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### Research in Developmental Disabilities



## Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism



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#### ABSTRACT

Research on adult typically-developing (TD) siblings of individuals with developmental disabilities remains limited, and outcomes for TD siblings appear to vary widely. For the current study, 82 adult TD siblings of individuals with autism spectrum disorder (ASD) or intellectual disability (ID) completed questionnaires about themselves and their affected sibling. Results of this study suggest that the attitudes possessed by adult TD siblings are important to consider when understanding adult TD sibling outcomes. Specifically, data indicate that higher levels of positive sibling relationship attitudes are related to TD siblings providing more aid/support to their sibling with a disability, along with having higher levels of general life satisfaction, and negatively related to levels of stress and depressive symptoms among TD siblings. Consistent with previous child research, siblings of individuals with ASD reported fewer positive sibling relationship attitudes compared to siblings of individuals with ID. Finally, group membership related to aid provided, depressive symptoms, and stress of TD siblings indirectly through sibling relationship attitudes. Overall, results indicate that sibling relationship attitudes may be particularly important to consider when conceptualizing sibling relationships when one sibling has an intellectual or developmental disability.

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#### What this paper adds

This study helps to fill gaps in the literature on adult typically-developing (TD) siblings of individuals with developmental disabilities by identifying a potential predictor of sibling outcomes: sibling relationship attitudes. The results of this paper indicate that TD siblings of individuals with ASD may possess less positive attitudes about their sibling relationships compared to TD siblings of individuals with ID without ASD. Moreover, sibling relationship attitudes were associated with TD sibling outcomes (e.g., stress, depressive symptoms, life satisfaction) and amount of support that TD siblings provide their affected sibling. Due to rising rates of diagnoses and a healthcare system already in crisis with regard to care for adults with developmental disabilities, siblings likely will be increasingly charged with assuming care after parents are no longer

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able. Thus, clinicians must be ready to assist TD siblings in this role, and improving attitudes and views about the sibling relationship may be one approach to consider.

#### 1. Introduction

According to the United States Census Bureau, data collected in 2010 indicated that 0.4% of the population (i.e., about 1.2 million adults) had intellectual disability (ID), whereas the estimated U.S. prevalence of autism spectrum disorder (ASD) is 1 in 68 children or roughly 1.5% of the population (Baio, 2014). Moreover, a significant portion of individuals with ASD also have co-occurring ID (e.g., Levy et al., 2010). These numbers alone are noteworthy, but it also is important to consider that each individual's disability is likely to impact their family members. Having a family member with a developmental disability (DD) places unique demands on those within the family unit and may have implications for the outcomes and functioning of all those involved (McHale & Gamble, 1989; Roper, Allred, Mandleco, Freeborn, & Dyches, 2014; Tozer & Atkin, 2015). It would seem that those closely connected to individuals with a DD may require support services themselves, substantially raising the number of individuals needing services related to any given disability.

#### 2. Sibling relationships

Generally, siblings seem to have strong and persistent influence over one another's development, life choices, outcomes, and functioning compared to individuals fulfilling other roles in a person's life. As Cicirelli (1995) observed, sibling relationships span a greater expanse of time than most relationships—including parents-child and spousal—rendering sibling relationships generally the longest lasting relationships in a person's life. The longevity of this particular familial relationship and the far-reaching nature of disability underscore the importance of understanding the outcomes and functioning of typically-developing (TD) siblings of individuals with a DD. Further, healthy functioning and positive outcomes in TD siblings is particularly relevant to the disabled sibling because, as adults, many TD siblings may assume the primary caregiver role once parents can no longer do so (Coyle, Kramer, & Mutchler, 2014).

#### 3. Adult siblings provision of aid/support

Adult siblings of individuals with a DD often play important, supportive roles to their siblings with DD (Atkin & Tozer, 2014). Most adult siblings in this population indicate that they desire to be involved in the care of their sibling (Tozer & Atkin, 2015), with many expecting to provide assistance in the future if they are not already doing so (Burke, Fish, & Lawton, 2015). Relatedly, TD siblings have expressed difficulty in balancing the demands of caring for their own family, caring for their aging parents, and being consistently involved with their siblings with ASD (Tozer & Atkin, 2015). Duignan and Connell's (2015) study suggests that caring for an individual with ASD can alter the home environment in ways that result in negative effects on siblings' social relationships. Many TD siblings expect to assume greater caregiving roles when their parents get older (Coyle et al., 2014), especially if they have a closer relationship with their sibling (Burke, Taylor, Urbano, & Hodapp, 2012; Heller & Kramer, 2009). Thus, consideration of adult sibling relationships is of particular interest when assessing the outcomes and functioning of adult siblings of individuals with a DD.

#### 4. Adult sibling relationships and developmental disabilities

Little research considers the importance of sibling relationships in this population (Hastings & Petalas, 2014), particularly in adults (Ferraioli & Harris, 2009). Adult siblings of individuals with a DD have unique sibling relationships as compared to similar but younger sibling dyads (Orsmond, Kuo, & Seltzer, 2009), adult siblings of individuals with other types of diagnoses (e.g., psychiatric, chronic health conditions), and TD sibling dyads (e.g., Hodapp & Urbano, 2007). Whereas the closeness of sibling relationships appears to fluctuate in typical sibling dyads (Orsmond et al.), closeness of siblings when one has a DD appears more stable over time (Orsmond & Seltzer, 2007). Thus any social and emotional difficulties related to a lack of closeness in the early sibling relationship may continue into adulthood (Orsmond & Seltzer, 2007). Furthermore, TD siblings of individuals with a DD who report positive, rewarding, close sibling relationships also tend to have good health and perceive benefits of being a sibling to a brother/sister with disabilities (Hodapp & Urbano, 2007; Hodapp, Urbano, & Burke, 2010). Although mostly unexplored in adults, childhood sibling relationship quality predicts psychosocial adjustment outcomes in adulthood (Dunn, Slomkowski, Beardsall, & Rende, 1994; Waldinger, Vaillant, & Orav, 2007). Considering the longevity and impact of this relationship, it is critical to assess adult sibling relationships in families of individuals with a DD.

#### 5. Consideration of group differences

Research concerning the functioning and outcomes of TD siblings of individuals with DDs when compared to siblings within typical dyads appears inconsistent, with some siblings exhibiting positive outcomes (Macks & Reeve, 2007), some negative outcomes (Gold, 1993; Verté, Roeyers, & Buysse, 2003), and some no differences (Di Biasi et al., 2015; Tomeny, Barry, & Bader, 2012). As suggested by Seltzer, Greenberg, Orsmond, and Lounds (2005), these inconsistencies in TD siblings' outcomes may be dependent upon their siblings' type of DD. Rossiter and Sharpe's (2001) meta-analysis suggests that

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