



# Families of Adolescents with Autism: Facing the Future

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The purpose of this report, drawn from a larger study, was to investigate family adaptation in families of adolescents with autism spectrum disorder and to determine whether family adaptation is influenced by: daily stressors, uncertainty regarding the adolescent's disability, and use of coping strategies on the family's adaptation process. Selection of variables was guided by McCubbin's Family Resilience Model. A total of 115 family members, all members of Interactive Autism Network, participated and completed the study using web-based technology. Hierarchical multiple regression analysis showed the independent variables, except use of coping strategies, had a statistically significant relationship with family adaptation. Because few studies have focused on this population, the findings may assist families and health care professionals during this important family life developmental milestone.

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AUTISM SPECTRUM DISORDER (ASD) affects nearly 1 in 68 individuals and its prevalence climbed dramatically from 2007 to 2012 (Blumberg et al., 2013). Although early intervention studies show promising results, families of adolescents with ASD, whose passage to adulthood is delayed or incomplete, there is no clear path to guide families through successful transition.

Although autism research has been identified as a national priority (Singh, Iles, Lazzeroni, & Hallmayer, 2009), few studies focus on families of adolescents with ASD (Orsmond, Seltzer, Greenberg, Krauss, & Floyd, 2006) or explore family adaptation with this population. However, long-term studies reveal unfavorable outcomes for adolescents and adults. Landmark studies indicated that individuals with ASD rarely gain independent living or full employment status (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006). These findings were confirmed in a more recent study

by Billstedt, Gillberg, and Gillberg (2011). Shogren and Plotner (2012) and Roux et al. (2013) noted similar findings using the National Longitudinal Transition Study-2 (NLTS-2). These recent studies demonstrate that individuals with ASD have less favorable outcomes than those with chronic illness or other disabilities. Students with ASD were less likely to participate in transitional services and needed more support after school services ended (Shogren & Plotner). Further, adolescents and adults with ASD had a lower rate of employment compared to those with speech/language impairment (SLI), learning disability (LD), or intellectual disability. Also the rate of college attendance among those with ASD was lower than for those in the SLI or LD categories (Shattuck et al., 2012). A national housing survey of 8,614 families or individuals with ASD found well into adulthood, the majority (84%) of the individuals with ASD are living at home, whereas their preferred living situation is outside the home (Autism Speaks, 2013).

A sizeable body of empirical literature has been amassed regarding autism, yet is focused on families of younger children or those newly diagnosed with ASD (Orsmond et al., 2006). By contrast the few studies with families of adolescents were qualitative (Fong, 1992; Gray, 1993) or investigated

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aspects of maternal well-being (Orsmond et al., 2006; Seltzer et al., 2003; Shattuck et al., 2007). No empirical literature was located which investigated the individual or combined influence of variables such as daily stressors, severity of behavior problems, uncertainty regarding the adolescent's disability, or use of coping strategies on family adaptation in families of adolescents with ASD. Therefore, to address this gap in the literature this study investigated these variables' influences on family adaptation in families of adolescents with ASD.

## Background

ASD is a life-long, pervasive, developmental disability that affects an individual's neurological and biological systems. To be diagnosed with ASD, an individual must have persistent deficits in two domains: 1) social communication and social interaction, and 2) restrictive interests or repetitive behaviors (American Psychiatric Association, 2013).

The experience of managing an adolescent with ASD differs from that of younger children with ASD. Several longitudinal studies demonstrated that mothers of adolescents with ASD experienced levels of depression, anger, and anxiety well above mothers of normally developing adolescents (Magana & Smith, 2006). Maternal stress is also elevated during these transitional years and remains elevated even after the child leaves home (Seltzer et al., 2003; Shattuck et al., 2007). However, families of adolescents with ASD face the complex task of managing their children's transition into adulthood with limited information available for guidance. Understanding the impact of influential variables is important.

## Severity of Behavior Problems

Numerous studies have established a relationship between behavioral problems in younger children with mental health and other disabilities and negative parental mental health outcomes, including stress and marital discord (Baker, Blacher, Crnic, & Edlebrock, 2002; Cronin, 2004; Neece & Baker, 2008). Also, researchers note the severity of behavior problems worsen as children with ASD enter puberty. Gray (1993) observed "the adolescent period usually marks...[a] difficult stage when the child develops sexually and... become[s] more aggressive (p. 117)." Also Konstantareas (1991) reflected that "older...children [with ASD] become management problems because of their increased strength and [they also] have older parents, with flagging energy levels and years of providing unremitting care (p. 366)."

Lounds, Seltzer, Greenberg, and Shattuck (2007) found a strong correlation between increased behavior problems in adolescents with ASD and negative maternal outcomes. However, no studies had investigated the relationship between the severity of behavioral problems of adolescents with ASD and the broader functioning of the family unit.

## Uncertainty

"Making meaning", or normalizing, are suggested as vital elements or important outcomes of a family's adjustment to

chronic illness or disabilities (Bayat, 2007; Knaf, Darney, Gallo, & Angst, 2010; Patterson, 1988). However, this adjustment process may be blocked by uncertainty regarding a child's chronic illness or disability and negatively impact the family's appraisal process (Skaggs & Barron, 2006; Stewart & Mishel, 2000). Holm, Patterson, Rueter, and Wamboldt (2008) reported that parents of adolescents with various disabilities worried about the unclear path of their child's future. Similar findings were detected in qualitative studies with parents of adolescents with ASD (Fong, 1992; King et al., 2006; Krajewski, 2005; Lutz, 2008). However, no quantitative studies were located that measured the influence of uncertainty on parental stress or family adaptation in families of adolescents with ASD.

## Coping

Family system theorists posit that certain coping strategies counterbalance the stressors and demands experienced by the family (McCubbin, Thompson, & McCubbin, 2003; Miller, Epstein, Bishop, & Keitner, 1985; Patterson, 1988). While there are hundreds of identified coping strategies, examples of positive or effective coping strategies would include exercise, stretching, sharing thoughts and feelings with others, or spiritual practices. Negative, or less effective, coping strategies would include overuse of alcohol or other substances, conflicts with family or colleagues, or social withdrawal (Lazarus & Folkman, 1984). Studies suggest parents of adolescents appear to cope differently, perhaps less effectively, than parents of younger children with ASD. Fong (1992) reported families of adolescents with ASD indicated they most often used coping strategies of cognitive reappraisal and social support. Similarly, the participants in Gray's (2002, 2003, 2006) qualitative longitudinal study reported that they coped by: 1) developing greater reliance on internal family support, 2) relying less on community support resources, and 3) more often using spiritual practices. Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter (2008) found that mothers of toddlers with ASD and mothers of adolescents with ASD used similar coping strategies. However, mothers of adolescents with ASD experienced an elevated level of psychological stress and lower level of maternal well-being when compared to the younger mothers (Smith et al., 2008). In light of these differences, it was important to gain a better understanding of coping strategies utilized by families of adolescents with ASD.

## Transition Literature

A consensus statement published by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine (2002) embraces the ideal of transition planning of young adults with special health care needs includes the goal of facilitating developmentally appropriate uninterrupted health care services. However, a decade after the statement was published, Colver et al. (2013, p. 1474) observed that transition healthcare services remain problematic. They stated "unsuccessful transition can lead to...negative health outcomes such as increased emergency [department] admissions, disease

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