identifying patterns and themes that emerged during data analysis. Audio recordings of the interviews were transcribed verbatim into a Microsoft Word document to allow the researcher to begin processing the data for possible themes and recurrent statements. Transcripts from each participant's first interview were read and coded by two researchers, to assure trustworthiness of the data. These researchers coded the transcripts independently, and then came together to discuss the findings. They similarly discussed observations and field notes. As the second interview was a follow up to the first, and was primarily used for confirming findings from the first interview, it was coded only by the primary researcher.

Each transcript was read multiple times. The first time it was read, the purpose was to get a sense of the whole transcript. During the initial read, the researcher did not attempt to develop themes from any aspect of the transcript (Giorgi, 1997). While reading, all thoughts and feelings of the researcher were written down to assist with the process of bracketing. In bracketing, the researcher's preconceptions are set aside to ensure researchers do not allow their assumptions to shape the data (Hamill & Sinclair,

2010). The purpose of bracketing is to enable the researcher to identify data in its pure form, without presuppositions (Patton, 2002). To aid in the process of bracketing, the researcher also discussed thoughts and feelings with a co –investigator throughout data collection and analysis as well as with her dissertation chair to help her remain open and objective.

Each transcript was then reread, and all aspects of the interview data were treated with equal value and divided into statements, a process known as horizontalization (Creswell, 2007). Through this process, the researcher extracted important statements from the transcript that provided an understanding of how the participants experience the phenomenon. The data were then organized into meaningful clusters, or meaning units (Creswell, 2007). Through this process, initial codes were formed. Although the researcher read the transcripts from an occupational therapy and occupational science perspective and from the perspective of the family quality of life literature, care was taken not to impose the expectations of these theoretical positions on the data (Giorgi, 1997). The researcher therefore tried to put aside her personal and theoretical knowledge, and focused on the participants' experiences and descriptions of the phenomenon of family quality of life in a family with a transition aged young adult on the autism spectrum. This approach was discovery oriented, whereby the researcher approached the data with an open attitude to let the meaning emerge (Giorgi, 1997). The clusters of meanings were tied together into themes to make a general description of the meaning and essence of the phenomenon, using rich description provided directly by the participants (Creswell, 2007). The researcher then described the expressions of the participants, in a language appropriate to occupational therapy and occupational science

and family quality of life (Giorgi, 1997). She reflected on the themes in order to determine which themes were essential to describing the phenomenon of family quality of life under study (Giorgi, 1997). This involved combining themes that were redundant and eliminating themes that were not consistent. Interpretation ultimately went beyond the descriptive data, and the researcher strived to make sense of findings, offer explanations, and draw conclusions (Patton, 2002).

Transcription followed each interview prior to the next interview, so that initial data analysis occurred simultaneously with data collection. This allowed the researcher to detect common themes during the interviews and expand the discussion where necessary. This is consistent with the aims of qualitative research, as the nature of naturalistic qualitative inquiry makes distinction between data collection and analysis less than absolute (Patton, 2002).

Atlas ti, (QDA software, 2007), a software program for qualitative analysis, was used to manage data and assist data analysis. This qualitative program facilitated data storage, coding, retrieval and comparing data. However the researcher decided what things go together to form a pattern, what constituted a theme, and what meanings to extract from the data (Patton, 2002).

Throughout the process of identifying themes and recurrent ideas, the researcher incorporated observations taken during the interviews and reflections from field notes to provide objective and subjective contextual details. Individual results for the 2011 MASS also were examined in order to triangulate data as well as to facilitate and support the relationship of responses on the MASS to the themes identified throughout the interviews. Additionally, the Adolescent/Adult Sensory Profile was scored, and the data

were also used descriptively to help to explore the topic of sensory processing of the young adult with ASD. As already mentioned, in one case, the Adolescent/ Adult Sensory Profile could not be scored, as the participant was unable to answer all the questions about the young adult. However, it was still possible to use descriptions provided by the answered questions. Two other participants were unable to answer two questions about their young adults in one quadrant on the Adolescent Adult Sensory Profile. These items were scored with the lowest possible score. Since these questions were in the quadrants of sensory sensitivity for one young adult and sensory avoiding for another, scores could only have been higher than the given scores, and therefore did not interfere with interpretation. This will become clear in chapter 4.

### **Role of the Researcher**

The researcher is considered a primary instrument in data collection in qualitative research (Creswell, 2009). Therefore, the perspective that the researcher brings to a qualitative study is part of the context of the findings of the study (Patton, 2002). In this study, the researcher's personal experiences and insights have been critical to understanding of the phenomenon of family quality of life.

Reflexivity is a quality of a qualitative researcher. A researcher who is reflexive is aware of one's own perspective as well as the perspectives of those whom he or she interviews. Biases, assumptions and personal values are acknowledged. The qualitative researcher needs to show openness, sensitivity, respect and responsiveness during the interviewing process, and be mindful when making observations (Patton, 2002). An important part of reflexivity is the researcher's willingness to engage in self- reflection.

As already discussed, this researcher assured that she engaged in continuous self-reflection throughout the research process.

### **Ethical Issues**

As this is was part of an ongoing multi -phase study, it had been already approved by the Towson University Institutional Review Board. Modifications were submitted to the IRB to allow for the exploration of sensory processing of the young adult with ASD. Any researcher involved with this project had human participant research training.

Maintaining confidentiality and the rights of the participants are also requirements of ethical research. All participant information was and will continue to be kept confidential. Identifying information has not been used during reports or transcriptions. All materials with identifying information such as signed informed consent forms of participants are kept in a locked cabinet. As already noted, all participants were informed of their rights as a participant. Participants were given a consent form that was explained to them, which they signed prior to engaging in the research study. Anyone participating in the study needed to sign a consent form, including the one young adult with autism who participated. As his parents do not have guardianship of him, he signed the same consent form as other participants, which was explained to him by both the researcher and his father. Participants also were informed of their right to terminate participation at any time. Additionally, as already noted, in the consent form, participants gave permission to be audio taped and also gave consent for the use of their already filled out 2011 MASS surveys.

As the interviews discussed sensitive information with participants, which had the potential to be stressful, participants had a say in how their statements would be

interpreted. Part of the purpose of the second interview was to engage in member checking, or taking specific descriptions or themes back to the participants (Creswell, 2009). This assured that participant's statements were interpreted how they were intended. Using validation strategies to check the accuracy of the data with participants demonstrates ethical data analysis (Creswell, 2009).

### **Trustworthiness of Data**

This study took many steps to assure credibility and trustworthiness of the data. Qualitative validity means that the researcher checks for the accuracy of the findings by employing certain procedures, such as the already noted member checking. In this study, the researcher developed themes based on converging multiple sources of data, or triangulating data sources, which adds to the validity of the study (Creswell, 2009).

Another form of triangulation that was used in this study, involved using more than one observer or data analyst (Patton, 2002). This study had a co researcher present during the first interviews to listen and to record observations and field notes, and also had a co-investigator review transcripts, themes, and findings of the primary researcher. This reduced the potential bias from having only one researcher collect and analyze data. This is known as peer debriefing (Creswell, 2009). The researcher regularly reviewed findings with the dissertation chair.

In addition, the researcher spoke with the participants more than once. The more experience that a researcher has with participants, the more valid or accurate or the study results are (Creswell, 2009). The researcher also used a consistent approach to data collection and analysis, thus demonstrating qualitative reliability. Data were constantly compared to codes to remain consistent during the coding process.

**Summary**

This chapter addressed the phenomenological methodology that was utilized to complete this study. This methodology structured the research process so as to systematically examine the quality of life in families with a transition aged young adult on the autism spectrum. This phenomenological methodology enabled the researcher to capture lived experiences as told by the participants, and to identify the core essence of the experiences of being a parent or grandparent of a young adult negotiating or soon to negotiate the process of transition to adulthood. The processes of data collection, data analysis, and verification were described in detail. Results are presented in the following chapter.

## **Chapter 4:**

### **Results**

#### **Introduction**

The purpose of this study was to examine the phenomenon of family quality of life from the perspective of families with youth on the autism spectrum at or nearing the age of transition from school to adulthood. Participants included ten families made up of two fathers, two grandmothers, and six mothers, with two of the six mothers including their husbands for part of the data collection. All but one of their sons, grandsons and daughters were described as intellectually disabled by their families, and all have moderate or severe difficulties in communication, independent living skills, behavior, relationships with peers, and academic performance. The primary form of data collection consisted of two in depth interviews. All interviews took place between August 2011 and April 2012. However, observations were used to supplement interview data, and survey results from the Maryland Autism Service Survey (MASS) previously administered in the spring of 2011 were examined in order to contribute to the triangulation of the data. Additionally, another purpose of this study was to begin to explore sensory processing in these youth, and the influence of sensory processing difficulties on everyday life. This was explored through the interviews, and through administration of the Adolescent/ Adult Sensory Profile (Brown &Dunn, 2002).

Results of the study are presented here. First, each participant family is introduced, using pseudonyms to assure anonymity. Demographic information for each family is displayed, and the salient parts of each participant's story are recounted, both in the researcher's words and in the participants' voices. Following this, thematic

descriptions of the essential elements of the phenomenon that emerged from the data analysis are discussed, using the rich depictions provided by the participants to support the generalized description of the phenomenon. The results of the exploration of sensory processing are also included. Following each thematic finding, a table is introduced that relates examples of families' representative statements of that theme to the research questions initially asked. Research questions are thoroughly answered in the next chapter.

Table 1. Demographic Information about Participants

<b>Participant</b>	<b>Marital Status</b>	<b>Family Income</b>	<b>Waiver Status</b>	<b>Employed?</b>	<b>Occupation</b>	<b>Other Family Members</b>
Ann D.	Married	>\$160,000.	Registry	Yes, Part time	Attorney	Daughter not in home
Shelly T.	Divorced/ Engaged	\$60,000- \$79,000	Waiver	Yes, Full time	Speech / Language Pathologist	2 other children, 3 step children out of state
Lia S.	Married	\$120,000- \$139,000	Waiver	Yes, Full time	Special Educator	Son not in home
Tina A.	Married	\$80,000- \$99,000.	Registry	No, Retired	(Former) Daycare provider	6 children,3 in-laws; 2 grandchildren not in home
May R.	Divorced/ Remarried	Did not disclose	Registry	No	Registered Nurse	1 daughter, 2 stepchildren, out of state
Roseann K.	Divorced	\$40,000.- \$59,000.	Waiver	Yes, Full time	Special Educator	Daughter and son in law not in home
Jan S.	Widowed	\$80,000- \$99,000.	Waiver	Retired teacher; still involved with autism organization	Teacher; Involved in development of an autism organization	3 sons (1 with autism), son inlaw, granddaughter none in home
Stan L.	Divorced	Did not disclose	Waiver	Yes, Full time	Computer Networking	4 other children in home
Dan C.	Widowed	>\$160,000.	Registry	Yes, Full time	Attorney	1 younger daughter in family home
Lois W.	Married	\$60,000- \$79,900.	Registry	No, Retired	Paralegal	1 older grandson in family home; 3 half siblings

Table 2. Demographic Information about Young Adults

Participant	Relationship to Young Adult	Gender of Young Adult	Age of Young Adult	Year Leaving School	Type of School	Adult Program	Living Situation
Ann D.	Mother/ Father also participated	M	22	Left 2011	Private	Yes- began summer 2011	With parents
Shelly T.	Mother	M	21	Scheduled 2012	Private	Still in school/ seeking program	Residential/current placement ends at end of school year
Lia S.	Mother/ Father also participated	F	20	Scheduled 2012	Public	Still in school/ Seeking program	With parents
Tina A.	Mother	F	23	Left 2010	Private	Yes/ began summer 2010	With parents
May R.	Mother	M	23	Left 2010	Public	None yet	With parents (mother and step father)
Roseann K.	Mother	M	19	Scheduled 2013	Non- public	Still in school	With mother (and grandmother)
Jan S.	Grandmother	M	20	Scheduled 2013	Private	Still in school	Residential placement
Stan L.	Father	F	18	Scheduled 2015	Non- public	Still in school	Alternates living with each parent
Dan C.	Father	F	19	Scheduled 2013	Public	Still in school	With father (and sister)
Lois W.	Grandmother	M	21	Left at 18/ 2009	Public	None presently	With grandparents

### Families

Families are described in the order in which they were seen by the examiner.

Table 1 includes demographic information about the main participant mother, father or grandmother in the study. Table 2 describes demographic information about the young

adult. Referring to these charts regularly may help to clarify information about the participants. Families are labeled by the main participant, a spouse if also a participant, and the young adult on the autism spectrum.

**Ann, Brian, and Ray D.** The D. family consists of Ann, a part time attorney, and her husband Brian, also an attorney. They live in an upscale neighborhood in metropolitan Washington DC. They have a daughter, who was away at graduate school at the time of both interviews. Ray is their 22 year old son on the autism spectrum, who lives with his parents. Both parents participated in the first interview at their home, and purposefully scheduled that interview at a time that Ray would be home so he could be included. Ann met the investigator for the second interview on her own. It is notable that at the joint interview, both husband and wife shared similar experiences, and often completed each other's sentences.

His parents described Ray as being in the "middle" of the autism spectrum. He has considerable receptive and expressive language and can do academic work at about the 3rd grade level, although conversation is difficult for him. Ray is a well- built young man, and appears to be physically fit. His mother described him as an "avid" bicyclist. He also swims, ice skates, and plays ice hockey, although according to his mother, he has quite a bit of difficulty with the "teamwork aspect" of hockey. Ray also has interests in art, and appears to have some talent in this area, as evidenced by his drawings and sculptures that adorn his house.

Although Ray began school in the public system, he spent most of his school years in a private school placement, as his local school district did not have an appropriate placement for him. He had many related services and therapies over the

years, some provided in school, but many provided privately at the parents' expense. Ray and his family never received the autism waiver, as due to his father being in the military, this family was outside of Maryland, at what would have been the optimal time to secure waiver services.

Ray "graduated" from the public school system with a certificate at the end of the school year prior to the first interview. He had recently begun in a day habilitation program for adults on the autism spectrum at the time of the first interview. Although he had job placements during high school, he has not had any supported employment experiences since completing school. Both parents expressed optimism that ultimately he would be able to work in a supported employment setting.

The most memorable parts of the interviews with Ann and Brian related to their discussions of their son's anxiety disorder, which coexists with his autism. Ray's anxiety complicates the life of this family. The anxiety disorder began around the age of 11, following puberty, and parents reported that Ray's anxiety has stemmed from a fear of growing up. When he was a young adolescent and about 5'6" tall, he started walking in a crouch or on his knees, until he got bursae on his knees. He became selectively mute for a period of two years "because his voice changed, and he didn't like the sound of his voice." One significant aspect of how life has been affected by their son's anxiety is suggested in Ann's discussion of their nightly routine, as she stated "one of us has to sleep with him [Ray] every night." Therefore, these parents haven't slept together for "quite some time." Ray does go away to camp, for a week twice yearly, and his parents stated, "We just can't wait until vacation to sleep in bed together."

Ray's anxiety is so pervasive that during the first interview both the investigator and the co-investigator were advised to avoid certain "trigger" words when speaking with Ray. These words included what the parents called "the J word" for job, "the G word", for graduation, and "the O word" for own, as in "do it on your own." Ann and Brian also avoid the numbers twelve through twenty, "all of the T words, for teen, as these imply growing up." Unfortunately, this anxiety about growing up has limited Ray's ability to engage in productive employment related activity. When he would go for an interview that his school recommended he go to, he would tell the interviewer that he didn't want to do the potential job. His parents emphasized that these positions would have been well suited to him if not for the anxiety.

Ann reported that she feels that it is important that people recognize that autism and everything that goes along with it "is not a difference, it is a disability, a seriously disabling disability." She stated that the neurodiversity movement emphasizes that autism is a difference and that all people with autism need is accommodation. While that may be true for some people on the higher end of the autism spectrum, Ann emphasized that for her son, it is "profoundly disabling" and that even with services and support, "life is hard."

**Shelly and Chase T.** The T. family consists of Shelly, who is a speech pathologist in a local school system and her son Chase, who is 21 years old, on the autism spectrum, and in his final year of school. Chase was attending a private school placement, financed through the public school system at the time of the interviews. Chase does not live with his mother, but rather resides in a residential facility. Chase's aggression towards his mother necessitated this residential placement nearly 5 years ago. Chase and

his family receive autism waiver services, which have paid for the much of the cost of residential services, as well as after school services. Like school based services under IDEA, waiver services will be terminated at the end of the school year. Shelly sought out support services early on for Chase, doing extensive research to learn what services were available for her son, and to secure them. She knew about Maryland's autism waiver services from her job in the Department of Welfare in the state in which she had lived before coming to Maryland, and was quick to sign up for them.

Shelly's other family members include her former husband, whom she divorced a couple of years following Chase's autism diagnosis. She emphasized that Chase was not the cause of their problems, but his issues exacerbated the existing problems between them. She also has three step children in their 30s, and two other biological children, all in their twenties. Shelly considers herself close to her step children. When asked to show the interviewers a picture of her family, she shared a picture of all six children, although explained that Chase was "photo-shopped" in to the portrait, as he wouldn't cooperate for the group picture. All the other children live in another state, not far from their father. They are within a two hour drive of Shelly as well. Shelly lives with her fiancé, who is a teacher, in a middle class community midway between Baltimore and Washington, D.C. At the time of the second interview, he had just picked up Chase for a home visit, and appeared to manage Chase easily and comfortably.

One remarkable part of Shelly's story concerns the ease with which she told it. She recalled dates of doctor visits, diagnoses, and medication changes, and the names and affiliations of every doctor she has seen. She likewise had a proficient recall of changes in Chases' autism symptoms and seizures over the course of his lifetime. When the

interviewers remarked about this ability when she recalled the exact date of his diagnosis, she simply said “you don’t forget something like that.”

Another compelling part of Shelly’s story concerns the lengths she has gone and is willing to go to attempt to meet her son’s tremendous needs, as well as to try to tend to her own. She tearfully described Chase’s aggression, which increased after puberty, and how she documented his aggressive behavior, reporting every episode to the police, and to the Maryland State Department of Education, (as the Department of Education administers the autism waiver). This documentation assisted her in securing the residential placement that she believed was the best chance for Chase to learn appropriate behaviors, and for her own mental health. She emphasized during the second interview that Chase’s residential services will end following completion of the school year, the same time that waiver services and school based services end. She articulated with conviction that should he not have another placement by that date, he will be homeless. There was desperation in her voice when she said that, but she emphasized that if Chase would have an alternative living situation with her, it is less likely that he would get an adult services residential placement, as those with the most serious needs are considered first. She stated, “It sounds so cold, but it is difficult for a parent to do this. It’s the hardest thing to say that you can no longer handle . . . [your child].”

Shelly similarly went to great lengths during Chase’s growing up years. She made the decision to go to graduate school shortly after Chase’s diagnosis. Her school was three hours from the family home. She took Chase with her, and got him into a program near her University. She returned home every weekend, and prepared her other children for the week. She opted for this arrangement, because she felt Chase’s father couldn’t

appropriately manage him, yet she didn't want to disrupt her other children who were "happy and in a good school system." Following her divorce and completion of her educational program, she opted to move to Maryland, where she believed her son would receive better services, but continued to parent her other children from a distance during the work and school week until they completed secondary school.

**Lia, Len, and Abby S.** The S. family consists of Lia, the primary participant, and her husband Len, who joined his wife during the second interview. They live in a middle to upper-middle class suburb of Maryland, not far from Washington, D.C. They have a 23 year old son who is employed and lives outside the family home. Abby, their transition aged young adult with autism, is 20 years old. She attends a public high school in a special education class, and lives at home with her parents. At the time of the first interview, Abby was at home, as it was a school vacation. Although she did come and meet the investigator and co-investigator, she did not participate due to her level of disability and limited verbal skills. She spent much of the time the interviewers were present in her room watching videos.

At the time of the second interview, Abby had begun her last year of public school. Her family was in the process of evaluating programs for her to attend following transition. Lia and Len are a team, with each taking certain responsibilities for Abby. As Len's schedule has more flexibility than that of his wife, he was in the process of investigating programs. At the time of the second interview, the parents had decided what programs they were interested in for Abby, and submitted applications. Len explained that their county had simplified this process by providing a "single point of contact" to submit applications. They were putting in applications for day habilitation programs, but

were hoping there would be opportunity for supported employment. Abby has participated in several work opportunities for a limited number of hours while in public school, some more successful than others. According to her mother, she enjoyed serving meals to the elderly, and greeting members at the gym. She was less successful with paper shredding and cleaning jobs. Lia reported that Abby needs to have a one on one aide at any work place.

When Abby and her brother were younger, Len, who works in county government, took on a second job, so the family could afford for Lia to stay home with the children. His doing this also enabled his wife to go back to school to become a special education teacher. Lia's teacher's schedule has allowed her to be home to take care of Abby during the summers when she is not in school. Lia's parents also have contributed to this family's ability to manage their daily routines. It is Lia's mother who comes in the morning to stay with Abby when Lia and Len leave for work, and who gets her off of the school bus and stays with her until one of them gets home. One of Lia and Len's biggest expressed concerns for the year following transition is transportation. Should the program they get not offer it, it will not work smoothly with their work schedules. Also, the programs under consideration are not all located close enough to Lia's mother for her to continue to help with morning and afternoon routines.

After being on the autism waiver registry for five years, Abby was awarded waiver services three months prior to the first interview. However, according to Lia, the family had difficulty finding an actual provider. She articulated that even when they first found a provider, that provider fell short of meeting Abby's and the family's needs. Fortunately, at the time of the second interview, they had found a service provider whom

they really like who had been coming three days a week to work with Abby on her service plan. This service provider is a young woman who is only “a smidge older than Abby”, and is becoming “more of a friend” to her.

The feature most salient in the story of the S family is Lia’s overall optimistic disposition. Even while speaking of the difficulties concerning schooling and post-secondary programming for her daughter, as well as demands on her time and limited ability for her husband and herself to spend time together, Lia presented herself as happy and truly appreciative of the good things in her life. Instead of focusing on the negative, Lia stated “life is great” and throughout the interview declared “I’m really fortunate,” “We are really lucky,” and “Abby’s issues are a blip in the road, not a roadblock.” She spoke several times about how fortunate she was that her daughter loves her so much and how in the summer she “gets to stay home with Abby and have fun.” She spoke with affection and gratitude about her parents’ role in taking care of her daughter as well as her “great” neighbors.

During the first interview without her husband she spoke of her “amazing” husband, who was taking off the next day so she could have some time to go shopping by herself. During the second, she described a recent evening at home with Len and Abby in “in front of the fire and watching a game on TV” and shared that “there’s no place I’d rather be.” She even spoke of the “happy accident” that her waiver case manager happened to come to that position from the office of transition services, and therefore was able to provide them with a lot of good information that no one else had given them. She clearly has an optimistic happy and easy going disposition.

**Tina and Nan A.** The A. family is composed of a mother, father, two daughters, five sons, two daughters in law, one son in law, two grandchildren and three dogs. The mother, Tina and father, Robert have been married for thirty-nine years. Their oldest children, a set of twins, are thirty-five years old. Their youngest daughter, Nan, is twenty three years old and was diagnosed with autism. The family is a deeply religious, Catholic family who lives in a well maintained single family home in a working class neighborhood in suburban Baltimore. Only Tina, Robert, Nan and the dogs reside in the home. The oldest children, the twins, are both married and each has one child. Tina helps watch the youngest grandchild on a regular basis at the family home. The third oldest child is also married. The three other sons are single and live independently. All of the adult children frequent the family home and provide support to their parents. Tina and her husband do occasionally rely on their children to watch Nan so they can go out, but don't ask them frequently. One son in particular spends a lot of time at home and occasionally sleeps there. The interviewers met him briefly during the first interview however Tina served as the only study participant.

The oldest six children all received private Catholic schooling, and all six obtained a college degree. Nan did not receive that private religious education. She went to public school, because her parents felt her needs would be met there, and the cost of a private education for her would have been prohibitive to them. Prior to entering middle school, due to dissatisfaction with the school placement and Nan's overall lack of progress, her parents were able to transfer her to a private school, at the school system's expense. Nan attended school until the age of 21 years. At the time of data collection,

she was enrolled in a day habilitation program in an adjacent county. She was at her program at the time of both interviews.

Tina earned a high school diploma as her highest level of education, and her husband received a college degree. She ran an in home daycare program out of her house for 24 years while her children were growing up, which she says gave Nan a “peer group,” and helped Nan develop skills. Additionally, it enabled her to manage Nan’s care while earning an income.

Aside from the large supportive family, the most memorable parts of the story of the A family concerns Tina’s depiction of Nan’s behavioral outbursts. Tina reported that even when Nan was a baby she would “throw herself around in the playpen” and she “hit, bit, and pinched.” Her behavior became more difficult to manage as she got older, with Nan continuing to “throw herself on the floor, kicking and flailing.” Tina described her daughter’s high pain tolerance as she “banged her head” and “bit her hands.” To fully illuminate the severity of Nan’s tantrums, Tina explained that “there were loads of holes in our walls. She used to bang, I mean we had loads of ‘em.” Tina vividly described an episode in which Nan “put her head through a window,” and another in which she “put her head through a fish tank.” Remarkably, Nan was not significantly hurt in either episode. These “meltdowns” have lessened due to Nan’s medication regimen secondary to an in-patient psychiatric hospitalization, and the family’s ability to “talk her down and distract her” because they have “learned a lot of the behavior techniques.” However, they still occur. Tina reported there only have been about three “full blown” episodes in the past six months, whereas they used to be daily occurrences.

Even though Nan's "meltdowns" are less frequent, they are still problematic for this family. For instance, at her day program, Nan requires a one on one aide, because she "will pinch out of the blue." Additionally, she "attacked" the bus driver after she started the adult services program, when he went over to fasten her seatbelt for her, as she was unable to do it. Furthermore, her behavior limits options for supported employment. Her day program will not let her do contract work outside of the program because of this.

**May and Greg R.** The R. family consists of May, her son with autism, Greg, and her husband Mark, who is Greg's stepfather. Her first marriage to Greg's father ended in divorce. May, Mark, and Greg live in an upper middle class neighborhood midway between Baltimore and Washington, D.C. In addition to Greg, May has an adult daughter, and Mark has an adult son and daughter. Since Mark had custody of his children when they were young, May reported that she raised his children, and considers them her own. May, Mark, and Greg are originally from another state but moved to Maryland for Mark's job when Greg was a teen. All of their other family members live in their home state.

Greg is a 23 year old male with autism. His functional ability consists of showering himself, shaving, fixing small meals, toileting, and dressing. Greg also is able to read at an 11th grade reading level, although comprehension is closer to a first or second grade level according to his mother. Greg already transitioned from high school. Before transitioning, he had been in a segregated public special education setting throughout school, both in his home state and in Maryland. Having moved to Maryland when Greg was already older, he remained on the autism waiver registry during his later school years, and never received waiver services.

Greg was present at the time of both interviews. His mother insisted he meet the interviewers. He was able to repeat a script that his mother gave him to greet the researchers. Greg spent the remainder of the time the interviewers were in the home either in his room or in the family room playing computer games and navigating the internet. He is a heavy set young man, and his mother stated that it is hard to engage him in active pursuits.

May was the informant in the R. family in the current study. She holds a Bachelor of Science degree in Nursing, which she received when her son was a young child, but reported that she has never practiced as a registered nurse because it “never worked out while trying to get my son an education.” She also stated that she will probably never work again, due to the demands of raising her son. This is one of the most compelling parts of May’s story. Although Greg had been out of school for more than a year, he was not receiving adult services at the time of either interview, so he was spending his days at home with his mother, working with her on some academics, functional living skills, and communication strategies. This period of time has been difficult for May, as she is her son’s care provider. She gets funding from the New Directions waiver for services, and uses that money for herself to be the service provider. She emphasized that the amount of money she receives from the waiver is minimal. May reported that she spends a good part of everyday working with her son. Although her son is not in a program, he went to “try out” three programs.

The first one accepted him, but May refused to send him there because he would have been in the most challenged group of young adults, and would not have gone into the community, which she stated he needs. In her own words, “they were just keeping

him in the big room . . . and they do puzzles and color and stuff, and it's quite useless in my sense you know. I don't see my son gaining anything from that." She nixed the placement because "there has to be some kind of learning and engagement going on." In the second placement he was offered, Greg would not have been brought into the community unless he did janitorial services, which May explained was a job not suited to him since he dislikes getting his hands dirty and "has a fear of cut out toilet seats." At the time of the second interview, May said there was a possibility of a placement.

May articulated that Greg should not be spending his time "with his fifty some year old mother," and pointed out that "he's isolated here and needs to be with peers." She also suggested that the only thing worse than the school system is not having her young adult child in the school system. "At least with IDEA you can try to make some headway."

The other notable part of May's story is that she disclosed during the second interview that she had been diagnosed with a "major depression." She articulated that this was related to the demands of taking care of her son. This disclosure did not come as a surprise, as the interviewers had noted during the first interview that May appeared sad, as evidenced by her tone of voice, her facial expression and her slowness in moving. Additionally, she and her home appeared a bit unkempt. May described herself as being "in limbo," because she did not know what was going to happen with Greg nor did she know what was going to "pan out" with herself. She suggested she might need to "go somewhere for a while to collect myself." This was consistent with her 2011 MASS survey results, where May reported herself to be dissatisfied to very dissatisfied relative to nearly all but one question concerning family quality of life.

**Roseann and Peter K.** The K. family consists of Roseann and her 20 year old autistic son Peter, who live in one of Maryland's western counties. Peter was attending a non- public school program for high school aged youth with emotional disabilities paid for through the public school system at the time of data collection. He was receiving autism waiver services, with Roseann reporting one particular service worker who comes to the home after school as being very good at interacting with him. Rosanne was married for 20 years, however, divorced four years ago because her husband "wanted a different kind of life." Roseann explained that her former husband wanted her to become a foster parent with him and bring children into their home and, in her words, she was "exhausted taking care of my son and I couldn't take on more. So he left." Her ex-husband is still very much involved with Peter, and Roseann described him as "my best respite provider." Roseann and her ex-husband also have a 22 year old daughter who lived with Roseann following the divorce, but married a year ago. The daughter attends college and she and her husband live nearby.

Roseann's mother moved from another part of the country after the divorce, and bought a house with her, so Roseann, her mother, and her son live together. Her ex-husband has maintained the family home, which according to Roseann, makes it easier for Peter to deviate from his routine and see his father. Although she expressed that her mother cannot help with Peter, Rosanne explained that her mother gets things done around the house, which is helpful to her.

Although originally a journalist, Roseann worked as a parent advocate in the local public education system when Peter was young. She then went back to school for a master's degree in special education. She is a special educator in a local high school.

The most powerful part of Roseann's story concerns her son's medical issues that co-occur and complicate his diagnosis of autism. Peter has severe gastro-intestinal (G-I) problems which, in hindsight, she reported he had in childhood. However they worsened gradually during adolescence, and worsened considerably in the past few years. Peter's digestive problems cause him to have a lot of pain and vomiting following eating. He takes a lot of powerful medications, including morphine several times a day, and is on a very restricted diet, consisting of few foods that are nearly liquid in texture. Even the smell of food can cause him to throw up.

These digestive problems, as well as urinary tract issues that are less severe than the G-I problems, interact with his autism symptomatology, as Peter lacks the verbal skills to explain what is hurting, and lacks understanding of his conditions. When he is in pain, he acts out. Roseann explained that at one point, this acting out took the form of doing "12,000 dollars in damage to the high school." She stated that this acting out is just his way of trying to tell them he is uncomfortable, and had the school staff realized this, perhaps this type of disruption would not have occurred. While there are episodes of acting out at home, Roseann is able to manage her son's behavior without major incident. She articulated that even those trained to work with youth with disabilities do not understand the interaction between the medical issues and behavior.

What makes this story even more disheartening to Roseann is the fact she had been very proactive in planning for eventual transition from school. When Peter was in middle school, he had difficulty sitting still. His mother reported that he always had to keep moving, and suggested that this may have been due to sensory issues, or it could have been due to the G-I issues, which were not known at that time. Peter was a large

strapping young man even at that time, so educators kept him moving by giving him jobs in school. He filled the soda machines and he helped the custodial staff make deliveries. When he transitioned to high school, he continued these jobs, and in addition did landscaping, catering, and any tasks in which strength was required. In his mother's words:

He could push those flat carts, haul all of that soda, load those machines, he could open and close them with keys, he could do all his deliveries ... He would set up and tear down for huge events, he would do everything. They would come and knock on the door and take him from class because they needed his help.

Roseann figured that when he would finish high school he naturally would move into a vocational setting doing a variety of similar tasks. She cried when she related the rest of this narrative saying "and here's where my story goes bad."

Unfortunately, as Peter's medical condition worsened, he lost a great deal of weight, in excess of 100 pounds, and became increasingly weaker. It pained him to bend down. Whereas before "his IEP was 120 pages of vocational goals", this is no longer the case. They are looking at "day habilitation because he's so sick." Roseann is very worried that she will not be able to find an appropriate program for her son, because "when he is uncomfortable, he gets aggressive." In his school placement he has a "two to one" [two aides assigned just to him], because "you never know when it will happen."

Roseann expressed her fear that after Peter leaves the school system, the programs that can manage his medical and dietary concerns won't be able to manage his behaviors, and the programs that are designed to manage his behaviors, won't deal with the narcotics and the diet. Roseann is extremely worried because, as she repeated several

times, “I have to be able to work. I don’t know how to take care of him if I can’t work.” There is a sense of despair in her voice as she explained, “it’s just that I just don’t know what we’re going to do for him during the day so that I can work and he can have a meaningful day and a meaningful experience and be safe and I don’t know who can help me.” This part of Roseann’s story is even more compelling when one remembers that, as a high school special education teacher, she regularly assists her students’ families in navigating the transition from secondary school to adult services.

**Jan and Nathan S.** Jan, a retired first grade teacher, is a widow who lives in a middle to upper middle class neighborhood, not far from Washington, DC. She is the grandmother of Nathan, a 20 year old youth on the autism spectrum. Jan describes Nathan as “verbal, but unable to read.” Nathan attends a private school program that is funded through the public school system, and actually housed within a public school. There is a vocational component to his school program. Nathan is the son of her daughter, who died in 2006, secondary to complications of a degenerative neurological disorder. Because Nathan’s mother was ill from the time he was very young, Jan described herself as his “advocate and surrogate mother.” Nathan went to live in a residential program following his mother’s death. He has a father who sees him weekly, and a sister who is away at college, however Jan is the family member who sees him most regularly.

Nathan’s residential program and his school are run through a private organization for individuals of all ages with autism. Jan has been involved in that private organization since its inception, and in fact, was instrumental in starting the organization and securing funding for its operation. As a result, Jan has been successful in seeing to it

that Nathan has received appropriate educational placements throughout his schooling, and has had an excellent residential placement. She does credit her local school system as well as the Maryland State Department of Education for recognizing her grandson's needs, providing funding for his education, and for not waiting for him to "go to public school and fail." Additionally, Jan was proactive in securing the autism waiver for her grandson, who was among the first in the state to receive it. Initially, the waiver provided in home services while Nathan was a young child, and has been providing residential services funding since he entered residential care.

As with other young people at the age of transition, Nathan's school, residential placement, and waiver services all will end following the school year after his 21st birthday. However, Jan has already planned for a seamless transition. She said, "I've been planning for years." She recently secured a grant which enabled her to remodel a basement in an existing group home, where Nathan will live once he completes school. She got him a one day per week volunteer position, outside of the vocational placements in school, and is already in discussion to increase his time there in preparation for transition. Jan stated that she expects that Nathan "will be able to contribute to society."

Clearly Jan's involvement in the provision of supports, and her proactivity in making sure Nathan's needs are and will be met are most noteworthy parts of her story. To fully understand this, however, one needs to know about Jan's life before Nathan. Jan's initial involvement with autism came from her experiences with her own nuclear family. She is the mother of three grown sons, one of whom has autism. Services for children and adults with autism were "non-existent" when her son was growing up. The only existing program for adolescents with autism was housed in an institution. Jan and a

friend insisted on visiting that institution, and found “about 30 adolescents with autism milling around in a room” which was barren, with a two way mirror. The “only time they [the staff] did anything was when someone got hurt.” After that visit, Jan vowed, “Well I know where hell is here on earth, and my son will never enter an institution.” After hearing repeatedly that “somebody should do something” to improve the situation for these young people, Jan decided, “I am somebody” and thus began her work developing services for those on the autism spectrum, beginning with adolescents. While it took her a period of several years, Jan managed to secure a small grant from her local county and repeatedly went to the Developmental Disabilities Administration (DDA), asking for funding. In her words, “I nagged and I pushed and I prodded” until DDA had some end of the year money left over and gave her ten thousand dollars. What this did “was legitimize the program because it was department funded by DDA.” By that time, her son was 21 years old, so she placed him, two other boys from the community, and three others from an institution into residential living. She didn’t have enough money to fund the program for even a year but “went back” and DDA gave her additional funds. Jan emphasized that it was only through “determination” and “persistence” that she managed to do all this, and that she didn’t have any specific skills that helped her accomplish all she has. She also pointed out that she believes that today, since parents are accustomed to getting supports and services from IDEA while their child is in school, they aren’t doing enough to plan for their child’s transition to adult services.

**Stan and Kelly L.** Stan L, a computer network expert, is a divorced father of five. Kelly, his 18 year old daughter with autism, is the second oldest of his children. Stan shares custody of Kelly and the minor children with his ex-wife. Two of Kelly’s siblings,

a brother and a sister, are in high school, and her youngest sister is in middle school. On Mondays and Tuesdays, the children stay at their mother's home, on Wednesdays and Thursdays they are with him, and the parents alternate weekends, which include Fridays. Stan appears to have a good working relationship with his ex-wife to manage their joint child rearing responsibilities, and an even better relationship with his ex- wife's parents, who are actively involved with helping in the care and management of Kelly. Both Kelly and her youngest sister need to be driven to their respective bus stops in the morning, and Stan shares this responsibility with his former in- laws, even on days that the children are staying with their mother. Family members, including Stan's mother as well as his former wife and in- laws, are responsible for watching Kelly in the afternoons, so someone is always at the home where Kelly is coming after school. This schedule allows Stan to manage his work responsibilities, and thanks to this family network, he rarely has had to take off time for child care. Stan stated that he wishes his children could be with him full time, and that he misses them when they are with their mother. However, he also acknowledged that he likely would "not be able to manage things if he had [Kelly] full time."

Kelly attends a non- public school program that is funded through the local school system. Although at one point she was bused 1 ½ hours each way to get to school, the school opened a satellite program which is housed in a local public school, making her commute much shorter. Her program has a vocational component. According to Stan, the school is "teaching her more life transition skills . . . and she's got a, technically, a job in the mailroom and she knows how to sort." Additionally, Kelly used to have a job

where she would sort laundry. The school program takes Kelly and her peers out to community stores for shopping trips.

Stan reported that he has been pleasantly surprised by some of Kelly's skills. He watched her put together a 100 piece puzzle "in less than thirty seconds" when he was visiting her at school one day. He also described her picking up a book and starting to read, a skill he hadn't realized she had. He reported that Kelly is able to read at the 4th grade level, although he stated that her comprehension is lower. Kelly also demonstrates fifth grade math skills according to her father. She can make change from five dollars at a cash register.

Kelly requires assistance with some of her self-care skills such as bathing and hair washing. She is able to put on her clothes independently. She demonstrates severe self-injurious behaviors such as head banging and biting her wrists, however Stan emphasized that his daughter is not aggressive to anyone else.

Kelly was awarded the waiver in December 2010 after being on the registry since 2004, however she did not begin receiving services until November 2011, due to paperwork and time spent finding a provider. Stan reported that he likes having the waiver because someone comes in the house and works with Kelly, giving him some time to focus on the other children, and help with homework. This appears to be a positive change since he filled out the MASS survey and reported he was dissatisfied with his ability to meet the individual needs of every child. The waiver providers also take Kelly out in the neighborhood to try to keep her physically fit. Stan actually shortened the hours in which Kelly was being provided with individual support services, as he felt that the amount of time someone was working with her after school was "too much" for her. The

L. family had actually applied for and received waiver services when they first began in Maryland, however decided against them, as the only service that the family was being offered at that time was respite. Stan reported that he would have had to drive for over ½ hour to bring Kelly to a respite provider, where she would have had two hours of care. This was of limited use for his family members, since they were caring for four other small children at that time, and driving Kelly over an hour to gain two hours without her, did not make sense to them. By the time Stan found out that waiver services had been expanded, and he reapplied, there was a lengthy registry list. Stan reports that he is pleased that Kelly is back on the waiver, and emphasized that given both his and his ex-wife's relatively high incomes, his daughter has not qualified for too many funded services. The waiver is the only program so far that he tried to secure in which their incomes did not restrict their eligibility.

As Kelly is only 18 and will not lose her school based and waiver services until 2015, Stan is at the beginning of the transition process. He stated that when Kelly was 14, vocational goals were added to the IEP. Stan has been to a transition fair, but he stated he finds the process confusing. He would love to speak with parents who have already gone through the process, although there is no mechanism in place in his school system to encourage this.

**Dan and Shira C.** The C. family consists of Dan, a 60 year old widower who is an attorney, and his two daughters. They live in an affluent area in a Maryland suburb not far from Washington, DC. His older daughter, Shira is 19 years old and on the autism spectrum. Dan describes her as "very sweet." Shira is verbal, and was able to maintain a short conversation with the investigator and co-investigator. According to her father, she

manages her basic activities of daily living, and is able make her own lunch. She has some interests that are like others her age, such as dancing and looking at People magazine. She is in a special education program in a public school system that focuses on independent living. It is “vocationally oriented,” and includes community work placements, although Dan doesn’t think that any of the placements will lead to a position after school ends. Her school program also includes instruction on using money, and public transportation. Dan reported that Shira has one more complete school year before she ages out of the school system.

Shira requires supervision, and cannot be home alone, because “she may try to cook something or do something that is dangerous.” She also might “wander off” if not watched closely in the community. At the time of the interviews Dan reported that he has a housekeeper who comes on weekdays before Sarah comes home from school, helps her with her homework, and prepares dinner with her for the family. Dan also has hired people to take on outings for a few hours over the weekend. His other daughter keeps an eye on her sister at times when she is at home, although Dan stated that she will be going away to college during the coming school year. Dan’s sisters live close by, and also take Shira out and are very involved in her life. Dan can count on one of his sisters to help out if the housekeeper cannot come, so he doesn’t have to take off from work.

Shira had just finished her third grade school year when her mother died, after a very short illness. Her mother had managed her day to day care as well as that of her typically developing sister. Both parents had actively sought out anything, both medical and therapeutic, that would help their daughter, often at great personal expense. Dan continued this after his wife’s death. While he felt there were some effective

interventions, he felt that most did not work for Shira, and felt that some providers were “quacks.” In his words, “when you have a kid with a disability like this which is pretty much of a mystery, there’s all kinds of people out there that are very wrong to take your money.”

Shira is on the autism waiver registry, and, due to the fact that she is still “about 1000” on the list, and she has only one more year of eligibility, most likely the waiver is “not going to do anything for her.” He applied when she was little, but according to Dan:

I screwed it up because . . . before we realized that she was disabled, I had put money in her name in a gift to minors account and so that disqualified me for the autism waiver and . . . by the time I reapplied, you know where I had taken the money out of that account and spent it on her, which is required by law, there was a waiting list of 2,000 names.

Dan is trying to be proactive in planning for Shira’s future, which he stated “petrifies” him. He has already identified programs he should visit to determine where she should be following her last school year. While his plan is to make arrangements first for what Shira is going to do after leaving school, he is also thinking about living arrangements. He stated that there are few available financially affordable residential placement options. He is planning to talk about “a collaboration” with another parent of a young adult daughter. They are starting to investigate whether it is feasible for them to purchase housing for their daughters. Dan has been in touch with the Department of Rehabilitation Services (DORS), and the Developmental Disabilities Administration (DDA), but emphasized that figuring out the adult services system is confusing, and “no one tells you who does what.” This is a telling statement when one considers the

resources that Dan has compared to many who are trying to navigate the world of adult services.

**Lois and Jason W.** Lois is a 61 year old grandmother, who lives mid-way between Baltimore and Washington in a middle class neighborhood. Lois has been having some health problems, and was recovering from orthopedic surgery at the time of her interviews. She raised two of her daughter's children since birth. The younger of the two, Jason, is 21 years old and is "at the higher end" of the autism spectrum. He has a diagnosis of Asperger syndrome, and also has diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), learning disability (LD), bipolar disorder and oppositional defiant disorder (ODD). He and his brother, who is a college student, reside in the family home with Lois, and her husband, Scott, whom she married when her children were still in elementary school. (She had been widowed very young.) According to Lois, her husband views her three children, as well as the two grandchildren whom they raised together, as his own. Lois and her husband adopted Jason's brother when he was an infant, and tried to do the same with Jason, however his father never signed the papers. In spite of this, Jason doesn't see his father and sees his mother only occasionally. Lois stated that she and her husband are the only people Jason trusts. Jason has three other half siblings, two older and living on their own, and one younger and living with Lois' daughter.

Jason left the public schools when he was 18 with a certificate. It is Lois' one regret that she agreed to the school's recommendation that he not get a diploma. This decision wasn't made until Jason was a junior in high school. Lois emphasized that since Jason was 18 and an adult, leaving school was his decision to make. Lois reported that

Jason has relatively strong mathematics skills. He was doing math on grade level when he was in school. However, his reading skills are at a fifth or sixth grade level and his written expression is an area of great difficulty. He only can write at an early elementary level. Jason was on the autism waiver registry. He never received waiver services, and his grandmother questioned whether he would have qualified for those services had there been a spot for him.

Jason received a job through DORS working at a supermarket while he was still in school. He maintained the job for several months. He had some difficulties at that job, including leaving early, or not calling in to work when he needed to be out, however the company tried to work with him, and he stayed there until he quit. He then held a job with a restaurant briefly. Lois reported that “when [other employees] found out what was wrong with Jason, they began talking about him.” This precipitated his leaving. He held one other job very briefly since leaving school. Lois reports that DORS has provided him with minimal monitoring. Jason also has a caseworker through DDA, however Lois stated that this organization has not followed through with Jason. For instance, they failed to provide promised transportation so that he could attend a meeting with them about employment opportunities. Jason has not worked in the last three years, and his grandmother described him as “bored.” However, she pointed out that Jason is easier to manage without the stress of working and attending school. She added that Jason spends the majority of his time playing on the computer, and suggested he would like to be doing something more. Ideally, Lois would like to see her grandson work part time doing something computer related. She would like something so that he could work sometimes from home. She suggested that the ideal job for Jason would be testing video games.

While Lois said that Jason “will never drive,” she reported he does know how to use public transportation. This is something that he learned when he was in school. She expressed concern about her grandson’s money management skills. When he used to work, he would “go to the bank and overdraw his account.” At the time of the interviews Lois reported managing Jason’s money for him by depositing his social security check in his account and giving him a small amount of money “to spend any way he wants.” While he dresses and showers and does other self-care tasks, he does not do laundry or much in the way of meal preparation. It is Lois’ plan to turn the basement living area into an apartment for Jason once his brother, who is currently living there, graduates and moves out.

Lois expressed concern about Jason’s social interaction skills. In her words, “He gets along with his brother, but doesn’t interact as well with his half siblings or other family members.” While he had a few friends when he was younger, he has not sustained any friendships. Lois articulated that Jason has difficulty trusting people, and the only people he feels he can count on consistently are his grandparents. Especially because she has had health issues in recent years, Lois expressed concern about what would happen to Jason should something happen to her. Despite the fact that Jason is considered “high functioning,” his productivity is limited and his dependence on his grandmother is great.

### **Thematic Descriptions**

Following the extensive data collection and analysis process, the researcher developed thematic descriptions of the essential elements of the phenomenon of family quality of life from the perspectives of these participants that emerged from the data. The three themes that are the results of the data analysis are presented here. These themes are:

changes associated with puberty and associated disorders that manifest or worsen during puberty affect autism and challenge quality of life; occupations are influenced and restricted when there is a family member on the autism spectrum, and the onus of responsibility for transition falls on the family. All themes are multifaceted.

**Theme 1: Changes associated with puberty and associated disorders that manifest or worsen during puberty affect autism and challenge quality of life.** The way in which puberty has interacted with autism was a very pervasive theme discussed to some degree by everyone. Participants mentioned the typical developmental physical changes associated with puberty, and the influence of those on their son's, grandson's or daughter's autistic symptoms. They also talked about the development or worsening of co-existing conditions during this time period. In some cases, the families described interactions between the physical changes and the associated condition. The extent to which these factors influence quality of life varies depending on the family. However, many families expressed that changes associated with puberty and adolescence complicated their son's, grandson's, or daughter's autism, and pose challenges to quality of life.

The typical physical changes accompanying puberty, consisting of increased size and strength, have greatly affected those families with young adult children who demonstrate behavioral outbursts and aggression. This was vividly illustrated by Shelly as she described how she felt during her son's early teen years. "I told myself, I cannot handle him on my own. There is no way. Even now, when I take him out, if he has an episode, he is bigger than I am. Not huge, but he is definitely stronger."

Tina's story is another example. Although her daughter always had a tendency to "throw herself around and bang her head," even when she was a toddler, as she got older, these tendencies grew worse, as her daughter made large holes in the wall when she banged her head, and, as discussed previously, put her head through a window and a fish tank just a couple of years ago. As with other families of adolescents with behavior problems, Tina described living with these behaviors as difficult. In her words, "The behavior problems got so bad, and nothing was working for us. I mean we were ready to just pack it in, because our life was just hell." Fortunately, through hospitalization, medication, and behavior management, things are better, but Tina reported that Nan's behaviors continue to worsen at certain times of the month associated with the menstrual cycle. Consistent with this, the other parents of daughters also initiated conversations about behavioral changes associated with the menstrual cycle. For instance Stan said of his daughter, "it usually lasts for a week, she's um . . . I call it out of sorts, you know what I mean? There's, how should I say . . . she'll spring more, she'll get easily agitated more if she doesn't get her way, she'll make it known or she'll do . . . or she'll take her hand, slam it on the table . . ." One of the mothers of daughters discussed a decision she made to give her daughter hormones as a way to reduce these cyclical behavioral outbursts; others mentioned considering this in the future. While behavior changes associated with the menstrual cycle were salient in three of the four young women with ASD as described by their parents, in the fourth female, Dan C's daughter, whose autism symptoms are milder than the other young women, there is only an increase in repetitive behaviors.

All participants' young adult family members have been diagnosed with conditions associated with autism spectrum disorder, and/or have taken medications for such conditions. Many of these associated disorders manifested during or following puberty, or became more problematic during this developmental period. Young adult children in this sample have been diagnosed with mental health co-morbidities such as anxiety disorder(3), obsessive compulsive disorder(5), bipolar disorder(2), attention deficit hyperactivity disorder (1) oppositional defiant disorder(1) , and emotional disability (1). Additionally, one adult has gastro-intestinal and urinary tract problems which he had to some degree prior to adolescence, but which worsened during this time. He also has migraines. Many of the young adult children in this sample are taking, in the words of one parent, "a pharmacopia of drugs." Only one young adult was not taking medication at the time of data collection.

In some cases, the associated disorder demonstrated by the child with ASD manifested during puberty, but improved in the intervening years. Of the five young adults who were diagnosed with obsessive compulsive disorder (OCD) or prescribed medications for OCD, three have shown improvements in symptomatology and/or reduced need for medication according to their families. This is illustrated by Jan's description of her grandson four to five years ago:

His obsessive/compulsive behavior was so difficult . . . and it would take five or six minutes to get him out of the house because he had to remove every leaf that was on the sidewalk, everything all the way down to the car. And in fact, we were seeing someone over at NIH to see about a trial medication that had worked for

OCD in typical children but they hadn't used it with autism. It turned out . . . we didn't, but anyway he is much better now.

She attributed his improvements to the structure of his residential living and school.

Similarly, Lois' grandson's anxiety was great at puberty, but has lessened considerably, which she believed is the result of him no longer having the demands of school and work. However as a result of not having work or school, his productivity is limited. Even his diagnosis of oppositional defiant disorder has not worsened with age. Although according to his grandmother he threatens to do harm, he has not followed through on any threats to do damage to property or person.

According to other participants, the associated disorder began or worsened during adolescence in their children, and is a source of continuing difficulty, affecting daily life. For instance, Shelly described her son Chase as beginning a "downward spiral" five years earlier. She added, "He has an anxiety disorder. I saw the fear in his face before I saw the aggression." He needed hospitalization to address the anxiety and aggression. Similarly, Ann and Brian's son Ray's anxiety began in adolescence. In his case, the degree of limitation due to this associated disorder is viewed as being far more disruptive to family life and potential productivity than the symptomatology that is typically thought of as part of the diagnosis of ASD. The anxiety coincided with the physical changes accompanying puberty. In Brian's words, during adolescence:

[Ray] was so stressed about what was happening to him . . . um, he didn't like the hair growing on his legs, so he hit his legs over and over again. He'd have like massive bruises. . . His voice changed and he didn't like that. It was a couple of

years to the point where we had to actually get an assistive device [since he stopped talking].

Roseann's son's physical symptomatology of gastric and urinary pain and dysfunction existed to a mild degree prior to puberty, although worsened significantly following his physical growth spurt during puberty.

It is very much like colic. He will scream and I tell you, he wants doctors to find the problem and he cooperates with absolutely every test and doctor and hospital visit and procedure and so we've taken him to the ER when he's in these hour and two hour [periods] screaming like a horror movie at the top of his lungs.

Roseann emphasized that Peter's negative behaviors are related to his physical symptomatology. Her son also has migraines, and to her, the connection between the negative behaviors and the pain in this case, is particularly obvious:

Because he has migraines, he will grab me, you can see, look, see these? He was doing this to me last night. This is not pushing, this is communication. His hands are like this big, and I know how to get out of these things. I'm trained. I go for the weak spot, you know, but he grabs me and he makes me hit his head where it hurts.

She is extremely concerned that those who work with people on the autism spectrum are "quick to assume the behaviors are willful," which she adamantly pointed out is not the case with her son. She also emphasized that her son's sheer size (6'4") and strength make those who have worked with him less likely to try to try to address his behavioral issues constructively, suggesting a connection between all that is going on medically, the autism, and the bodily changes occurring during puberty.

Clearly, these associated disorders have complicated the management of the young adult with autism in many of the participant families. In the case of some of these families, the changes accompanying puberty and co-morbid diagnoses have been instrumental in limiting functional outcomes to date, and have affected family quality of life. Behavioral outbursts and anxiety have limited several participants' young adults being placed in the community for transition related job activities, and as noted previously, in Roseann's case, her son who appeared headed for meaningful employment prior to the time his physical disorders came to a head during adolescence, is not able to work presently.

Seizure disorders, frequently associated with autism, do not appear to be particularly problematic in this group of young adults. While some participants' young adults have a history of seizures, and have had isolated seizures since puberty, only in one family, did the seizures begin in adolescence. In the other families, the seizures did not worsen during adolescence or young adulthood, and most lessened considerably. In addition, the seizure disorders were not described as disruptive to family quality of life at the time of data collection in any family. In all cases, families stated that the seizures are infrequent. The young adult with the most frequent seizures gets one at most once every 6 weeks to 2 months, and they are small lapses in consciousness, not full blown tonic clonic seizures.

Also, in terms of co-occurring conditions, six of the adult children on the autism spectrum are, as observed in person or in pictures, obese. While families did not bring this up in conversation as problematic, some did mention that their children gained weight as they got older. They also discussed the need for their young people's existing

programs, and future programs for those not yet receiving adult services, to incorporate opportunities for their young adult to be active. This is exemplified by Stan who described what the people providing autism waiver services are doing with his daughter to try to keep her active and healthy:

The company that comes in, I give them a copy of her IEP and they try to match up the goals and to make sure they're still working with it. Part of that is you know they wanted her ... to walk around more or hourly, she does a treadmill one place, she walks around the mall at some other place you know and I know she's going to walk around the neighborhood.

The obesity could pose health risks for these young adults as they get older, but given the range of other issues facing these young adults, the obesity was discussed matter of factly and did not appear to be particularly troublesome or emotion laden to family members.

Sensory processing difficulty is frequently associated with autism, and one of the purposes of the current study was to begin to explore sensory processing in young adults on the autism spectrum. While this does not have the same link to puberty as the other conditions, it is discussed here due to its association with ASD. In the current sample, all ten participants reported some difficulties in responding appropriately to sensory information in their young adults. Although both Dan and Lois reported that sensory issues in their adult children are mild, some of these families have incorporated adaptations and modifications into their daily lives and routines to address their young adult's sensory needs. Seven of these families brought up the issue of sensory processing on their own, without being asked explicitly by the researcher. For example in describing her son, May R. volunteered, "high piercing babies' screaming will set him off, somebody's car

horn expectedly just going off, and fire alarm was a big deal at the school.” Lia S’s story of her daughter’s “prom” illustrates her difficulty with sensory modulation, as well as how these difficulties may be handled.

When she got to the prom she walked in the door you know um to where the dance was being held and turned around and walked out. You know because the lights and the music were just so over-stimulating she just could not stay in... but she enjoyed dinner and she enjoyed the limo ride. Um what they had done is they divided the kids in half. You know the kids they thought would last the whole time and the ones they thought would have to come home early and Abby was in the first group [to leave] and so about 9:30, after they had been there for about an hour-ish, she got in the bus and came home.

While most families have adapted to the sensory processing difficulties their young adult children face, there are instances where these difficulties impact what the adult child is willing to do, thereby affecting overall productivity. As May described one of the programs she considered for Greg:

but they didn’t initially take new people out into the community is my understanding unless they were janitorial services. Now my son doesn’t do janitorial services because he has a thing about cutouts on the toilet seats. Yeah, and two, he doesn’t like to get his hands dirty and three, he’s never cleaned the bathroom.

Similarly, Stan described efforts in school to take Kelly out in the community.

there’s like a little strip mall, and there’s like a pet store and there’s a grocery store and I know she won’t really go into a grocery store because apparently the

overhead speaker just, I don't know, must go right through her or something really goes off.

Shelly suggested that although her son's difficulties in sensory processing currently limit his productivity, she believes that professionals might be able to turn it into a job related task.

Well sensory-wise, he pulls at trees and leaves. Why? Because they give resistance . . . No, he may not do well at a job that has a lot of trees around it and stuff . . . or leaves flying around because he can't refocus on the task at hand.

Exactly, that's going to be a problem for him job-wise. But these are things he likes to do. But how can you take what he does sensory and incorporate it into vocational? Well, you give him a bale of hay, and he can spread it on a lawn.

Because he'll tear the . . . he's strong. He could take the bale of hay and do it. He may need some verbal guidance where to put it, but he could spread the hay. They haven't come up with a machine for that yet so . . . there's a job.

The Adolescent/ Adult Sensory Profile (Brown & Dunn, 2002) for the most part confirms interview findings. Scores fall into one of five categories in this assessment: much more than most people, more than most people, similar to most people, less than most people, or much less than most people, in each of the four areas tested by this measure (low registration, sensation seeking, sensory sensitivity, and sensation avoiding). As shown in table 3, nine of the ten young adults showed some differences in sensory processing, which is a score other than similar to most people, in at least one of the quadrant areas addressed by the measure. One family member, Dan, felt unable to answer enough questions about his daughter to get a score.

Table 3. Results of Sensory Profile

<b>Young Adult (Participant)</b>	<b>More low registration than most</b>	<b>Less sensation seeking Than most</b>	<b>More sensory sensitivity than most</b>	<b>More sensation avoiding than most</b>
<b>Ray (Ann)</b>	X	X	?	
<b>Chase (Shelly)</b>	XX	X		X
<b>Abby (Lia)</b>	X	X		X
<b>Nan (Tina)</b>	X		X	?
<b>Greg (May)</b>	X	XX	X	X
<b>Kelly (Stan)</b>	X	XX	X	XX
<b>Peter (Roseann)</b>		X		X
<b>Nathan (Jan)</b>		XX		
<b>Jason (Lois)</b>		X		
<b>Shira (Dan)</b>	Unable to assess	Unable to assess	Unable to assess	Unable to assess

Notes: X= more or less XX= much more or much less

Eight of the young adults showed less or much less sensory seeking when compared to most people on the Adolescent/ Adult Sensory Profile. That is, they do not seek out sensory experiences in the environment. Additionally, six of young adults demonstrated more or much more low registration of sensory information than most people. That is, they do not necessarily respond to sensory information that most people do. Five of the six with low registration, also demonstrated reduced sensory seeking. Five of the young adults tend to avoid sensory exploration, scoring more or much more than most people in sensory avoiding according to the Adolescent/ Adult Sensory Profile. There is possibly another adult who fits in this category, as unanswered questions by one

family in this one quadrant area of sensory processing, may have affected the scoring. The young adult was given the lowest possible score for the missed items in this section by the investigator, so the actual score could be higher. All three of these areas of sensory processing suggest adults who would be less likely to interact within their environments, which in general is consistent with parent reports.

There is one inconsistency in that Shelly's description of Chase's behavior with leaves and trees suggests sensory seeking behaviors, yet the result of the profile suggests decreased sensory seeking. However, since the measure examines a general tendency in all sensory modalities, rather than a specific modality or occurrence, it is possible that Chase can be sensory seeking in this one area and still overall show a different pattern of responsiveness.

Three of the young adults scored sensitive to sensory input according to the Adolescent/ Adult Sensory Profile. This would make them more likely to overreact to sensory information. It is possible that one other adult falls in this category as well, as due to unanswered questions in this area his score may appear lower than it is. The families of Nan, Greg, and Kelly, the three young adults with sensory sensitivity according to this measure, also reported sensory sensitivity in their interviews. Ray's family also reported this sensitivity in the interview, and his sensitivity to his dog's noises was observed in the interview although his is the score that is in question. It is noteworthy that whenever differences from most people were noted in the group on the Adolescent/ Adult Sensory Profile, the direction of the difference, either more than or less than most people, was consistent among the whole group.

As is apparent from family members' depictions of their young adults on the autism spectrum, this first theme found in the course of the current study points to a number of co-occurring conditions and symptoms, some of which developed or worsened during puberty that complicate everyday life for families of transition aged youth with ASD. It also appears that bodily changes accompanying the growth from childhood to adulthood add complexity to the management of young adults according to these families. Sensory processing differences likewise complicate ASD in young adulthood. All these influence quality of life of these families. Table 4 addresses the ways in which this theme impacts FQOL by relating it, using the participants' own words, to the current study's research questions. Having a transition aged young adult with the complex needs identified in this theme impacts what a parent or grandparent does on a regular basis which links to the following theme.

Table 4. Theme 1- Changes Associated with Puberty and Associated Disorders that Manifest or Worsen during Puberty affect Autism and Challenge Quality of Life

<b>Research Questions</b>	<b>Example Statements</b>
<b>How do families describe FQOL?</b>	<p>“The anxiety is worse than the autism.”</p> <p>“ Life is hard.”</p> <p>” It is better now.”</p> <p>[In the past] "We were just ready to pack it in. Our life was hell." (because of behavior meltdowns).</p>
<b>What factors contribute to FQOL?</b>	<p>“Risperidol sort of keeps the behaviors in check.”</p> <p>“She’s very sweet.”</p> <p>“He is much better now [talking about OCD]. He’s had a structured environment and very well trained staff.”</p>
<b>What factors inhibit FQOL?</b>	<p>“It’s the hardest thing to say that you can no longer handle [your child].” (describing aggression in a young adult post puberty)</p> <p>“ She’ll get easily agitated more if she doesn’t get her way, she’ll make it known or she’ll do....or she’ll take her hand, slam it on the table” (describing changes relative to menstrual cycle.)</p>
<b>How do families describe roles</b>	<p>“One of us has to sleep with him [young adult with autism] every night”</p> <p>“They’re (the young adults) telling you something. We just have to</p>

<b>and occupations?</b>	figure out what they're telling us." "I feed her breakfast in the morning . . . to start her day off calmly.
<b>How do families describe supports and services?</b>	"It's just that I don't know what I'm going to be able to get for him so he can have a meaningful day." "The places that are designed to manage his behaviors, won't deal with his narcotics and diet." "I had to stop this team (high school team meeting) and say, my son is not an animal. They were talking about him like he was an animal, like a wild tiger or something. So that was sad that I had to say that to people in that line of work." "He was in a good school program [before transitioning]."
<b>How does sensory processing impact family's occupations and activities ?</b>	"High piercing babies' screaming will set him off, somebody's car horn expectedly just going off." "She won't really go into a grocery store because apparently the overhead speaker just, I don't know, must go right through her or something."

**Theme 2: Occupations are influenced and restricted when there is a family member on the autism spectrum.** The word *occupation* in this theme has dual meanings. Having a son, grandson, or daughter on the autism spectrum has influenced and continues to influence family members in terms of job choices and job performance. In this sense, occupation is used in its colloquial meaning relative to employment. Additionally, family members' occupations are influenced in terms of the meaning occupation holds in the person-environment-occupation (PEO) theoretical framework, in that it pertains to activities in which people engage (Strong et al., 1999). This theme relates to both meanings of occupation, and both are presented here, beginning with the employment related meaning of occupation.

It is striking that all the women participants, both mothers and grandmothers, initiated conversation about job related issues and their connection to their child's or grandchild's autism. Six out of eight women participants returned to school while raising

a child with autism, which resulted in a career change for them. These include Ann, Lia, Shelly, May, Roseann, and Jan. Although Jan is a participant in the current study because she is Nathan's grandmother, she is included in this group, as she went to school and changed professions when her own children, including her son with autism, were growing up. A few of these women expressed that going to school offered them flexibility, which is a reason they chose to undertake these educational endeavors while handling the demands of raising a family that included a child on the autism spectrum. In the words of one of them, "I think school's easy for me. I could turn around the work pretty quickly." And in the voice of another, "I love going to school. If I didn't have to earn a living I would go back."

Several women chose professions that were related to the demands they were facing at home. Roseann and Lia are special educators; Shelly is a speech pathologist, and Ann went back to law school, ultimately choosing to work in disability law as part of her practice. As one of them said, "it's because the interventions and the supports are so weak and the only way to be a strong advocate is to learn it and then get in and do it," and another suggested, "I had learned so much already, I thought I might as well use it to help others." Jan chose to go to school for general education; she described herself as a retired first grade teacher. She emphasized that she "didn't want special education as I was living that at home." However, as already mentioned, despite deliberately choosing a career away from autism, which in and of itself suggests an influence of her child's autism on her career, she ultimately became involved with developing services that were not yet being provided within the community, so her son with ASD, and others, including ultimately her grandson, could benefit.

While May went to school for nursing, she never worked in the field. She had a difficult time reconciling the needs of her son on the autism spectrum with her profession. This continues to this day. In her own words:

And then I went back to school [for nursing] . . . that was 17 years ago and I have not practiced though, because it just didn't, never worked out with trying to get my son an education at school and watching what was happening with him impacted . . . so there is a social-economical impact I think, really a big one to autism. . . It is also the loss of an income because typically it is the mother who now is going to try to treat or try to jump in and help the child with autism. So I probably will never, you know, work in a real or um, I probably won't work again I don't think . . . I would never do nursing again it has gone too far, things have changed too much.

Although May is the only woman to have given up working professionally to meet the demands of her child in this sample, Roseann expressed concern over her ability to continue to work if she cannot find the right program for her son following his transition from school. Additionally, others have had to negotiate flexible schedules to balance the demands of their child with their professional lives, with varying degrees of success and career satisfaction, as well as economic impact. For instance, Ann has worked part time so as to try to address her son's "demanding" needs. She points out that while she has managed this, it hasn't worked out exactly as she might have wanted. In her own words:

I went to law school because I wanted to make a difference, that's even very difficult to do. It's just because the problem that I had was working for a non-

profit didn't pay me enough of a salary to pay for my daughter's college and my son's therapies and my law school loan. . .Being a lawyer, has not been great because for the most part to get ahead in the legal profession, you have to work incredible hours, and I worked at two large firms and in both of them, it was same old story, they talked a good game about flexible schedules, but in all honesty. . . yes, I'm a lawyer, but I don't have a career because the demands of the career in the law, are too great to juggle with having a disabled child. At least that's what I've found.

Other women view their flexibility in scheduling more positively. For instance, Lois reported that she would not have been able to continue working as a paralegal, had her schedule not allowed her to begin work after Jason was in school, and to be back before he returned. Additionally, her job allowed her to take off as needed for meetings or when called to school. The women who work or worked at schools talked about the flexibility of having summers and holidays off, allowing them to be home when their children were home, and Shelly added that she was in a contract position for several years rather than a school employee, because that work arrangement gave her even greater flexibility. Additionally, although Tina began her work as a day care provider before Nan was born, she continued this work because when she was little, Nan could receive infant and toddler services at home while Tina was working. Tina believed then and continues to believe that having the other children around Nan was "good for Nan, because it gave her a peer group."

Of the men, only Lia's husband Len made any job related changes that were influenced by having a child on the autism spectrum, as he took on a second job so his

wife could stay home with the children and attend school. Even now, however, he expressed that should his daughter get into an adult services program that doesn't offer transportation, he would likely be the one to change his schedule to transport her. In his words:

I don't know what's going to happen because some of these programs are ready to wrap up by 2:30 or 3:00 every day and if she doesn't have transportation that means somebody has to pick her up and you know as of right now, my current work hours are 6 to 2:30 so I mean I could, I guess I would be the one doing it, but that kind of limits the choices as to places that she can go to, because they can't be too far from where I work. So, and the other unknown thing is like you know I'm not guaranteed . . . because of changes in my work environment and all this other kind of stuff like that, I don't know if I'm going to be working 6 to 2:30 for ever. I mean, you know if that changes to 3:30 and then what do we do? You know so I mean you know, if you try to project what's going to happen too far in the future, you're like you know it's too overwhelming you know, it's just too much to handle and so much to deal with. Because then we don't know what's going to happen. You know the only good thing is I already have my thirty years in with the county so I could leave anytime and get a pension. So, you know I mean maybe I'll have to leave there and get just like a part-time job in the hours in between when Abby's wherever she is, you know what I mean. So, I mean we'll just have to see.

Dan commented that he was in a "very traditional marriage" when Shira was a young child, and it was his wife who revolved her schedule around their daughter's

needs. Currently, his sisters live close by and both have addressed issues that have come up with Shira and can pick her up from school, so that it is rare that he needs to take time off from work. He does have the flexibility to do so when necessary. He continues to have a housekeeper come in Monday through Friday to meet Shira after school, as his other daughter is involved in extra- curricular activities and does not get home before Shira. If the children were younger, these adaptations would sound much like the responsibilities of any single father however, the need to continue this with a twenty year old daughter is reflective of Shira's continued need for supervision. For Stan, having the support of his mother and in- laws has allowed him to work regular hours. He has occasionally needed to take off to address Kelly, but it is infrequent.

Not only does having a family member on the autism spectrum affect the work occupations of the caretaking parent, and impact women more than men in this sample of participants, but it also appears to have influenced and be influencing the generation of adults that grew up with a sibling on the autism spectrum. Interestingly, two sisters of these young adults are special educators, and two are or are training to be occupational therapy practitioners. Another sister of one of the young adults is a youth minister, who has instituted programming for those with disabilities in her parish. None of the male siblings have studied or are working in related fields at the present time.

In addition to affecting occupation defined as a job or profession, having a young adult on the autism spectrum has impacted other daily occupations, incorporating a more general meaning of occupation. In the words of one mother, having a son or daughter with autism "is such a tremendous strain, so it impacts all aspects of your life." For those who are married, occupations with one's spouse are impacted to a great degree. The most

poignant example of this comes from Ann and Brian, who, as already mentioned do not sleep together on a regular basis, as one parent always needs to sleep with their son. In their emotionally charged words, as they completed each other's sentences:

One of us of us has to sleep with him every night because he will not sleep alone.

Um, he was seeing a psychologist for a few years and, um, the psychologist kinda finally said "Well just, ya know, lock your door" ya know. And, well... he pounded on the door for hours. I mean he didn't sleep, we didn't sleep. I mean it just...didn't work.

While not as extreme, other married participants discussed the difficulty in going out with a spouse or doing something together as a couple. As exemplified by May:

I am thinking you know is it ever going to end? Am I ever going to stop teaching him [her son]? Am I ever going to be able to travel you know? Am I ever going with my husband? If he [her husband] goes somewhere, one of us has to stay here or we take our son with us you know. We do not have romantic anniversary dinners, we do not do that.

Similarly, Lia shared:

So my husband and I switch off. So one of these days we will spend some time together. We don't get to do it that often so when we do it together it's like a big huge deal. I'm like on Facebook like listen I am going out (laughing). Um so um the amount of time we spend together without Abby is very, very limited and sometimes it's just a pain. Would I love to have more time with my husband? Yeah. I would love to go away for like an overnight now that she is older. We

used to a little more often when she was younger because it's easier and my parents were younger to so it was a little easier on them but now yeah.

While difficulty spending time with one's spouse was described by all married couples, there do appear to be factors that do help families engage in desired occupations with their spouses, at least occasionally. While May stated she has no family locally and thus has few resources to provide respite to her when needed, Lia has parents and neighbors who volunteer to take care of her daughter. That difference is reflected in the tone and affect of their statements, with May being tearful she spoke, and Lia being upbeat. It is also reflected in responses on the 2011 MASS survey, in which Lia reported that she was satisfied with her support from friends and others, whereas May was very dissatisfied. A mediating factor for Tina is the size of her family, as all of Nan's siblings take turns helping their parents. Ann and her husband have a support group, and their friends through this group help each other with caregiving. The couple also pay neighborhood high school and college students to spend time with their son, giving them some time together, and while this has helped the two of them spend time together, Ann expressed sadness that "everybody in his life, I have to pay." Lois is able to go out without her grandson for short periods, as his needs are not as intense as the other young adults; she also finds comfort in her church, as does Tina.

As all but one of the participants have young adults that require constant care or supervision, respite care, which gives temporary reprieve to the care taking family member, can also make daily life easier for the family. As already stated, Ann and Brian pay students to come in and work with Ray, which does make things better, although comes at an economic price. Despite this, they reported on their MASS survey that they

were satisfied with their ability to take care of expenses. Similarly, some of the families who have gotten or get autism waiver services commented that a good waiver provider gives them time to pursue other occupations, even if it's simply helping other children with homework.

However, for some families, the need for respite is balanced by a fear that the respite person will not provide their adult family member with what he or she needs. In Tina's words, "Well that's the thing, its finding someone qualified... That I felt could deal with her. That's, I wish we could have some of that on there." Similarly, Shelly tearfully described leaving her son with a respite provider she got through the autism waiver care to attend the high school graduation of her daughter before he entered residential care. This was the only time she got a respite provider for him during the period that his behavior was so difficult. Although everything went well, she called this "the scariest thing I ever did." She became emotional when she said, "It's only when I...think that someone might be doing him more harm than good" if unable to handle his behavior. Roseann recalled leaving her son with someone who couldn't control him and, as a result there was substantive damage to her home when Peter had a behavioral outburst, and the provider did not know how to address it. Therefore, caretakers' desires and needs for respite are balanced by concerns about this process.

Family members don't just want a break, but they want that break to be positive for their young adult. Jan, the grandmother who is involved in running an autism services organization confirmed this in a way when she spoke about the value of her excellent service providers, and discussed how essential it is to pay them and treat them well, so

they feel appreciated, and stay with the job. She reported that she is totally comfortable that her grandson's needs are being met.

Despite the child care challenges and limited time to go out together, the marriages of the D. family, the S. family, the A. family, the R. family (who is in a long standing second marriage), and the W. family appear to be working. But, having a child on the autism spectrum can indeed impact the health of a marriage. In the words of one mother, a child with autism presents "big hazards between the husband and wife". While some divorced participants have stated that the divorce was not caused by having a child on the autism spectrum, but they believed that having that child on the spectrum exacerbated existing difficulties, Roseann described a more direct relationship between the demise of her marriage and the demands of raising an autistic child, particularly during the teenage years.

About four years ago, my ex-husband now, he left. He left because he wanted a different kind of life. He wanted me to become a foster parent with him and bring kids in our home and I'm exhausted taking care of my son and I couldn't take on more. And I didn't think he should ask me to and he thought I should and so I said well, I can't. I can't. So he left.

Similarly, Dan remarried for a few years his wife died, but stated that the failure of that second marriage was related his having a daughter on the autism spectrum. In his words:

I have to sort of get full time coverage so you know a lot of it is just having somebody always having to make sure that there's somebody here with her and, most of the time that's me; otherwise it just gets very expensive. You know other than that um it was an issue during my second marriage because my wife I guess

thought she could deal with it and it turned out she couldn't deal with it. I had a full time nanny so she really didn't have any childcare responsibilities but she just sort of hated having Shira around and you know just sort of her actual presence would annoy her so that made things difficult.

For those participants who are not married, having a young adult of the autism spectrum limits the adult pursuits one can engage in as well. Dan pointed out that now, as a single man, it's difficult for him to date. In his words, "you know I always have to be around or arrange for childcare so that you know there's not much spontaneous kind of things. It just makes your life very restricted." Stan, the other unmarried male participant in this study commented that the fact that he does not have his children every weekend provides him with time to go out. So, despite the fact he stated that he misses his children, including Kelly, when they aren't with him, not having Kelly full time has allowed him to engage in some desired occupations with friends. Similarly, Roseann gets a little time weekly to do activities of choice, even if it's just to take care of herself, when her son is with her ex-husband. However, this does not occur for May, whose young adult's father is in another state and only sees him when May travels with her son to see him.

Shared family occupations also may be limited when there is a family member with autism. The most extreme example of this came from Shelly's story of moving to another state with better services for Chase when he was younger, leaving her other children at their existing schools and home with their father. However, each participant family provided every day examples of limitations of family occupations and interactions that persist even as their children are young adults. Families with transition age youth in

residential care, commented on this just as much as those whose children live at home.

For example, Jan described Nathan's interactions with his uncles, cousins, and sister:

Now they'll go out to dinner with him, but they don't come around and visit him and they don't really often come and visit my son, either because he's not a bit welcoming. I mean you just don't get the reward that you get from seeing typical people. . . I am the one who spends the most time with both of them.

Family interactions and family occupations are difficult, because in Ann's words, "it is difficult to meaningfully include him" [the young adult with autism], even with the best of intentions. She described a holiday event at her home, where the cousins were all outside talking, except for Ray. As her daughter typically makes an effort to interact with Ray, Ann later asked why she had been excluding her brother, and in Ann's words,

She's like "well it's hard to include him." They were talking about college. They were talking about relationships. They were talking about their careers. I said well gee it's hard, I wish I had that excuse. I'm not gonna do it because it's hard. So it was a mother- daughter moment that probably didn't show the best in me, but it's often the way we feel that, ya know, the other members of the family have not put a lot of effort into, um helping or even like trying to connect with Ray.

Having a young adult with ASD may require modifications to the activity to engage in family outings. For instance, as described by Stan:

We would have like a hotdog grill thing or whatever, you know fourth of July, stuff like that and you know I'll be there [with the other kids] and Kelly would be in the car. But you know because it takes time, like any new place, you know she takes about twenty minutes to forty . . . .twenty minutes to an hour and sometimes

she won't even get out of the car, but sometimes just being there and seeing what's going on, she will come out of the car. We've done that at times, so I'm waiting her out basically . . . Unfortunately, when you have five children, you know, I can't really wait that long. I won't leave her . . . you know I won't leave her down at the end of the parking lot, but in fact, I usually try to park my car where I can see it and I can see where she is.

Likewise, family vacations require some adjustments. As Lia shared:

And um so when we go um we stay in a condo so I can cook meals because going out to a restaurant is just not worth it. You know we have done it a couple of times and every time it has ended a disaster because the combination of being in a new place, um it's very crowded and very noisy and you know that sensory piece, so you know we just, I cook all our meals. I cook them here too so it's not a big deal. Um but my parents um sometimes stay in the same building where my husband and I stay . . . so we were staying in a real small building and so mom and dad were down there and we were up here and they got down there first because they can arrive very early, beat all the traffic and go spend an hour or two at the mall or whatever you know walk around or get something to eat . . . well we can't do this. Our timing has to be just perfect so we get there in time so we can get to the rental office and get our keys and get straight into the place and one of us will leave and go to the grocery store while the other stays with Abby and makes sure everything [is ok].

She added that she needs to bring a lot of things for Abby to enjoy her vacation such as her DVD player, certain DVDs to watch, two sets of sheets, since her daughter is not toilet trained at night, and “it’s planned every inch of her life.”

One solution that works for some is to not do everything together as a family. Jan reported that she and Nathan tend to go out together without other family members.

Similarly, as illustrated by Dan:

So and you know when I take Shira and her sister on a vacation together it’s not really fair to [her sister] because all of the activities are restricted by what Shira can or will do so I’ve sort of taken them in the last couple of years on separate vacations where I’ll go for a week with [my other daughter] and I’ll go for a week with Shira. Well last year when I took Shira’s sister, Shira was at the sleep away camp. So everything’s got to be very tightly scheduled.

It appears that certain typical occupations that families engage in are made difficult when there is a child on the autism spectrum, even at the age of transition.

On the other hand, there are occupations or activities in which families of young adults with ASD need to engage, even though their peers with typical young adults at the age of transition do not. The need for family members to parent their young adults is pronounced, and while parenting doesn’t necessary end at transition for parents of a typical young adult, the types of parenting activities families do with their sons, grandsons, and daughters with ASD are different than those they do with their typical children, and more time consuming. As already suggested, most families of young people with ASD engage in caretaking responsibilities long after caretaking responsibilities of typical children end. Many of the family members in this sample physically assist with

feeding, dressing, toileting, or showering to varying degrees or at least supervise these activities. As discussed by Tina:

I feed her breakfast in the morning. I know I shouldn't, but she can feed herself. She does when she's home. But in the mornings she's always tired, 'cause she has to get on the van, be ready at seven to get on the van when it comes . . . I've done it ever since she was little, because . . . it started her day off calmly. We have a routine. And now if we have a lot of time . . . I'll fix her breakfast and she eats it on her own. But I try to let her sleep as late as I can, 'cause she does like to sleep.

Others supervise their children as they go about their self-care tasks, but don't physically assist. Family members also supervise to make sure their young adults are safe. For instance, Dan mentioned that Shira needs supervision, so she doesn't decide to "cook something on her own," which would be unsafe. He also discussed that since she looks typical and is good natured, trusting, and naïve, he needs to keep a close eye to be sure she is not taken advantage of.

Parenting occupations go beyond care taking and supervision of self-help skills. For instance, family members manage undesirable behaviors in their young adults who have them. For examples, Roseann discussed a way in which she stands in front of her son when he gets upset or gives him paper to tear, which seems to prevent his behavior from escalating. Similarly Shelly was observed to count backwards from five, to give her son a chance to calm down and comply with directions. Parents and grandparents discipline their young adults so that they behave appropriately, and they help their loved ones to develop the skills they need to be socially accepted and to live as independently

as possible. For example, Roseann discussed how she talks to her son, so he knows when he wakes up during the night, he needs to go back to sleep.

if he gets up in the middle of the night, and I'll say, look I know you don't feel . . . you might not feel well, but it is the middle of the night, we are in bed. Unless you have to go pee, we go back to bed or if you wet your bed, we'll change it, we go back to bed. No bath, no TV, no food, no, we're not. . . .no, and I've been doing that since he was this big and I sat outside his door for hours, go back to bed, go back to bed, go back to bed. So he knows the expectation. I'm not going to drive you around town; I'm not going to, no. He sleeps all night if he does pop up; he knows I'm not going to let him in the bath. I'm not going to let him watch TV, and every once in a while, he'll ask and he might try to push it and I have to stand firm. And he's 6'4" and it's harder now, but yeah and the minute he's got it, it will never end. So and I felt bad, I feel bad because it might not be on purpose, but it's a behavioral piece of it. So I talked to him today and I said, if that happens again, we will wash off quick with a shower, I have like a shower wand, we'll wash off quick with a shower, and then we'll go back to bed. So I thought maybe it might be a nice compromise, he'll get a little water on him, but it's no bath.

Some of this teaching of appropriate skills was observed when May insisted her son Greg meet and greet the researcher and co-researcher. She helped him to use a script that they have practiced time and again. Similarly, Lois described how she plans on helping her grandson to learn some home management skills, once his brother graduates college and moves out of the basement.

I want to try it here first, but I hope for him to have a place of his own, where he can cook for himself, and buy his own groceries, and manage his own things, and go back and forth, and eventually maybe do a part time job. . . As far as uhm right now we have a basement which my one grandson going to college lives there. I hope to have the basement for teaching him how to get along on his own and if I live long enough then I can get him going on his own, put a refrigerator down there, and things like that. And he would have his own space and I'd teach him how to do things like that.

It is clear that these family members continue to engage in many parenting types of occupations to facilitate growth and development in their young adults, as well as to take care of them and to keep them safe. They also engage in a variety of advocacy activities so that their young adults' needs are met, and they help their loved ones to have opportunities to optimize successful developmental outcomes, as is discussed in the following section.

It is important to note that at times parents' participation in all these activities on behalf of their child on the autism spectrum affected their parenting of their other children as their children were growing up. While parents reported "juggling" to meet the needs of all their children, compromises needed to be made. The most noteworthy example, was Shelly's decision to be "the parent doing the parenting [of the other children] from a distance" during the week, while she decided to go to graduate school and to work in a location where her son would receive better services. However, two other mothers spoke of having to make compromises with the other children as well. To

this day, May reported that her daughter feels that she chose Greg over her, because Greg needed so much attention, and that she wasn't looked after the way she should have been.

It is obvious that parent and family occupations have been greatly influenced by having a child on the autism spectrum, and that these occupations continue to be influenced during the transition period. This affects the quality of life of the family.

Table 5 shows the relationship between the second theme and the research questions posed in the current study. Additionally, the transition process brings with it additional roles and responsibilities for family members. This is incorporated into the next theme.

Table 5. Theme 2- Occupations are Influenced and Restricted when there is an Adult on the Autism Spectrum

<b>Research Questions</b>	<b>Example Statements</b>
<b>How do families describe FQOL?</b>	<p>"I am doing what I want to be doing right now."</p> <p>"I have a productive life."</p> <p>[Having an adult with autism] " impacts every aspect of your life."</p>
<b>What factors contribute to FQOL?</b>	<p>" I have wonderful parents and neighbors who help out."</p> <p>"Before [ the autism waiver], we didn't have anybody; it was all the family."</p> <p>"She's just one of the cousins."</p>
<b>What factors inhibit FQOL?</b>	<p>"Everything is always very scheduled. There's no spontaneous kind of thing."</p> <p>"They [the extended family] don't come around and visit him."</p>
<b>How do families describe roles and occupations?</b>	<p>"I hired two teenagers and told them what to do and I used a systematic discrete trial approach and we um and he learned how to ride a bicycle."</p> <p>"The amount of time we [parents of young adult] spend together is very limited and sometimes it's just a pain."</p> <p>"All of the activities are restricted by what she can or will do."</p> <p>"I am a special education teacher."</p> <p>"I can't work because .my son's needs are so great"</p>
<b>How do families describe supports and services?</b>	<p>"My mother gets her on the bus so we can get to work."</p> <p>"I am his service provider."</p>
<b>How does sensory processing impact families' occupations and activities?</b>	<p>"Going to a restaurant ends in disaster because it's crowded and it's very noisy and you know it's the sensory piece."</p> <p>"She hates the ocean. It's so the sensory piece, the movement and the noise. So one of us goes with her to the pool [on vacation]."</p> <p>"He grinds his teeth a lot. So I introduced a...an adult oral chew. We take it with us in a baggie."</p>

**Theme 3: The onus of responsibility for transition falls on the family.**

Transition to adulthood can be a difficult process to navigate according to study participants, and the burden for planning for transition rests squarely on the shoulders of parents or parent surrogates. Even Jan, who works with an autism services agency, acknowledged the work she has done to assure that when her grandson completes school, he will have residential services and programming that includes a job. When discussing supports and services Nathan will need, she stated, “I already put them in place.” The rest of the families all commented on the transition process itself. They recognize the difficulties in securing services when their loved one with autism is no longer entitled to services under IDEA, whether or not they already are enmeshed in the transition process, and appreciate that although their young adults are eligible for services, services are by no means guaranteed. During the year before leaving school, families go through the process of visiting adult services sites, and they submit applications to the programs they think are best suited to their young adult children. However as there are limited placements available, every young adult who needs services will not get them. This can be a major source of stress to families, affecting overall emotional well-being. In Shelly’s words, describing the process of seeking a program for her son following completion of his final school year:

And we’ve already experienced adult services telling us, “No, we can’t take him. We can’t meet his needs.” So my fear now is that he will be turned away. And not residentially but for the day program because the skills are so low. He is definitely always going to need a job coach or somebody there to shadow him at

almost any job to help him follow his daily schedule. So I'm trying to make DDA and them realize that too.

Similarly, for May, the stress of having her son home without an adult program, and for her to be his service provider, has been extremely difficult, and has contributed to her being clinically depressed. Additionally, Roseann expressed that she is worried that she will not be able to find a program for her son after he finishes school that meets both his needs secondary to autism and his medical needs. And in Dan's words, "The future petrifies me". Some of this concern is expressed in the 2011 MASS surveys. For instance, for the item that examines whether the family member has enough support to take care of the special needs of each family member, four responded that they were satisfied or very satisfied, but three were dissatisfied, and three were neither satisfied or dissatisfied. Moreover, Greg was already out of school when May filled out the 2011 MASS survey, and the MASS reflects her decreased emotional well-being and quality of life in practically every one of her responses.

Many families expressed difficulty in getting help in navigating the adult services system. Individual programs and service providers are not always responsive to requests for information. This can also contribute to parental stress. The following comment by one of the mothers, not only reflected her views, but is typical of comments of other families.

All we do is call and leave messages to speak to the person who's the head of this particular service and keep leaving you know messages on the voice mail and you know never have gotten a return. And then after a while, I mean personally I go back and forth between being annoyed and like giving up or forgetting about it

and like I haven't done anything with it. I think it's been maybe three weeks since the last time I called and left a message; and you know, you get kind of fed up with it and I haven't. . . something you should follow up on, but I just haven't.

In the state of Maryland, all counties have transition fairs, with the expressed purpose of educating families about the process of transitioning to adult services. Parents are urged to begin attending these programs when their sons and daughters reach high school age. However, according to the three families who commented about them, they are of limited value. In the words of one:

Um you know it's out there but you have to figure it out for yourself because it's not, it hasn't been forthcoming from any place and I think that's probably one of my main frustrations is that the county, has a lot of workshops and stuff that they put on for transitioning, but it's the same thing over and over every year. . . so if you go once you're not learning anything new and it's not always stuff that is um necessarily applicable to where you are at that particular time. For instance if you go when she's in 9th grade and they talk to you about well when she transitions you're going to have to visit these places and you're going to have to do this this and this and that's really nice and all well and good, but down the road for me.

What do I need to do now? Yeah know people have not always been rather there really isn't this or you should go look at these places. Well we've gone but one of the places we looked at is out of business. Well what good is it really doing me now?

One mother mentioned that having one good person who knows the transition process to help them understand how to navigate, has helped make the transition process more manageable. In her words:

And our case manager for autism waiver was in the adult services. So she's been able to give us some heads up on some different things we can do. So we've gotten . . .but it's just luck that you know we've stumbled onto this.

However many families suggested that such information isn't clearly communicated to them. As discussed by one, "and then I come to find out, there's something called the Coordinating Center or Service Coordination. They're the ones that are, I guess, as I talked with people at school know, nothing was ever explained about that." Another participant elaborated:

I don't feel like he has been as helpful as he could be . . . because I will send him an email or whatever, what do we need to be doing now? . . . Oh you are fine. Like seriously . . . fine? Are you sure? He's like no you are okay until [the child] turns whatever age and then all the sudden it's like *wham* you need to get this done now, *wham* you need to get this done here. Here's a Xerox copy of an article you can read . . . talk to me you know. So that's, and it may just be more my dissatisfaction with him than with the process in general but it just feels like there is so much I don't know . . . and nobody's able to sit down and say here are the things, you know here is where you need to go, here's what you need to do, like here is a timeline.

While transition age youth are still in school, they are engaged in programs that have a vocational piece, and "try out" different jobs, however this does not necessarily

lead to continued participation in a job after transition. This adds to the burden on families, as they cannot expect their young adults to have an ongoing position that was begun in school. Jan's grandson is the only young adult who has been holding a one day per week position at a local hospital, which will likely continue and even expand post school. She actually found the job for him.

Of those four young adults who have already transitioned, two are in day habilitation programs. Neither has a vocational component, as of the time of the interviews. The other two young adults are not in a program at all, nor are they doing anything employment related. It appears that both young men spend the majority of their days in their own homes on the internet. Neither is receiving much in the way of supports and services which might enhance their overall productivity. All of these young adults (the two in day programs and the two at home) did at least some job related work while at school. One, Jason, actually held paying jobs. According to his grandmother, he didn't have the support that might have helped him develop the work related behaviors and skills to maintain a job. Additionally, there were no supports given to others in his workplace. The other young man, Greg, worked to restack library shelves with videotapes as part of the vocational program in his school. He was able to place them alphabetically without assistance, but there wasn't any continuation beyond the assigned period, no matter how positive his performance was.

This appears to be the case with the youth that are still in school. While they are trying out jobs, they are switched from one to the next on a schedule. There does not appear to be consideration of the youths' skills or interests, based on family reports. As Dan described his daughter's interest in photography:

She likes to take pictures. So I got her a digital camera, which is great because she can take a million pictures. She kept asking for the camera and she would do like . . . she'd do this and then she'd kind of do this and then she'd lean around corners and I was kind of like wow she's like really into this. [Her pictures] They're not bad. I mean once we were at the beach and we were on the boardwalk and there was some guy who was dressed up as a character or something and she goes over and she hugs him and she grabs the camera and took a picture of herself [with him] and I was like how did she know to do that? It was just really funny, it made me laugh. But so like she'll take pictures and stuff at family events. She'll sit and eat with everybody and take pictures.

When asked about the types of pre-vocational opportunities she has had in school, he replied that she is currently folding towels and putting them on a cart at a nursing home, and has previously cleaned tables, and hung up clothes at a clothing distribution center, but nothing related to her interest.

Because the responsibility for facilitating a smooth transition falls to families, parents and grandparents find themselves having to participate in activities of support that they hope will benefit their transitioning children. While, as one participant pointed out, many parents advocate for their typical sons and daughters during transition, the extent to which this occurs is far greater in families with transition aged youth on the autism spectrum. Advocacy activities during transition are continuations of advocacy activities performed throughout school, although are focused on the young adult's future.

Every family described advocacy activities during the transition period. Most evident is the search for a proper placement. Families visit prospective placements and

ask questions to try to determine whether the adult program will be a good fit for their child. Because Shelly worries about Chase's options, she has advocated for him by presenting him in the best possible light to potential adult placements and residential services providers. In her words:

I took a green, just a simple green folder like this, and then what I did was I took all of his information, his packet, which I happen to have because I was so involved naturally, but just like with all of his. . . so what I would do is you know write on the front, application for adult services and then if they had an application, and I listed everything that was included in the packet; if there was an application, I'd put it on the front and behind it would be the assessments, which for Chase, and a lot of our students to that degree of disability with autism, his formal assessments were from '95 and '98 when he was first diagnosed . . . and I put those behind and then I . . . one place asked me for an audiology, so I actually had one . . . Then in the center, I placed his current IEP along with monthly tallies on behavior [from his current residential placement], I included those along with his medication list and how they were kept up over . . . since he's been at [his placement], then in the back, is where I put a behavior plan, the autism waiver certification forms, because that's really an account of where he is as far as activities of daily living. Behind that is his residential individual plan and then behind that was the Chase 101 quick overview packet [that she made]. So it's very . . . obviously it's thick. But I found the places that I had sent them were very like oh, this is great, okay we have everything, and I included a picture of him and his siblings that you have seen. Because I think sometimes we need to see you

know somebody just opening the packet, they don't have a visual . . . We're in the midst of doing a video [of Chase] now.

She also described buying clothes for him to make him look typical, hoping that will make a program more likely to offer him a placement. As she says, "because that's important. Because he's not going to get a foot in the door based on him, how he is. So you want you want him to appear as typically developing."

Ann and her husband as well as Tina spoke about scheduling meetings with their adult child's program to try to incorporate desired changes. In Ann and Brian's case, they were seeking more vocational opportunities to be added into his program, and in Tina's, she was seeking a one to one aide for Nan, which Tina reported "she is supposed to have." Both families commented on the need to gently ask for things but "not demand," recognizing at this stage, that they don't want to appear as if they think they're entitled. Tina's advocacy on behalf of Nan was effective in securing her aide. Ann's was in progress at the time of the second interview. Similarly, Lois has been talking to a caseworker with DDA trying to arrange meetings with her and her grandson.

Even Jan described steps she personally has taken to assure a successful transition for Nathan. Not only has she worked to get him a one day per week position at a hospital, but is currently advocating to be sure this continues. In her words, "I spoke to the coordinator at [his school program] this morning and I said hasn't it been almost a year that Nathan has been there at his job? I said, well it's about time we make a visit and see if they can find something else for him to do." Additionally, she reported:

I have written a grant and gotten a house, the lower level rehabbed, so that my grandson, I know my grandson where he's going when he graduates in a year and

a half and that's been done for six months. And . . . we remodeled the house, and the basement had a half bath, now has a full bath with a bathtub because Nathan does not like showers, it's cool. So I think of things years ahead....

Similarly, whereas Shira still has over one year left of school, as mentioned previously, her father Dan is already meeting with people re: the possibility of purchasing a home with another parent that they ultimately could use for their daughters.

While these parents engage in advocacy on behalf of their transition age sons, grandsons, and daughters, their advocacy is not something they began doing at this point in their child's or grandchild's life. Every participant has a long history of advocacy, especially regarding schooling. In many cases, advocacy took the form of trying to secure a particular service that the parent believed their child was entitled to. The advocacy was specific in scope and limited in time. For examples, Dan went to school on behalf of Shira when she was in elementary school and her county school was planning on discontinuing her aide, and Stan and his family advocated to get Kelly into a different school program when he felt her public school was no longer meeting her needs. In both cases, the advocacy was successful, and the families remained satisfied with their children's education from there on. In other cases, parental advocacy, not only benefitted the child of the person doing the advocacy, but the advocacy enhanced programs that help other children as well. For instance, Roseann told of the time when her son, at 7 years old was "aging out" of a home program his county schools offered, and there did not appear to be an appropriate next step in existence. In her words:

so I met with the supervisor of special ed and I said you have that I know of, ten kids in the County public schools doing home programs at least forty grand a kid

aging out. That's four hundred thousand dollars in maintenance of effort money. Let's create something. So she met with me for a couple hours and then met with her team of teacher specialists and that's exactly what they did and they created the upper level programs and as those kids grew, they created them higher and higher and higher. Programs I, II, III, and IV, we have in the county and Peter was in [all of] the programs.

When discussing her advocacy, she added "Yeah, it's helped the county. It has helped the county." Her advocacy made things better for many children with autism being educated in her county, similar to the role Jane's advocacy had played in providing adult residential services for her own son and other young adults in another county many years earlier.

Not every participant's experiences with advocacy have been so positive, and in fact advocacy can be adversarial. Lois discussed learning about schools in her county and "fighting" to get her grandson into a special middle school with typical children and special education classes, when the school system was planning to send him to another middle school for troubled youth. In her words:

I know of two kids who went through that school . . . actually there are three.

They go there and end up in the court system. So that was upsetting. The mentally challenged kids who go there end up with the short end of the stick. So I fought them and got him into [the desired school].

May, who described ongoing fighting with her son's teachers, shared her thoughts about teacher resistance to her observing at school, so she could see whether Greg was getting the programming he was supposed to be getting at school:

I'm saying that teachers lie, and that makes their life easier if you don't come down because I've had them fight me on observations before and what I've had to do is say, IDEA says that I'm an integral part of this team and in order to do that, to function as that, I have to see what you're doing, and you know it makes sense, I have to reinforce what you're doing at school, which they really weren't doing anything but I used that. If I can't see what you're doing, how can I reinforce it at home? So you've got to let me in and they fought and fought and finally they relented. But it took a lot and most parents won't do that . . . I'm just saying they take the tact that teachers are the professionals, they're not and they just can't . . . they won't or they can't and I wouldn't have been. . . .and I'll tell you, I was not a loved person among teachers.

Similarly, Tina found herself constantly working with Nan's service providers as well as arguing and fighting to ensure that her daughter was getting the services she deserved.

She:

checked up on [the county] constantly. And I'd just show up. I had to . . . Um, I played their games. I learned to play 'em. And I had handouts at meetings. I called meetings. I was a royal pain and they didn't really like me. But I wanted what was best for my child, and I knew what she was entitled to and she wasn't getting it.

She ultimately sued her county, and secured a private placement, since Nan's needs weren't being met in her local public school. Although, as in Tina's case, advocacy produced a successful outcome, the process was a great source of stress to this family.

Positive parental relationships with teachers and other professionals as well as good educational experiences in general appear to decrease stressful advocacy experiences, according to these families. Even after Tina spent years battling for Nan, once her daughter was moved to her private school setting and Tina was satisfied with the services, she no longer needed to continue the battles. Even when Nan was in the public schools, one year she had a teacher whom Tina described as “wonderful” and found that her need to be at school that year declined. She felt that this teacher would push to get what Nan needed. Parents described similar experiences with doctors, particularly psychiatrists, who, in the words of one parent are “pretty dismissive of parents.” However four of the parents mentioned a special doctor, who made a difference for them and their child, mostly by listening to them. Most families expressed satisfaction with the caregiver who worked with their transition aged young adult on the 2011 MASS survey.

Overall, families assume much of the responsibility for transition of their young adults, and have a history of advocating on behalf of their son, grandson or daughter that continues into young adulthood. This influences quality of life of the family. Table 6 shows the relationship between the third theme, using the words of the participants, to the research questions.

Table 6. Theme 3- The Onus of Responsibility for Transition Falls on the Family

<b>Research Questions</b>	<b>Example statements</b>
<b>How do families describe FQOL?</b>	“These things are like kind of like unsettling or whatever. I mean, I don’t know what’s going to happen. “So my fear now is he will be turned away.”
<b>What factors contribute to FQOL?</b>	“Our case manager for the autism waiver used to be in adult services, so she advises us. It’s a happy accident.” “My grandson has well trained staff. I value them “

<b>What factors inhibit FQOL?</b>	<p>“I kept saying are you sure we shouldn’t be doing more?”</p> <p>“She[my daughter] liked being a greeter, but they wanted her to clean and she didn’t like that”</p> <p>“He [my son] is not going into the community right now”</p>
<b>How do families describe roles and occupations?</b>	<p>“I have written a grant and gotten the lower level [of a house] rehabbed so I know where he’s going when he graduates in a year and a half .”</p> <p>“I got him clothes. That’s important. Because he’s not going to get a foot in the door based on him .You want him to appear as typically developing.”</p> <p>“ I am making a video now... so that they[adult service agencies] could see what he is doing and, hopefully, that will give them a better idea [whether they can meet his needs].</p>
<b>How do families describe supports and services?</b>	<p>“We call and leave messages.”</p> <p>“At least with IDEA you could make some headway.”</p> <p>” I’d like him to get out in the community.”</p> <p>“He will need a job coach.”</p>
<b>How does sensory processing impact families’ occupations and activities?</b>	<p>“ A janitorial job won’t work for him. He hates getting his hands dirty and has a fear of cut out toilet seats.”</p> <p>“[The house] now has a full bath with a bathtub. [The young adult] doesn’t like showers.”</p>

## Conclusion

This chapter identified the participants, and presented the themes extracted from the data collected primarily from interviews, but also from observations and survey data. The purpose was to present a description of family quality of life from the perspective of ten participating families with a transition aged young adult on the autism spectrum. Three themes were discussed, which are: the changes associated with puberty and associated disorders affect autism and challenge quality of life, occupations are influenced and restricted when there is a family member on the autism spectrum, and the onus of responsibility for transition falls on the family. Collectively, these themes, including the rich depictions in the words of the families, capture the pervasiveness of autism and the stressors associated with having a transition aged young adult on the autism spectrum, and relate to the research questions initially put forward.

Another purpose of this study was to begin to explore sensory processing in this group of young adults and the influence of sensory processing difficulties in everyday life. Similar patterns of sensory processing were observed in a majority of the young adults, according to the Adolescent/Adult Sensory Profile, and comments by families suggest sensory issues do affect daily living, and require adjustments. .

The subsequent chapter answers the research questions in detail and explores these findings within the context of the existing literature. Before moving to the next chapter, however, some impressions of the researcher should be noted. As is discussed individually in the presentation of each family, it is important to recognize that this is a group of participants, who, as a whole, have resources. As a group, they are articulate, educated professionals. Six out of ten have graduate degrees, some in fields related to autism, and three of the remaining four are college graduates. Additionally, all of these families are at the very least financially secure. In spite of commenting on the costs of raising a transition aged young adult on the autism spectrum at times, most families reported on the 2011 MASS survey that they were satisfied with their ability to meet expenses. These points may actually contribute to the importance of the results of this study, as it is suspected that the issues affecting quality of life in this group may be less pervasive than in those with fewer personal advantages.

## **Chapter 5:**

### **Discussion**

#### **Introduction**

The purpose of this study was to describe the phenomenon of having a transition aged young adult with autism on quality of life of the family. This study also set out to explore sensory processing so as to investigate whether atypical sensory processing is present in these young adults and if it influences family quality of life (FQOL).

Participants were ten mothers, grandmothers, and fathers of a young adult at or nearing the age of transition from school based services to adulthood, who were experiencing the phenomenon under study. Participants described their experiences of having a young adult child or grandchild on the autism spectrum, and discussed situations and conditions that influenced their experiences of quality of life.

As explained in chapter four, three themes were revealed that describe this phenomenon from the participants' perspectives: a) changes associated with puberty and associated disorders that manifest or worsen during puberty affect autism and challenge quality of life, b) occupations are influenced and restricted when there is a family member on the autism spectrum and c) the onus of responsibility for transition falls on the family. Each of these themes is multifaceted. Additionally, the investigation into sensory processing in young adults revealed the existence of difficulties in sensory processing that influence quality of life of their families. These findings are discussed in relation to the research questions asked, as well as in the context of the relevant literature.

## **Quality of Life of the Family**

Families in the present study described in vivid detail many difficult and challenging life experiences concerning their son, grandson, or daughter, and the quality of life of their families, often with a great deal of emotion. Families also discussed many stressors that impacted quality of life, such as difficult behaviors in the young adult or worry concerning securing an appropriate adult services placement. Many recalled experiences that were so difficult it brought them to tears, even if describing an event that occurred several years earlier, such as when a mother reported a behavioral meltdown in her daughter in which she put her head through a window or a mother who described an outburst in her son in which he injured her. Some spoke of periods during their lives when quality of life was poor, and when they felt that they were struggling to manage their day to day responsibilities. All this is consistent with the literature, which points out that families and especially mothers of adults on the autism spectrum are more likely to experience stress and depression than parents of same aged youth with other disabilities, due to the demands of parenting their adult children (Abbeduto et al., 2004, Barker et al., 2010, Lounds et al., 2007). Similarly, the literature suggests that the unique impairments and behavioral challenges associated with autism may constitute conditions which make family members more susceptible to developing psychological and emotional distress (Lee et al., 2009, Tehee, Honan, & Hevey, 2009).

Despite this stress, at the time of data collection, most families reported a relatively positive quality of life. When families were asked to describe their quality of life, the language used included, “it is a 7 on a scale of 10,” “it is good,” “it is OK,” “I

am doing what I want to be doing right now,” “I am happy and content,” “it’s actually gotten better,” “overall things are better now than they were a few years ago,” and “quality of life has gotten better.” One family member described an even more positive quality to her life, saying, “I have a wonderful quality of life,” however this was the grandmother of the young man who was in residential care and was in a strong school program. These descriptions by family members suggest that when raising a son, daughter or grandson on the autism spectrum, positive coping and adaptation can occur as the child with ASD grows into adulthood and the family adapts (Lounds et al., 2007). Only one mother described her family quality of life negatively at the time of the interviews, and she expressed that it was related to the fact that her son had been out of school over a year, and was not in any type of program.

While still describing a satisfactory quality of life, families facing transition imminently expressed concern about the ability to maintain their quality of life. Families were aware of the limitations in adult service provision (OAR, 2009, Shattuck et al., 2009, Graetz, 2011), and were concerned for their young adults’ continued growth and development and for their ability to be, in the words of one mother, “safe and productive.” Blacher et al. (2010) found in their survey study that parents of young adults with autism reported that they worry more about transition than parents of sons and daughters with other disabilities, especially in the areas of general transition planning, future living, and employment. They also reported a significantly greater impact of worrying about their son/daughter’s transition on their own personal daily life and well-being and the daily life and well-being of the whole family. Thus, transition planning contributes to stress in families with a son or daughter with autism, as was noted by

participants in the current study. That the families experienced stress regarding transition makes sense when one considers that improvements noted through the secondary school years have been shown to decline in young adults following school, especially when there are unmet service needs (Taylor & Seltzer, 2011). Families with problematic associated disorders such as anxiety or somatic ailments, as well as difficult behaviors, seemed more fearful as they looked toward the future than other families, consistent with existing literature (Graetz, 2010; White, McMorris Weiss & Lunsky 2012).

**Contributors to FQOL.** First and foremost, according to participant families, adequate supports and services for the young adult with ASD contribute to quality of life of the family (Graetz, 2010; Hare et al., 2004). At the time of the interviews, all of the families with sons, grandsons, and daughters still in school were satisfied with the support their young adults were getting. Therefore, a positive educational program enhanced quality of life for those with youth still in school getting a variety of services. Those families with young adults in adult programs did not report being unhappy at the time of data collection, although they were interested in “tweaking” programs to get their loved ones out more into the community. Of the families out of school, all expressed that they missed having their adult child in school due to the supports and services received there. As already mentioned, one of the two families whose young adult was not in a program described a decreased quality of life.

Positive family professional relationships, when present, enhanced FQOL, as reported by several of the participants. In the current study, some families reported finding a special professional who made a positive difference by offering information and

providing honest communication. The literature suggests that the transition process is better and less stressful to families when there are more open relationships with school and related service professionals (Defur, Todd- Allen & Getzel, 2001; Hetherington et al., 2006; Neece et al., 2009), however, as illustrated by the families in the current study, this was not always the case.

**Work.** Positive work experiences also appeared to enhance FQOL in these families. Only one mother stayed at home as a result of her son's needs while he was growing up and at the time of the interviews. All other participants worked outside the home in their desired fields, or were retired, and reported past positive work experiences. Although one of the working mothers reported that her need to work part time limited her professional options, families in general described satisfaction with work. Even the mother who was feeling desperate about her son's transition options secondary to his medical and behavioral needs, pointed out that she needed to work, not only for the financial security it provided but also for its contribution to her quality of life. Consistent with the findings of the current study, Shattuck et al. (2011) maintains that employment is a quality of life indicator. Hence, the positive work experiences of these participants may have contributed to a relatively positive quality of life that most described.

These families depicted more positive work experiences than conveyed in the literature, which reports that the family challenges associated with having a child of any age on the autism spectrum impact parental employment (Baker, & Drupela, 2010; Eskow, Pineles & Summers, 2011; Graetz, 2011), and is more likely to differentially affect women's employment in a negative way rather than men's. Men in the current

study made adjustments to work to accommodate their family situation, but having a child on the spectrum did not impede their ability to do the work they wanted to do. Having a child on the spectrum prevented one mother from working in her profession, and affected the exact types of positions a second mother could get in her field, because of her need for part time work. However, these negative work experiences affected only a small number of participants. The other women in the present study chose flexible schedules, including school schedules, and reported their current work to be positive. Baker & Drupela (2011) found that when mothers are able to schedule work hours to better accommodate their child's needs, employment is less likely to be adversely affected by the demands of the child, which may account for the generally positive work experiences for this group, and the limited number of women who were, at any time, forced to stay at home with their child with autism

*Informal support.* Families who perceived that they had support from friends and family reported a more positive quality of life, especially if it enabled them respite from caretaking or the ability to engage in a preferred occupation or activity. This was especially clear in the participant whose mother, the young adult's grandmother, took care of getting the young adult with autism on and off the school bus, so the parents could get to work. This finding is consistent with literature that suggests that informal support from friends and extended family reduces stress associated with raising a son, grandson, or daughter with ASD, decreases caregiver burden, and is important to a family's well-being (Barker et al., 2011; Ekas, Lickenbrock, & Whitman, 2010; Graetz et al., 2010). A related factor for one mother concerned the support of her large family as a contributor to FQOL, also consistent with existing literature (Orsmond et al., 2009). Also, a positive

marital relationship may have contributed to overall well-being in several of these families, a finding also seen in the literature (Hartley et al., 2011). For two families, their religious beliefs and commitment to their church appeared to contribute to their overall ability to cope with difficulty, thereby enhancing quality of life. Gray (2006) suggests that religious faith may enhance parental coping as their children get older.

**Financial support.** These families reported that having the financial resources to be able to afford things like a tutor for a young adult, or a baby sitter, or housekeeper, enhanced their FQOL, which is seen in the literature (Dillenburger & McKerr, 2009). While several families lamented the costs of paying for needed services out of pocket, 7 out of 10 reported satisfaction with their ability to take care of expenses on their 2011 MASS surveys. As suggested previously, this group of participants had better financial resources than most.

**Autism waiver.** For those whose young adults were still in school at the time of the interviews and on the autism waiver, the waiver contributed positively to the families' quality of life, consistent with the findings of Eskow et al. (2011). Half of the participating families were still in school at the time of the data collection and receiving waiver services. Two of these families began actually getting those services after they filled out the MASS in 2011, and attributed an increase in their quality of life since filling out the MASS, to securing the waiver services. They reported improved FQOL in terms of having time to pursue other endeavors when the adult child was with a waiver provider, and also in terms of feeling that the waiver provider was meeting their son's, grandson's, or daughter's needs. Two participants described the waiver in terms of what

it contributed financially, especially for its paying for residential services for their loved ones. Moreover these two participants believed that having their young adult in residential care contributed to FQOL.

***Additional factors.*** A few other factors warrant brief mention. The first concerns dispositional optimism as a contributor to family quality of life, particularly in mothers. Both Greenberg et al. (2004) and Orsmond et al. (2006) emphasize that a mother who is inherently optimistic is likely to demonstrate enhanced emotional well-being in the face of demands of taking care of a young adult with autism. This was seen in one mother in the current study. The nature of a child can likewise enhance quality of life (Orsmond et al., 2006). The father who described his daughter as sweet enjoyed spending time with her, which had a positive influence on his FQOL. Another family similarly noted the good nature of the child as a positive contributor to FQOL. Additionally, two parents indicated that medical care that effectively managed their children were positive contributors to FQOL, consistent with the work of Graetz (2010).

**Factors hindering FQOL.** A salient finding in this study concerned disorders associated with autism and changes associated with puberty. Many of the young adult sons, grandsons, and daughters of the participants had co-morbid mental health diagnoses that developed or worsened following puberty. These contributed to challenges in attaining a positive quality of life in some of participating families. Due to the pervasiveness of this finding and the impact on FQOL, a further review of the literature was warranted, and it was found that several studies address mental health comorbidities. In one, a full 72% of those with ASD met the criteria for a mental health comorbidity

such as ADHD, OCD, ODD, and anxiety (Gjevik, Eldevik, Fjaeren-Granem, & Sponheim, 2010), consistent with the young adults in the present study. Likewise, in a large scale study of adults with ASD, there was an increased risk for meeting the diagnostic criteria for mental health problems. Moreover, risk estimates increased with the number of autistic traits that the individuals had (Lundstrom et al., 2011). In the current study, most of the young adults demonstrated several autistic traits, thus based on the literature, the number of psychiatric co-morbidities are not surprising.

As discussed in the previous chapter, the degree to which anxiety challenged the FQOL in one family in the present study was greater than the degree to which the symptoms typically thought of as part of autism affected the family. This was also reported by Farrugia & Hudson (2006), who found that in those adolescents with ASD and anxiety, the degree to which the anxiety interfered with the adolescents' lives was greater than in those adolescents with a primary diagnosis of anxiety disorder. Gillot and Standen (2007) suggest that the anxiety in young adults on the spectrum makes it less likely for them to cope with change, anticipation, and unpleasant events, which also was reported by families of young adults in the present study. Despite the many existing studies addressing the presence of mental health disabilities in adolescents and young adults with autism, few relate them to daily living (Farruga & Hudson, 2006; Gillot & Standen, 2007). In only one study was the effect of the mental health co-morbidity on the family even mentioned (White, McMorris Weiss & Lunskey 2012). The current research therefore contributes to this body of knowledge and suggests a need for further examination of the relationship between mental health disabilities in youth and young

adults with autism and family quality of life. This is important given the degree to which these associated disorders challenged FQOL for participants in this study.

As seen in young adults in the present study, comorbid somatic disorders such as G-I disturbances, seizure disorders, and obesity frequently co-occur in autism, and often begin or worsen during puberty (Erickson, Stigler, Corkins, Posey, Fitzgerald, & McDougale, 2005; Mourisdon, 2011; Rimmer, Yamaki, DavisLowry, Wang, & Vogel, 2010; Steyart & De La Marche, 2008). Seizure disorders and obesity, while present, did not hinder family quality of life for participants in the present study, however G-I problems and pain limited quality of life for one young man and his family. Kring et al. (2010) suggest that the presence of a somatic problem like a G-I disturbance is likely to increase the behavioral aberrations in a young adult with ASD, and can increase the caregiving burden parent of such an adult, which indeed was the case in this family. Carr and Owen-DeSchryver (2007) also emphasize this link between pain and behavior and point to the need to recognize pain as a cause of negative behavior, as the mother of this young man emphasized.

**Behavior.** According to participant families, negative behavior hindered family quality of life especially as the child grew bigger and stronger following puberty. This is consistent with existing literature (Graetz, 2010; Hastings, 2002). Families described feeling desperate when their sons, grandsons, and daughters had regular behavioral meltdowns. They discussed these behavioral episodes with emotion, illustrating how disruptive and difficult they were to family in the years prior to data collection. Fortunately at the time of the interviews, families whose members had experienced regular negative behaviors earlier in adolescence described that episodes were less

frequent. They attributed these improvements in their young adults' behaviors to behavior management techniques, medication, and maturation.

In the present study, families reported an increase in negative behaviors in three out of four of the young women with ASD coinciding with the menstrual cycle. Two of these young women demonstrated severe self-aggressive behaviors, which challenged their families' quality of life. While self-aggressive behaviors in females with autism has been reported in the literature (Cohen et al., 2010), a link to the menstrual cycle has not been firmly established. Hare et al. (2004), however, reported that parents suggested a possible link between "premenstrual tension" (p.429) and self-aggression in their daughters. This is an area that requires further investigation by the medical community, as there are potential implications for management of young women with autism should this finding be confirmed.

**Lack of support and services.** Although appropriate supports and services are included as enhancing FQOL, the lack of such services was discussed prominently, and therefore must be considered separately as a hindrance to family quality of life. When the young adult's needs are perceived as not being met, family quality of life is affected (Graetz, 2010, White et al., 2012). This was most apparent in the mother whose adult son was not in a program. The full time supervision he required precluded this mother's ability to address anything other than her son's needs, which she believed were impossible to meet in his present circumstances. Other family members were not experiencing this at the time of the interviews, although some were fearful that their children wouldn't be accepted to a program that addressed their multiple needs, and were concerned about the potential effect this might have on their lives. Others described

periods in the past in which they felt that their young adult wasn't receiving something he or she needed, sometimes while still attending school, which influenced FQOL. Related to transition, difficulty navigating the adult services system, and not having a specific person to go to get needed answers was also somewhat disruptive to families in this study (Foden & Anderson, 2011).

Not having sufficient informal support was reported to be a detriment to FQOL. In the present study, one mother expressed angst over the fact that her extended family didn't make an effort to see her son, or to plan family events where he could actively participate with the others. She reported that the absence of this informal support impeded her overall life satisfaction. Having to pay for certain services, including babysitters, detracted slightly from FQOL for some, only because parents didn't avail themselves of the services as frequently as they might have had they not been costly.

**The need for planning.** Another hindrance to FQOL in the present study concerned the need to plan and orchestrate activities and occupations that the family needed and wanted to do. The need for alteration and modification in family activities as well as the inability to be spontaneous were reported by participants in the current project and are noted in prior studies with families of children and adolescents with autism (Dillenberger et al., 2010 Gray, 2002; Larson, 2006). As the need for planning and modification of activities was often related to sensory processing difficulties in the young adult with ASD, this is discussed further in the section on sensory processing. Similarly, some of this relates to the caretaking occupations of the family member and is discussed in the section on roles and occupations.

## **Roles and occupations**

Most participant families engaged in roles and occupations similar to other families. Many parents and grandparents were workers, and engaged daily in their work occupations. An interesting finding in the current study that is not documented in existing literature was that several women participants went back to school while raising a child with ASD, and entered fields related to disability and autism. There is also limited information in the literature concerning the emerging finding in this study that female siblings of individuals with ASD chose occupations in related fields, although one dissertation study (Allgood, 2010) suggests that having a sibling with ASD may influence one's choice of jobs.

Many of the participants were spouses, friends, and sons and daughters themselves, and accordingly engaged in family occupations, as well as adult leisure occupations. However, as already suggested, engagement in these occupations required extensive planning, and opportunities to engage in them were more limited than in other families, a finding that is consistent with existing literature (Larson, 2002; Larson, 2006, Larson, 2010, Smith et al., 2010). Participants pointed to the restrictive impact of having a son, grandson, or daughter with ASD on the adult activities in which they engaged as well as on family activities, due to the adult's need for supervision and inability to participate in activities that other family members enjoyed. However, it is noteworthy that most families reported positive adjustment in siblings to challenges in engaging in family occupations (Orsmond et al., 2009; Pilowsky et al., 2004). Although time spent with a partner or spouse was limited by their son, grandson, or daughter with ASD, not

all families considered this a major detriment to their quality of life, a finding also reported in existing literature (Dillenburger, 2010).

**Caretaking.** Family members in the present study continued to engage in caretaking occupations with their young adults on the autism spectrum, as is seen in existing literature (Lee et al., 2008, Smith et al., 2010.) Smith et al. found that in comparison to those without disabilities, mothers of adolescent and adult children with ASD spend significantly more time providing childcare and doing chores, which limits participation in occupations of choice. Blacher et al.'s (2010) study found that 74% of adults with autism reside in the family home, with the family continuing to provide care to the individual, similar to eight of the ten families in the current study. An improved parent child relationship was noted by one mother following her son's placement in residential care in the current study, which has been indicated in the literature as well (Krauss et al., 2005).

In addition to caretaking, some family members assured their young adults' participation in leisure activities, and all encouraged participation in self-care and positive behaviors in their young adults. They also engaged in teaching opportunities to help their young adult develop needed skills. These findings are congruent with a study of parents of adolescent boys on the spectrum that showed that families promoted participation in self-care, leisure, and social activities, and prevented frustration and behavioral meltdowns (Larson, 2010).

**Advocacy and case coordination.** As already noted, many families were involved in parenting of their young adult with ASD, often while maintaining

employment outside the home. Some of the parents and grandparents in the current study were in professional positions related to the educational system or the legal system, and thus were likely more knowledgeable about transition than the average consumer. Yet, even many of them were finding that entrance into the world of adult services for their young adult was complex and difficult to navigate. Hence, families bore the responsibility for assuring that their young adult's needs were met, and they needed to actively advocate on behalf of their young adult.

The role of advocate for the young adult child was a prominent one for all of the participating families. Even though families typically assist and advocate for their children as they grow older, advocacy continues to a far greater degree and with a different focus in families with a youth with ASD (van Ingen & Moore, 2010), as was seen here. Families in the current study advocated to assure that their young adults' needs were being met and to foster community participation. Consistent with Roush et al. (2007), these family members often found themselves as the sole advocate on behalf of their son, grandson, or daughter. In some participating families this advocacy was even more salient as they took on a case coordinating role in preparation for transition (Taylor & Seltzer, 2011).

The literature emphasizes that advocacy is essential during the transition years, especially because supports and services are insufficient for this population and adult outcomes such as employment and community participation are often limited (Brown et al., 2003; Eaves & Ho, 2008, Graetz, 2010; Howlin et al., 2004, OAR, 2009). In the current study, even with parent and grandparent advocacy during the transition process,

the situations for the adult children who had already transitioned were less than optimal. One issue that complicates advocacy efforts is that most of the agencies set up to oversee services for individuals with disabilities do not actually provide these services or employ the service providers. Rather, services may be delivered by outside providers who are certified by the responsible agency (Foden & Anderson, 2011). This makes it hard to figure out just where to go to get services or answers to questions. This was experienced by two parents in the present study trying to get waiver services that they were approved for and also was experienced by families researching adult services programs. Parents had difficulty finding the right person to talk to, which is telling considering the level of sophistication of these participants.

Issues related to the school's role in transition planning contributed to the need for parental advocacy and case coordination for families in the present study. None of the young adults with autism were actively involved in transition related activities, even though according to IDEA (2004), they should have been at the center of transition. This not only has implications for transition, but also for the development, or lack thereof, of self-determination, which has been linked to positive outcomes for transition aged young adults (Held et al., 2004).

In Hetherington et al.'s (2011) study, parents felt communication with the school was inadequate, that the school made faulty assumptions about their children, and that there was a tendency to push the youth into traditional adult service programs whether or not these would meet their needs. Also, parents in Hetherington et al.'s study expressed concern that the schools were starting transition planning too late. As a result, parents perceived that they needed to "nag" (p.168) the school to begin transition. Families in the

current study reported the same issues as documented in the Hetherington et al. study, and therefore indicated that they as family members needed to take greater charge.

Hendricks and Wehman (2009) emphasize that, in order to achieve the best outcomes during transition, community participation must be part of the transition planning process. They maintain that planning needs to involve the community in which the person will take part after high school. While community participation includes productive engagement in activities, those authors emphasize that transition must also encompass the desired goal of integrating the youth into social networks and relationship development. So, returning to the current study, not only should students practice jobs in the community while in high school on a trial basis, but also the school should establish on- going relationships between the young adults and the community sites so that work achievements are continued following school. This clearly did not happen with the young adults in the present study, except with the one participant whose grandmother worked with an autism services provider agency, who made those connections herself on behalf of her grandson. Similarly, Hetherington et al. (2011) emphasize that transition planning requires a coordinated set of activities based on the individual student's interests, strengths, and needs. Yet, in the current sample, interests of the young adult children were not being considered, as youth were put into jobs based on a schedule, rather than interest. The need to establish relationships with the community and to consider interests of the transition age youth and include him or her in the planning process are articulated in IDEA (2004), so, consistent with the conclusions of Henderson and Wehman (2009), schools are falling short of their obligations, and, as a result are leaving more responsibility to families, including those in the current study.

While limitations of the transition process might affect a child with any disability, a report from a national study on special education students followed over time, the National Longitudinal Transition Study-2 (NLTS2), stated that, when compared to children in other disability categories, children with ASD are least likely to participate in transition planning in a meaningful way (Cameto et al., 2004; Foden & Anderson, 2011), which impacts their families. Tehee et al. (2009) found in their survey study of parents of children with autism, that parents of transition aged youth reported that they are getting less information from professionals than are parents of younger children, again indicating that families, like participants in this study, need to more actively seek out information.

It is important to recognize that in the present study, families had multiple years of experience with the special education system and their past advocacy experiences created a historical context for their involvement during the transition process. Mothers, grandmothers and fathers all spoke of past experiences in which they advocated on behalf of their children, especially to secure services that they believed were needed. Families described different types of advocacy experiences. Some were incredibly positive, whereby their advocacy efforts enhanced service delivery, not only for their own child, but also benefitted others and the system as a whole. Others were contentious, with family members using the words “fight” and “battle” to describe them. Consistent with literature on advocacy for parents of children with disabilities (Stoner et al., 2005; Wang et al., 2004), participating families reported positive and negative aspects of advocacy, and suggested that positive parent professional partnerships and good educational experiences mediated the need for advocacy and reduced stress. This reinforces the link between support and quality of life.

## **Supports and Services**

Families in the present study reported supports and services that enhanced their FQOL as well as insufficient supports and services. Families who received the autism waiver and whose sons, grandsons, and daughters had good educational experiences described services as more positive than those with more complaints educationally. Support from professionals likewise affected FQOL. Some participants described dedicated professionals who added to the quality of their experiences and some described professionals who did not help their sons, grandsons, and daughters. Many families had experiences with both.

At the time of data collection, four of the young adults had transitioned out of their school systems. Consistent with the literature, even families who reported some dissatisfaction with the educational system acknowledged that the entitlement services of school were better than the eligibility based adult services system. They also reported that their young adults had more opportunities in the community when they were in school (Foden & Anderson, 2011; OAR, 2009; Shattuck et al., 2011). Two of these families were receiving minimal services at the time of data collection.

Additional services to enhance and support productivity according to these families would include increased community based opportunities to engage in work related tasks. Families discussed wanting their young adults to have the support necessary to be visible in the community. Additionally, some parents mentioned that their adult children would need additional supports to be able to hold a job, including, for some, one-on-one assistance. Families stated that they wanted their young adults to have

the support they need to be productive. Many were hopeful that with proper supports and services this indeed could happen for their loved ones. While most hoped for some job related opportunities, some parents expressed that if not a job they would want their young adult to engage in something else that is productive, such as volunteering. Families mentioned that their young adults could benefit from continued educational tasks and related services to help maintain their skill sets following transition. Although most families were not yet ready to take the step toward residential care for their young adults at the time of the interviews, they articulated that they wanted residential services to be available for their adult children when they are ready, and they expressed concern about a lack of availability of residential services, which is also reflected in the literature (Graetz et al., 2010). While the literature suggests that parents want more social opportunities for their young adults (Graetz, 2010), only two parents expressed that their young adults needed to spend more time with peers. Families' desires for productive programming during the day for their young adult appeared to be their greatest priority.

### **Sensory Processing**

Atypical sensory processing was a noteworthy finding in the current study, a result that is congruent with the research literature identifying sensory differences in autism (Crane et al., 2009, Kern et al., 2007, Leekham et al., 2007). Many of the young adults in the present study showed consistent patterns of responding to sensory information according to the Adolescent/ Adult Sensory Profile, displaying higher scores (more or much more than most people) in the low registration, sensory sensitivity, and / or sensory avoiding quadrants, and lower scores (less or much less than most people) in the sensation seeking quadrant. These scores might explain some of the behaviors seen

in these adults with ASD, as individuals who demonstrate low registration tend to be perceived as indifferent with a lack of interest in the environment. Those with sensory sensitivity may act aggressively because of their intense negative reactions to sensory stimulation, and those with sensation avoiding might appear withdrawn to limit their exposure to sensation. Whereas similar results were found in Crane et al.'s study with those with Asperger Syndrome using the Adolescent/Adult Sensory Profile as a self-report measure, no other studies were found that looked specifically at sensory processing with adults with autism and intellectual disability using the Adolescent/ Adult Sensory Profile. Some authors have proposed that mixed reactivity is present in children and adolescents with ASD, with some of the same individuals showing sensory sensitivity and avoiding and also demonstrating low registration, as was seen by some of the young adults in the current study (Pfeiffer, Kinnealey, Reid, & Herzberg, 2005).

**Sensory processing, affect, and behavior.** According to Engel-Yeger and Dunn (2011), sensory processing is related to affect, or mood, at least in a non-clinical population. In their study with healthy adults, negative affect correlated with low registration, sensory avoidance, and sensory sensitivity on the Adolescent /Adult Sensory Profile, and positive affect correlated with more sensory seeking behaviors. Therefore, the sensory response patterns of the young adults in the current study as reported on the Adolescent/ Adult Sensory Profile, were the ones associated with negative affect in Engel- Yeger and Dunn's research. Engel- Yeger and Dunn also showed that individuals with either more than most sensitivity or sensory avoiding display the most negative affect characteristics, such as distress, upset, fear, hostility, and irritability. Over half of the young adults in the present study demonstrated these patterns. Additionally, Dunn and

Engel-Yeger reported that low registration, found in six young adults in the present study, is associated with fear. While Engel-Yeager and Dunn's study was not with an ASD population, it does support the possibility that certain behaviors demonstrated by young adults on the spectrum in the current study may indeed be related to their disordered sensory processing, and that disordered sensory processing could account for some of the defining characteristics of autism. It is also interesting to note that similar patterns of sensory processing have been found in prior studies in adults with schizophrenia (Brown, Cromwell, Filian, Dunn, & Tollefson, 2002) and in young people with OCD (Reike and Anderson, 2009), again suggesting a link between disordered sensory processing, affect, and behavior.

Kinnealey, Koenig, and Smith (2011) studied the relationship between sensory over-reactivity, as defined by sensory sensitivity and sensory avoiding patterns on the Adolescent/ Adult Sensory Profile, and affect in a group of volunteers without ASD or another formal mental health diagnosis. They found that as sensory over-reactivity increased, one's participation scores decreased, indicating less likelihood of engaging in activities in the environment. Sensory sensitivity, sensory avoiding, and low registration, all patterns revealed in the present study, showed a significant, negative relationship to emotional and mental health indicators in Kinnealey et al.'s research. Sensory avoiding was uniquely related to decreased general health and increased bodily pain, and is considered by the authors to be a risk factor to decreased health related quality of life. Low registration was also correlated with poor social functioning (Kinnealey et al.). While Kinnealey et al.'s study was with a non-clinical population of adults with normal intelligence, their results do support a possible connection between atypical sensory

processing and atypical behavior, including decreased participation, decreased social functioning, and even pain, all characteristics seen in the young adults in the present study.

**Sensory processing and the family.** Sensory processing difficulties persisted into adulthood in most transition age young adults in the current study and impacted families' ability to perform daily occupations and activities. However, in spite of them, families did engage in many daily occupations and activities. The sensory issues contributed to the need for accommodation in the ways families engaged in activities, and also contributed to the amount of planning families needed to put into certain activities. .

While no existing studies were found discussing accommodations made by families of adults with ASD, recent studies with children and adolescents suggested similar results. Bagby, Dickie, and Baranek (2012) found that families of children with autism avoid certain occupations and have social limitations created by their children's sensory experiences. These authors also highlighted the need for in-depth preparation for sensory-laden activities. This bears similarity to the stories provided by families of young adults in the current study of avoiding certain places such as restaurants, and making extensive preparations for vacation. Similarly, Schaaf, Toth-Cohen, Outten, Johnson, & Benevides (2011) found that outside the home, parents of children and adolescents reported that flexibility is necessary in order to engage in chosen activities. This flexibility was seen in families in the present study, for instance, when a father left his daughter in the car (where she could see her) until she felt comfortable coming out to join her family during a family function.

The need for order and routine has been associated with people who have avoiding and/or sensitivity patterns (Engel-Yeger & Dunn, 2011; Reich and Williams 2003). Similarly, routine helps to manage fear reactions associated with low responsivity. In the current study, families reported setting routines and accommodations in place. These appeared to be strategies they used for managing unpredictable sensory input for their young adults as a way to reduce emotional reactions and negative behaviors. To a lesser degree, families reported completely avoiding activities that were difficult for the young adult. For instance, one family mentioned not going the beach because her daughter hated the sand; others did not eat out with their adult child. Some families described avoiding more activities when their loved ones were younger than they did with their young adults. It is possible that these families figured out accommodations over time. It is also possible that the young adult adapted as well.

While this study demonstrated the presence of sensory modulation difficulties in a small sample of adults with autism which impacted FQOL, it is suspected that sensory related issues may be greater than reported, because of problems a few families had in filling out the Adolescent/ Adult Sensory Profile. This suggests the need for questions about sensory processing that are more family friendly. A future study might involve piloting questions that pertain to adolescents/adults with greater autism symptomatology that could more easily be answered by caretakers. This idea is not unprecedented, as other assessment tools for those on the autism spectrum have been developed with high functioning and classic autism versions (Aspy & Grossman, 2011) for greater applicability. The idea that family members may not easily recognize sensory difficulties and their connection to behavior could also be suggested by a 2012 administration of the

MASS survey to families with children of all ages on the waiver or waiver registry which incorporated a question about sensory processing. The majority of participants did not recognize this as a difficulty for their family member (K. Eskow, personal communication, April, 2012), and therefore may not understand the connection between sensory processing and behavioral regulation. However, the question examined sensitivity, which is the quadrant of the Adolescent/Adult Sensory Profile with the smallest number of families identifying as problematic in the current study, so it may be that different questions should be incorporated into the MASS.

### **Implications of the Current Study**

**Relation to theory.** Having an adult child on the autism spectrum poses challenges to families that influence family quality of life. These include additional caretaking and parenting responsibilities, the need for planning and orchestrating of daily occupations, as well as the need to assume responsibility to advocate for what the young adult needs to successfully transition from school to the adult services system. While there are many stressors, the current study suggests that services for the young adult child and supports for the family can indeed contribute to overall well-being, and enhance outcomes. Appropriate supports help parents and grandparents participate in desired occupations including activities that are meaningful as well as employment, and with services, the young adult can likewise participate in the community. However, as discussed by families in the current study, family members and young adults with ASD do not always have what they need to fully participate. This suggests that the Person Environment Occupation Model (Strong et al., 1999), seen in figure 1, can be applied to the examination of family quality of life in families with transition age young adults with

ASD. It is noteworthy that families described interventions that they performed in their daily lives in each of the P, E, and O areas, thus reinforcing the applicability of PEO.

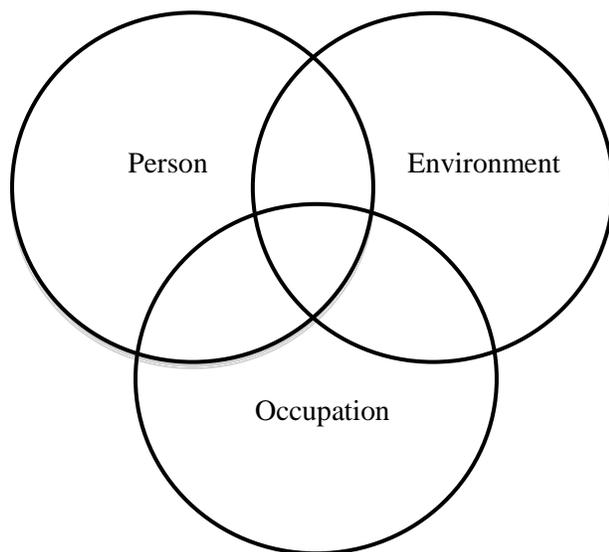


Figure 1. The PEO Model (Strong et al., 1999)

While the purpose of this study was to understand quality of life in these families, and not necessarily to advance theory, this author would like to propose some minor modifications to PEO to better align it with the study of quality of life. Instead of *environment*, it is proposed that *context* is a better match for the study of quality of life in families with a young adult with autism. Therefore, PEO becomes PCO (Figure 2). When an individual (or a family) engages in occupations, which is the O in PCO, those occupations take place in a physical and social environment situated within a context (AOTA, 2008). Hence, context is a broader term than environment, and environment therefore is subsumed under context in the PCO model. Context typically includes a variety of interrelated conditions, such as cultural and temporal factors. Family and community provide much of the context for individuals with ASD (AOTA, 2010).

Context also includes laws that influence access to resources and assure personal rights as well as opportunities for employment (AOTA, 2008). Based on families' concerns about unmet needs of their adult sons, grandsons, and daughters, this context is important to the ability to engage in occupations in these young adults. Context is a good match to the disability related support domain of family quality of life.

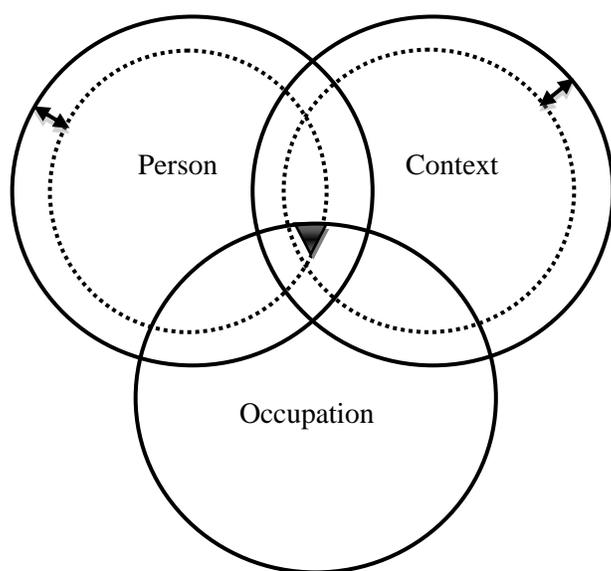


Figure 2. Proposed Modifications to PEO: The PCO Model

Context is represented in the PCO model by two concentric circles, indicating multiple levels of context, such as community programming and family. When support and services are insufficient, the gap between the circles enlarges; minimizing occupational performance, as represented by the overlap between P, C, and O. When contextual support is sufficient to optimize participation, the inside circle approximates the outer circle, therefore enlarging the occupational performance. Similarly, person is illustrated by concentric circles, representing the family and the adult with autism, so technically the word *person* represents *persons*. When person factors are favorable, as

when behavior of the young adult is positive or the stress level of the family member is lower, the inside circle moves closer to the outside circle and occupational performance, is enhanced. Therefore, when person and contextual factors are optimal, one's occupational performance, through participation in the community, or work performance is enhanced, thus enhancing quality of life of the family. While occupation is unchanged from the original PEO model, it appears that in many cases, young adults with ASD, are lacking opportunities to engage in occupations of choice, reducing the PCO overlap. Reduced opportunities to engage in occupations of choice also may occur for the family member of the young adult with autism.

Adults who have aged out of the school system who are not in a program, who spend their days in their family homes, and who are less visible to their communities are indeed experiencing social and occupational injustices. They are also experiencing occupational deprivation, or a state of long-lasting exclusion from meaningful occupations, due to circumstances beyond their control (Whiteford, 2000). This was reflected in two of the young men with ASD in families in this study; half of those out of school. Because of the limited services at the time of the interviews, they were not provided with opportunities and life chances they needed for optimal outcomes. People experiencing occupational injustice and occupational deprivation need assistance from practitioners such as occupational therapists to advocate for their individual rights and influence policy (Braveman & Bass Haugen, 2009).

**Relation to Practice.** This has implications for the practice of occupational therapy. While not the focus of this study, it is noteworthy that only half of the young adult sons, grandsons, and daughters were receiving occupational therapy services when

participants filled out the MASS in 2011. This number was likely lower at the time of data collection due to the fact that a young adult left school after the family filled out the MASS. This is consistent with the literature that suggests that the role of occupational therapy during transition from high school is very limited (Spencer, Emery, & Schneck, 2003). This is unfortunate, because occupational therapy could indeed be effective in fostering work, community, and independent living skills by intervening at every level of the PEO/PCO model. Occupational therapists might work to enhance capacity of the young adult with autism (P), adapt contexts (E or C) in which activities and occupations are performed, make adjustments to activities in which the young adult engages (O), and assist families in doing the same. An occupational therapist would therefore be an ideal professional to work with the young adult with autism, as well as to help an employer or other employees understand the young adult's needs, in order to optimize occupational performance at a job. Also, the results of the exploratory study of sensory processing included in the current study, suggest the possible need for occupational therapy and sensory based strategies to enhance engagement in occupations, although further study is necessary before this can be concluded.

### **Limitations of the Current Study**

In this study the essence of the phenomenon of family quality of life in families with a transition aged young adult with autism was described. Additionally, sensory processing in the young adult and the relationship of sensory processing to FQOL were explored. Although this study was rigorous, there are inherent limitations in any research endeavor. Limitations in this project could be the result of flaws in study design, in sampling techniques, and in data collection and analysis.

Although use of a qualitative phenomenological approach was appropriate for this topic, it is inherently subjective and susceptible to bias on the part of the investigator. However, several steps were taken to reduce researcher bias, including the use of research partners to observe the interviews, write field notes, and review transcripts, and frequent discussion of findings with a dissertation advisor. Bracketing personal experiences was ongoing during the research process, because the researcher, as a sibling of an individual with intellectual disabilities, the mother of a son who is the same age as a young adult in a participant family, and as an occupational therapist, was acutely aware of the assumptions brought to this topic, and took extra care to accurately portray the depictions of the participants. In addition, themes were brought back and discussed with participants.

Also, the sampling could be a limitation. The participants in this study were obtained through criterion sampling, which has its limitations. All participants from the original 2008 MASS survey study who expressed interest in further participation may have similar characteristics. While this limits the ability to generalize results, the aim of this study was to develop an in depth understanding the phenomenon of quality of life in families with a transition aged young adult with autism. Also, participants, consistent with the survey sample from which they were selected, are better educated, and are more financially secure than the average person residing in the state of Maryland or elsewhere. Participants are also all Caucasian. Results might reflect a greater limitation to family quality life in a more demographically diverse participant group.

In addition, there is a possibility that the researcher's presence impacted the participants during the study. A participant may have acted atypically because of the

presence of the researcher, which is known as observer effect (Patton, 2002). The reactivity of the participant to the interviewer might have prevented participants from fully disclosing information or caused them to answer questions the way they felt the researcher thought they should. By including multiple data sources within the study, and looking for consistency in answers, the researcher minimized this possibility. The researcher also minimized this by establishing rapport with participants.

### **Recommendations for Future Research**

While this study has enhanced understanding of the essence of having an adult child with autism on family quality of life, it has also lead to further questions and recommendations of topics for future study to further expand and refine insights into this phenomenon. Firstly, as already suggested, this was a group of participants with strong educational, intellectual, and financial resources. This is also a very articulate group of participants. It is therefore recommended that this study be replicated with lower income and/or minority participants who are less likely to have these advantages to determine whether the current findings apply to them as well.

It is also recommended that further research be completed with the same group of participants. While this study examined quality of life of the family as reported by a parent or grandparent, siblings were only cursorily addressed. A closer examination through interviews with young adult siblings would be worthwhile, and is of particular interest to this researcher, as a sibling of an adult with a developmental disability.

As only four young adults had exited the school system at the time of data collection, longitudinal follow up of these families is needed. It would foster better understanding of transition to continue to follow up with these families as each of their

young adults enters the adult service delivery system. Further follow up with young adults already in the adult system would also be valuable to more closely examine both family quality of life and individual outcomes over time. Since so many comments from families addressed shortcomings in school and the transition process, future examination of the transition planning process by, for examples, observing IEP meetings, or interviewing school personnel, could also be very valuable using a group of participants still in school.

Although the present study was a good first step in examining sensory processing in young adults with ASD and intellectual disabilities, this also requires further investigation. A mixed methods study using the Adolescent/Adult Sensory Profile with more participants to see if the current findings are replicated, and to evaluate the utility of the Adolescent/ Adult Sensory Profile as a caregiver report measure for more involved individuals who cannot self-report are highly recommended. The effects of sensory modulation difficulties on family life also need to be further elucidated.

Similarly, further investigation into disorders associated with autism, particularly at the time of adolescence and young adulthood is needed. These add to the complexity of autism, and the way in which they interact with autism must be further understood. One question that begs to be answered is do associated conditions co-exist with autism or might they actually be part of autism? Might autism be more of a multisystem disorder, as suggested by Steyaert and De La Marche (2008)? While this question and its subsequent answers are far beyond the scope of the current research, the results of this current study do suggest that premorbid mental health diagnoses, somatic disorders, as

well as the interaction between these disorders and puberty need to be explored if quality services are to be provided that meet the needs of this complex population.

## **Conclusion**

For families navigating the transition process and day to day life with a young adult on the autism spectrum, it is hoped that this research will serve as a source of assistance and encouragement by allowing their collective voices to be heard. It certainly will influence how this investigator views service delivery and interactions with families of children with ASD in her everyday work as an occupational therapist and an education professional. This study contributes to the existing body of literature by articulating factors that contribute to and detract from quality of life in families with a young adult with ASD, and shows that despite tremendous challenges and stressors, many families can attain a positive quality to their lives with adequate support and services. It emphasizes the importance of both formal and informal supports to the achievement of family quality of life. This study also suggests the value of further examining factors affecting young adults and their families that heretofore have not received sufficient attention such as sensory processing difficulties, as well as conditions associated with autism and the relationship of those conditions to puberty.

Despite the growing societal focus on autism, adults with ASD continue to face limited preparation for employment and participation in their communities (OAR, 2009). This also translates into reduced opportunities for families. The President of the United States has promised to provide Americans with disabilities with the educational opportunities they need to succeed (The White House, 2012), and to increase support for

inclusion and improved educational outcomes of students with disabilities. The President is also committed to increasing opportunities for employment for those with disabilities (The White House). With the large numbers of youth with ASD exiting schools, it is imperative that we as a society assure that these promises and commitments come to fruition.

## Appendix A: IRB Approvals

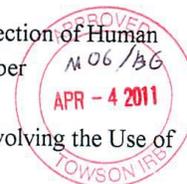
**APPROVAL NUMBER: 11-A063**

To: Karen Eskow  
CAMPUS MAIL

From: Institutional Review Board for the Protection of Human  
Subjects, Melissa Osborne Groves, Member

Date: Monday, April 04, 2011

RE: Application for Approval of Research Involving the Use of  
Human Participants



Office of University  
Research Services

Towson University  
8000 York Road  
Towson, MD 21252-0001  
t. 410 704-2236  
f. 410 704-4494

Thank you for submitting an Application for Approval of Research Involving the Use of Human Participants to the Institutional Review Board for the Protection of Human Participants (IRB) at Towson University. The IRB hereby approves your proposal titled:

*Case Study Exploration of Quality of Life for Families with a Child/adolescent/young adult with Neurodevelopmental Disabilities*

If you should encounter any new risks, reactions, or injuries while conducting your research, please notify the IRB. Should your research extend beyond one year in duration, or should there be substantive changes in your research protocol, you will need to submit another application for approval at that time.

We wish you every success in your research project. If you have any questions, please call me at (410) 704-2236.

CC:

File

**RENEWED APPROVAL NUMBER: 11-A063R1**

To: Karen Eskow  
From: Institutional Review Board for the Protection of Human  
Subjects, Melissa Osborne Groves, Member  
Date: Wednesday, April 04, 2012  
RE: Application for Approval of Research Involving the Use of  
Human Participants



Thank you for completing the Annual Review Notice for Projects  
Involving Human Participants for the project titled:

*Case Study Exploration of Quality of Life for Families with a  
Child/adolescent/young adult with Neurodevelopmental Disabilities*

Since you have indicated that your research project is still active, we are granting you a renewal of your approval. If you should encounter any new risks, reactions, or injuries while conducting your research, please notify the IRB. Should there be substantive changes in your research protocol, you will need to submit another application for approval at that time. This protocol will be reviewed again one year from this date of approval.

We wish you every success in your research project. If you have any questions, please call me at (410) 704-2236.

CC:  
File

## Appendix B: Email Script

Hi. I am a faculty member in the department of occupational therapy and occupational science at Towson University. I have been working with Dr. Karen Eskow in the Department of Family Studies and Community Development on the Maryland Autism Services Survey study. I thank you for your participation. We would like to follow up the surveys with an interview to discuss your family's quality of life. We will ask you questions about your family, including your adult child on the autism spectrum, about supports and services your family members receive, and about how you view your family's quality of life. We have asked you to participate in this portion of the study as we are interested in learning about families who have a young adult son or daughter on the autism spectrum, who are at or nearing the age of transition to adult services. We think your story is important, and the more ways we can share it, the more we can influence the professionals who provide services to those on the autism spectrum and their families. The broader results of our study will be disseminated through presentation and or publication.

Please know that anything you tell us will be kept strictly confidential, and will not affect any services your child and your family receive in any way. Your participation is strictly voluntary. If you agree to participate, I and a co- investigator, a graduate student/ recent graduate of our occupational therapy program, will meet with you for about an hour to ask you some questions. We would like to do this within the next few weeks. I will also follow up this meeting with a second short interview a few weeks later. We can meet you at your home or any other place that is convenient for you.

I hope you are interested in participating. I will be following up with a phone call or another e-mail to schedule a meeting time. Which do you prefer? What days and times are best for you? Where would you like us to meet you?

Thank you very much. Please feel free to contact me at this e mail address [bdemchick@towson.edu](mailto:bdemchick@towson.edu) or by phone at 410-804-2670 with any questions.

Sincerely,

Barbara Demchick, MS, OTR/L

## Appendix C: Informed Consent

Towson University  
8000 York Road  
Towson, MD 21252-0001

**INFORMED CONSENT FORM**

Title: Quality of Life for Families with a Transition Aged Young Adult Child on the Autism Spectrum

Investigators: Karen Goldrich Eskow, Ph.D. Barbara B. Demchick, MS, OTR/L

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**PURPOSE OF RESEARCH STUDY:**

The purpose of this research study is to provide additional information to health professionals about your adult child with autism, meaningful activities, the home and school and post secondary environments, family concerns, and family satisfaction. We are interested in learning how things are going in life for your young adult child with autism and your family.

**PROCEDURES:**

If you agree to join this research study, you will be asked for a written or verbal agreement to participate. You will then participate in two meetings during which time you (and other interested family members if you wish) will be interviewed for 1-2 hours the first time, and  $\frac{3}{4}$  of an hour the second time, each time at your convenience and at a location that you choose. Between meetings you will be asked to complete a questionnaire about your adult child that will take you 10-15 minutes. We would like audio tape our meetings if that is o.k. with you (please check below). You may change your mind about audio taping at any time, just tells the interviewer. We would also like your permission to look at the surveys that you have already filled out (please check below..

- I am willing to be audio taped .
- You may review the Maryland Autism Services Surveys that I filled out..

All information will be kept confidential. The information will not have any of your names or other identifying information on it. Only the researchers will have access to the specific information provided.

**RISKS/DISCOMFORTS:**

There are no anticipated risks to you or your family. If any problem occurs during the time of the study that requires intervention from a professional, the appropriate person will be contacted. If you have questions or concerns at any time before or during the study you are welcome to call the primary researchers, Barbara B. Demchick, at 410-704-2507 or Karen Goldrich Eskow at 410-704-2238 or Dr. Debi Garland, Chairperson of the

Institutional Review Board for the Protection of Human Rights at Towson University at 410-830-2236.

**BENEFITS:**

There are no direct benefits to you by joining this study. The results of this work may benefit the health of society if the findings contribute to a better understanding about the quality of life for families with young adult children who have autism. The results may also be of interest to you.

**WITHDRAWAL PROCEDURES:**

If you wish to withdraw please notify the study staff. You may withdraw from the study at any time.

**ALTERNATIVES TO PARTICIPATION:**

If you choose not to participate, your decision will in no way affect any services that you receive. If you change your mind during the course of the study you may stop at any time, call Professor Barbara Demchick at 410-704-2507.

This project has been explained to me, in language I can understand. I have been encouraged to ask questions, both now and in the future about this research study.

**JOINING OF YOUR OWN FREE WILL (Volunteering for the study):**

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, you will not be penalized or lose any benefits to which you are otherwise entitled.

**WHAT YOUR SIGNATURE MEANS:**

Your signature below means that you understand the information given to you about the study and in this consent form. If you sign the form it means that you agree to join the study.

**WE WILL GIVE YOU A COPY OF THIS CONSENT FORM.**

---

Participant's signature

Date

---

Signature of Investigator

Date

---

Witness to Consent Procedures

Date

## Appendix D: Interview Guide for First Interview

1. Tell me the story of your family.
  - a. Describe each of your family members (names, ages, jobs, personalities)
  - b. Tell me about your son/ daughter's (with autism) life beginning with pregnancy .(Diagnosis, key life cycle times, current situation)
  - c. Can you show me any pictures?
2. How has having a son/ daughter with autism impacted your family?
  - a. Describe a typical week day/ weekend for your family.
  - b. How does your son/ daughter with autism act with other family members? others outside your family?
  - c. How does your son/daughter participate in activities such as birthdays and holidays?
  - d. How do characteristics of your child influence his interactions (e,g, need for routine, atypical sensory reactions)
  - e. How has this changed in the past couple of years as your son/daughter has gotten older?
3. Could you describe your experiences with supports/ services (professionals, school system, waivers, health care,as your child is preparing to transition/ or has transitioned from secondary school
  - a. What has been done to prepare your son/ daughter for transition?
  - b. Tell me about any concerns you have (or had with the school system, upcoming changes with school placement, or post school situation (future plans).
  - c. How do you envision your son's/daughter's future?
  - d. How do you expect your life to change once your son/daughter transitions from secondary school? or How has it changed now that your child has made the transition from secondary school?
  - e. What additional supports/ services could enhance your family's quality of life?
  - f. What are you doing/ have you done to gain these supports/ services)?
4. What (if any) roles have you or other family members assumed in the absence of receiving a service?
5. What advice would you give to professionals working with families of young adults with autism in order to enhance FQoL?
  - a. Is there any additional information you would like to tell me about your family?

## Appendix E: Sample Interview 2 Questions

1. I just want to confirm what you said in the first interview. Is this correct?  
Probe: Can you elaborate?
2. Did you choose the job you held before you went back to school because of your son's autism?  
Probe: How did that come about?
3. How did your son's autism affect your daughter?
4. Can you think of any sensory issues that your son had when he was younger?  
Probe: How did he do with birthday parties?  
Probe: How did he do with changes in routine?
5. Has your son gone on vacation with you?  
Probe: Can you tell me about it?

## Appendix F: Observations and Notes

Participant:

Location of Observation:

Those Present:

<b>DESCRIPTIVE NOTES</b>	<b>REFLECTIVE NOTES</b>

## Appendix G: Adolescent/Adult Sensory Profile



## ADOLESCENT/ADULT SENSORY PROFILE™

Catana Brown, Ph.D., OTR, FAOTA  
Winnie Dunn, Ph.D., OTR, FAOTA

### Self Questionnaire

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

Birthdate: \_\_\_\_\_ Gender:  Male  Female

Are there aspects of daily life that are not satisfying to you? If yes, please explain.

---



---



---

#### INSTRUCTIONS

Please check the box that **best** describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

**Please answer all of the statements. Use the following key to mark your responses:**

- |                      |   |
|----------------------|---|
| <b>ALMOST NEVER</b>  | When presented with the opportunity, you <b>almost never</b> respond in this manner (about 5% or less of the time).   |
| <b>SELDOM</b>        | When presented with the opportunity, you <b>seldom</b> respond in this manner (about 25% of the time).                |
| <b>OCCASIONALLY</b>  | When presented with the opportunity, you <b>occasionally</b> respond in this manner (about 50% of the time).          |
| <b>FREQUENTLY</b>    | When presented with the opportunity, you <b>frequently</b> respond in this manner (about 75% of the time).            |
| <b>ALMOST ALWAYS</b> | When presented with the opportunity, you <b>almost always</b> respond in this manner (about 95% or more of the time). |

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Item		A. Taste/Smell Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).					
~	2	I add spice to my food.					
-	3	I don't smell things that other people say they smell.					
~	4	I enjoy being close to people who wear perfume or cologne.					
	5	I only eat familiar foods.					
-	6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).					
⊙	7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).					
~	8	I go over to smell fresh flowers when I see them.					

Comments

Item		B. Movement Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
⊙	9	I'm afraid of heights.					
~	10	I enjoy how it feels to move about (for example, dancing, running).					
	11	I avoid elevators and/or escalators because I dislike the movement.					
-	12	I trip or bump into things.					
⊙	13	I dislike the movement of riding in a car.					
~	14	I choose to engage in physical activities.					
-	15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					
⊙	16	I become dizzy easily (for example, after bending over, getting up too fast).					

Comments

Item	C. Visual Processing		ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
~ 17		I like to go to places that have bright lights and that are colorful.					
18		I keep the shades down during the day when I am at home.					
~ 19		I like to wear colorful clothing.					
⊗ 20		I become frustrated when trying to find something in a crowded drawer or messy room.					
— 21		I miss the street, building, or room signs when trying to go somewhere new.					
⊗ 22		I am bothered by unsteady or fast moving visual images in movies or TV.					
— 23		I don't notice when people come into the room.					
24		I choose to shop in smaller stores because I'm overwhelmed in large stores.					
⊗ 25		I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).					
26		I limit distractions when I am working (for example, I close the door, or turn off the TV).					

Comments

Item	D. Touch Processing		ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
⊗ 27		I dislike having my back rubbed.					
~ 28		I like how it feels to get my hair cut.					
29		I avoid or wear gloves during activities that will make my hands messy.					
~ 30		I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					
⊗ 31		I am bothered by the feeling in my mouth when I wake up in the morning.					
~ 32		I like to go barefoot.					
⊗ 33		I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).					
⊗ 34		I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).					
35		I move away when others get too close to me.					
— 36		I don't seem to notice when my face or hands are dirty.					
— 37		I get scrapes or bruises but don't remember how I got them.					
38		I avoid standing in lines or standing close to other people because I don't like to get too close to others.					
— 39		I don't seem to notice when someone touches my arm or back.					

Comments

Item	E. Activity Level	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
~	40 I work on two or more tasks at the same time.					
—	41 It takes me more time than other people to wake up in the morning.					
~	42 I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					
—	43 I find time to get away from my busy life and spend time by myself.					
—	44 I seem slower than others when trying to follow an activity or task.					
—	45 I don't get jokes as quickly as others.					
—	46 I stay away from crowds.					
~	47 I find activities to perform in front of others (for example, music, sports, acting, public speaking, and answering questions in class).					
⊖	48 I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					
—	49 I avoid situations where unexpected things might happen (for example, going to unfamiliar places or being around people I don't know).					

Comments

Item	F. Auditory Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
~	50 I hum, whistle, sing, or make other noises.					
⊖	51 I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					
—	52 I have trouble following what people are saying when they talk fast or about unfamiliar topics.					
—	53 I leave the room when others are watching TV, or I ask them to turn it down.					
⊖	54 I am distracted if there is a lot of noise around.					
—	55 I don't notice when my name is called.					
—	56 I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).					
—	57 I stay away from noisy settings.					
~	58 I like to attend events with a lot of music.					
—	59 I have to ask people to repeat things.					
⊖	60 I find it difficult to work with background noise (for example, fan, radio).					

Comments

Appendix H: Maryland Autism Services Survey

2/15/2011

# Maryland Autism Services Survey



*Department of Family Studies and Community Development*

Adapted from the Partnership and Family Quality of Life Survey developed by  
the Beach Center on Disability, University of Kansas

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See <http://www.beachcenter.org> for further information about these scales.

ID:

## Survey Information and Instructions

Thank you for agreeing to complete this survey. We want to know more about families who have children with autism and the services they need. You can help by telling us about YOUR family. In this survey questions ask about:

The services your family uses;

The main person who works with your child;

Family quality of life;

Your child's progress; and

General family information.

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

### Background & Definitions

Maryland's Autism Waiver is administered by the Maryland State Department of Education (MSDE), with support from the Department of Health and Mental Hygiene (DHMH). The Maryland Autism Waiver is approved to serve 900 children and is currently at capacity. However, there is a registry for children who are interested in applying as slots become available.

The following terms will be used throughout this survey. It is very important that you read and understand them:

*Waiver:* This term refers to the Maryland Autism Waiver, which allows eligible children with autism spectrum disorder to receive necessary waiver services to maintain them in their home and community.

*Registry:* This term refers to the Maryland Autism Waiver Registry, a waiting list for children interested in applying for the Waiver as slots become available.

By completing this survey, you indicate that you have been informed of the important aspects of this study.

## Background Information

Please answer the following questions about yourself:

1. Date of birth: \_\_\_\_\_
2. Gender:  Male  Female
3. Do you have a diagnosed disability?  Yes  No  
Please describe: \_\_\_\_\_
4. Which of the following best describes your current work status?  
 Employee in full-time job (30 hours or more per week)  Fully retired from work  
 Employee in part-time job (less than 30 hours per week)  Full-time education at school, college or university  
 Self-employed (full or part time)  Looking after home/family  
 Government-supported training  Permanently sick/disabled  
 Unemployed and available for work
5. Do you contribute to the household income?  
 Yes  No

Please tell us about the individual with autism in your family.

If you have more than one person with autism in your family, please choose one for the purpose of this survey.

6. Date of birth (mm/yyyy): \_\_\_\_\_
7. Gender:  Male  Female
8. In addition to autism, does this person have a diagnosed disability?  Yes  No  
If yes, please describe: \_\_\_\_\_
9. What is this person's relationship to you?  
**\*\*Note: Throughout this survey, this person will be referred to as your child.**  
 Biological/adopted child  Sibling  
 Grandchild  Stepdaughter/Stepson  
 Niece/nephew  Foster child  
 Other (please describe below) \_\_\_\_\_
10. Has your child ever received Maryland Autism Waiver services?  Yes  No (please skip to question 6)  
 What year did this child begin receiving waiver services? \_\_\_\_\_  
 What year did this child stop receiving waiver services (if applicable)? \_\_\_\_\_  
 Was this child on the Registry (waiting list) before receiving services?  Yes  No  
 How long was this child on the registry? \_\_\_\_\_



2/15/2011

In the last 12 months, how often did your family use the following EDUCATION services:

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Early Intervention	<input type="checkbox"/>					
Special education	<input type="checkbox"/>					
Transition services (for example, pre-k to kindergarten)	<input type="checkbox"/>					
Summer school or extended school year (ESY) services	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

In the last 12 months, how often did your family use the following RELATED services:

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Occupational therapy	<input type="checkbox"/>					
Physical Therapy (PT)	<input type="checkbox"/>					
Social Work	<input type="checkbox"/>					
Transportation	<input type="checkbox"/>					
Financial Services	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

In the last 12 months, how often did your family use the following INFORMATION services:

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Online social networks (e.g., Yahoo groups, email listservs, blogs)	<input type="checkbox"/>					
Parent/family organization (e.g., Autism Society)	<input type="checkbox"/>					
Service coordinator/case manager	<input type="checkbox"/>					
Outreach or consulting	<input type="checkbox"/>					
Legal/advocacy rights groups (e.g., Maryland Disability Law Center)	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

2/15/2011

In the last 12 months, how often did your family use the following FAMILY AND FRIEND SUPPORT services?

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Extended family (such as step parents, siblings, aunts/uncles)	<input type="checkbox"/>					
Friends	<input type="checkbox"/>					
Contact with other parents of children with autism or other disability	<input type="checkbox"/>					
Neighbors	<input type="checkbox"/>					
Religious organization	<input type="checkbox"/>					
Coworkers	<input type="checkbox"/>					
Support for siblings	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

In the last 12 months, how often did your family use the following CHILD CARE services?

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Respite Programs (e.g., church, mothers' day out, agency services)	<input type="checkbox"/>					
Babysitting	<input type="checkbox"/>					
Regular after-school programs	<input type="checkbox"/>					
Full- or part-time center or child care in a licensed home setting	<input type="checkbox"/>					
Family care (including extended family members such as step parents, siblings, aunts/uncles)	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

In the last 12 months, how often did your family use the following SERVICE COORDINATION services:

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Case management and/or care coordination	<input type="checkbox"/>					
Financial management services (for example, fiscal intermediary/agency)	<input type="checkbox"/>					
Medical home (comprehensive primary care)	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

2/15/2011

In the last 12 months, how often did your family use the following HEALTH services:

	<i>Daily</i>	<i>3-4x/week</i>	<i>1-2x/week</i>	<i>1-2x/month</i>	<i>1-2x/year</i>	<i>Not at all</i>
Healthy kids check-ups	<input type="checkbox"/>					
Nursing services	<input type="checkbox"/>					
Nutrition services	<input type="checkbox"/>					
Mental health services including behavioral, psychological services, family counseling	<input type="checkbox"/>					
Social work services	<input type="checkbox"/>					
Hearing services	<input type="checkbox"/>					
Vision services	<input type="checkbox"/>					
Other (please specify below)	<input type="checkbox"/>					
<input type="text"/>						

During the past 12 months, how many times did your child see a doctor, nurse, or other health care provider for preventive medical care such as a physical exam or well-child checkup?

During the past 12 months, how many times did your child see a dentist for preventive dental care, such as check-ups and dental cleanings?

Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. During the past 12 months, has your child received any treatment or counseling from a mental health professional?

Yes  No  Don't know

During the past 12 months, has your child taken any medication because of difficulties with (his/her) emotions, concentration, or behavior?

Yes  No  Don't know

Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. During the past 12 months, did your child see a specialist other than a mental health professional?

Yes  No  Don't know

### Section 1b: Service Decision Making

	<i>None</i>	<i>Some</i>	<i>Enough</i>
To what extent do you feel you have choices about the types of services your child receives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent do you feel you have choices about the providers who serve your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent do you believe the services you receive are flexible in terms of meeting changing needs for your child and family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent do you believe you have control over decisions made about services for your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you! Please continue to the next section: **Partnership**.

## Section 2: Partnership

In this section, we will be asking you to rate your satisfaction with the quality of your relationship with the person who works directly with your child the most. Please remember, we asked you to keep one child in mind. Please remember to keep the same child in mind as you complete this section.

Please identify about the person who works directly with your child the most as you answer the questions in this section.

- |   |   |  |
|---|---|--|
| <input type="checkbox"/> Teacher                | <input type="checkbox"/> Family trainer         | <input type="checkbox"/> Psychologist/Psychiatrist |
| <input type="checkbox"/> Doctor                 | <input type="checkbox"/> Respite worker         | <input type="checkbox"/> Speech therapist          |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Special education aide | <input type="checkbox"/> Residential manager       |
| <input type="checkbox"/> IISS Worker            | <input type="checkbox"/> School counselor       |  |
- Other (please specify)

Please select the box in the next set of columns to show how satisfied you are with that statement.

Selecting the first box means you are very dissatisfied.

Selecting the last box means you are very satisfied.

How satisfied are you that the individual you identified above...

	<i>Very dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very satisfied</i>
Helps you gain skills or information to get what your child needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has the skills to help your child succeed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provides services that meet the individual needs of your child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speaks up for your child's best interests when working with other service providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lets you know about the good things your child does.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeps your child safe when your child is in his/her care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treats your child with dignity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Builds on your child's strengths.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Values your opinion about your child's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is honest, even when there is bad news to give.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is available when you need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uses words that you understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Protects your family's privacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shows respect for your family's values and beliefs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Listens without judging your child or family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is a person you can depend on and trust.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pays attention to what you have to say.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you! Please continue to the next section: **Family Quality of Life**

### Section 3: Family Quality of Life

In this section of the survey, we want you to tell us how you feel about your life together as a family. Your "family" may include many people - mother, father, partners, children, aunts, uncles, grandparents, etc. For this survey, please consider your family as those people:

- ✓ Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
- ✓ Who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items in the next section are things that hundreds of families have said are important for a good family quality of life. We want to know how satisfied you are with these things in your family. Please choose the answers that reflect your level of satisfaction with each item.

How satisfied are you that...

	<i>Very dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very satisfied</i>
My family enjoys spending time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members help the children learn to be independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has the support you need to relieve stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have friends or others who provide support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members help the children with schoolwork and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have transportation to get to the places you need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members talk openly with each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members teach the children how to get along with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members have some time to pursue their own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family solves problems together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members support each other to accomplish goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family members show that we love and care for each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has outside help available to us to take care of special needs of all family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family teach the children to make good decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family gets medical care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has a way to take care of expenses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family know other people in the children's lives (friends, teachers, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family is able to handle life's ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adults in my family have time to take care of the individual needs of every child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family gets dental care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

					2/15/2011
	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
My family feels safe at home, work, school, and in our neighborhood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child with autism has support to accomplish goals at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child with autism has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child with autism has support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has good relationships with the service providers who provide services and support to my child with autism.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you! Please continue to the next section: **Child's Progress.**

### Section 4: Child's Progress

In this section we want to know how well you think your child has progressed over the last 12 months. Please remember, we asked you to keep one child in mind. Please keep the same child in mind as you complete this section.

	<i>Improved</i>	<i>Stayed the same</i>	<i>Gotten worse</i>
In the past 12 months, has your child's academic report...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 12 months, have your child's independent living skills...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 12 months, has your child's ability to communicate...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 12 months, has your child's relationship with peers...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 12 months, has your child's behavior...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you! Now we have only a few more questions. Please continue to the last section: **General Information.**

### Section 5: General Information

The last thing we need to do is ask a few questions about you and your family. Towson University will use this information to generally describe the people who responded to our survey. We will describe people in groups, never as individuals, so your answers will be kept confidential.

Please answer these questions about yourself.

- What year were you born? \_\_\_\_\_
- What is your marital or civil partnership status?
 

<input type="checkbox"/> <i>Single (never married nor in a domestic partnership)</i> <input type="checkbox"/> <i>Married (first marriage)</i> <input type="checkbox"/> <i>Re-married</i> <input type="checkbox"/> <i>Separated (but still legally married)</i>	<input type="checkbox"/> <i>Divorced</i> <input type="checkbox"/> <i>Widowed</i> <input type="checkbox"/> <i>Living with a partner/domestic partnership</i>
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Other (please specify): \_\_\_\_\_

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3. What is the highest level of education that you have completed? (please select ONLY one)
- |  |   |
|--|---|
| <input type="checkbox"/> Grades 1-11                                     | <input type="checkbox"/> Bachelor's degree (BA, BS) |
| <input type="checkbox"/> High school graduate (diploma or GED)           | <input type="checkbox"/> Graduate degree            |
| <input type="checkbox"/> Some college or post-high school, but no degree | <input type="checkbox"/> Post-graduate degree       |
| <input type="checkbox"/> Associate degree (AA, AS)                       |   |
- Other (please specify): \_\_\_\_\_
4. If you are not employed full time, please specify the reason:
- |  |   |
|--|---|
| <input type="checkbox"/> It is my choice               | <input type="checkbox"/> Do not need to work (for example, on disability, retired, have money from other sources) |
| <input type="checkbox"/> Unable to find full time work | <input type="checkbox"/> I choose to be a full time homemaker   |
| <input type="checkbox"/> I am looking for work         | <input type="checkbox"/> The needs of my child with autism prevent me from working                                |
- Other (please specify): \_\_\_\_\_
5. To what extent do the needs of your child(ren) with autism affect your employment status?
- |                                     |                               |                                |
|-------------------------------------|-------------------------------|--------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> Some | <input type="checkbox"/> A lot |
|-------------------------------------|-------------------------------|--------------------------------|
6. How have autism services affected your employment status?
- |                                     |                               |                                |
|-------------------------------------|-------------------------------|--------------------------------|
| <input type="checkbox"/> Not at all | <input type="checkbox"/> Some | <input type="checkbox"/> A lot |
|-------------------------------------|-------------------------------|--------------------------------|
7. What is your primary occupation?  
\_\_\_\_\_
8. What is your spouse's primary occupation?  
\_\_\_\_\_
9. County where your child receives services:
- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Allegany County     | <input type="checkbox"/> Charles County    | <input type="checkbox"/> Prince George's County |
| <input type="checkbox"/> Anne Arundel County | <input type="checkbox"/> Dorchester County | <input type="checkbox"/> Queen Anne's County    |
| <input type="checkbox"/> Baltimore City      | <input type="checkbox"/> Frederick County  | <input type="checkbox"/> St. Mary's County      |
| <input type="checkbox"/> Baltimore County    | <input type="checkbox"/> Garrett County    | <input type="checkbox"/> Somerset County        |
| <input type="checkbox"/> Calvert County      | <input type="checkbox"/> Harford County    | <input type="checkbox"/> Talbot County          |
| <input type="checkbox"/> Caroline County     | <input type="checkbox"/> Howard County     | <input type="checkbox"/> Washington County      |
| <input type="checkbox"/> Carroll County      | <input type="checkbox"/> Kent County       | <input type="checkbox"/> Wicomico County        |
| <input type="checkbox"/> Cecil County        | <input type="checkbox"/> Montgomery County | <input type="checkbox"/> Worcester County       |
10. What is your zip code?
11. What was your total household income from all sources for the past year? Be sure to include income from all sources (such as family subsidy or child support).
- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Less than \$20,000   | <input type="checkbox"/> \$60,000 to \$79,999   | <input type="checkbox"/> \$120,000 to \$139,000 |
| <input type="checkbox"/> \$20,000 to \$39,999 | <input type="checkbox"/> \$80,000 to \$99,999   | <input type="checkbox"/> \$140,000 to \$159,999 |
| <input type="checkbox"/> \$40,000 to \$59,999 | <input type="checkbox"/> \$100,000 to \$119,999 | <input type="checkbox"/> Over \$160,000         |
12. How many CHILDREN (under age 18) live in your household?  
\_\_\_\_\_
13. How many of these children have a diagnosed disability?  
\_\_\_\_\_
14. How many FEMALE ADULTS (over age 18) live in your household (including children away at college)?  
\_\_\_\_\_

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15. How many MALE ADULTS (over age 18) live in your household  
(including children away at college?) \_\_\_\_\_
16. How many persons of Hispanic or Latino origin live in your  
household? \_\_\_\_\_
17. Please specify the number of persons of each race living in your household:
- White, Caucasian: ..... \_\_\_\_\_
- Black, African American... \_\_\_\_\_
- American Indian, Eskimo,  
Aleut: ..... \_\_\_\_\_
- Asian or Pacific Islander: . \_\_\_\_\_
- Other/multiracial: ..... \_\_\_\_\_
18. Please tell us about the employment status of the individuals in your household:
- Number of persons employed full time (more than  
30 hours/week or more): ..... \_\_\_\_\_
- Number of persons employed part time (30  
hours/week or less): ..... \_\_\_\_\_
- Number of persons not employed but looking for  
work: ..... \_\_\_\_\_
- Number of persons not employed but not looking for  
work (e.g., retired, stay-at-home parent, child, etc.): . \_\_\_\_\_
- Number of full time students: ..... \_\_\_\_\_
19. How many individuals contribute to the total  
household income reported above? \_\_\_\_\_

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20. Would you be willing to be interviewed as part of a more in-depth study?

Yes     No

If yes, please provide the following contact information:

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

E-mail: \_\_\_\_\_

Phone numbers

Home: ..... \_\_\_\_\_

Work: ..... \_\_\_\_\_

Mobile: ..... \_\_\_\_\_

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Please submit your survey using the enclosed postage paid envelope.

**Thank you** very much for participating!

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