



# Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses



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## ABSTRACT

Factors predicting the emotional well-being of adult siblings of those with developmental disability (DD) remain under-researched. In this study adult siblings of individuals with Down's syndrome (DS), autism (ASD), Prader-Willi syndrome (PWS) and those with DD but with unknown aetiology (DUA) were compared with each other and a closely-matched control group to ascertain if sibling disability type made a difference to anxiety and/or depression levels. Also considered was the interactive effect of gender, age, parental and sibling educational attainment levels, socio-economic status and birth order on anxiety and depression outcomes. With the exception of siblings of those with DS, adult siblings of those with ASD, PWS and DUA reported significantly higher levels of anxiety and depression than the control group. There were some predictive effects of the demographic variables upon anxiety and depression but none common to all disability types and no moderating effects of demographic factors were found. Consequently other solutions must be found as to why this important group of people have elevated rates of anxiety and depression in comparison to the general population.

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## 1. Introduction

Sibling relationships can offer one of the most mutually supportive and enduring bonds over the course of a lifetime (Bank & Kahn, 1997; Voorpostel & Blieszner, 2008), improving emotional, cognitive and social growth (Brody, 2004). It is a relationship that exists through circumstance and because of shared influences it is often a relationship of relative equals (Cicirelli, 1995). However, when one of the siblings has a developmental disability (DD) the relationship can be viewed as a caring function as opposed to being reciprocally supportive (McHale & Gamble, 1989; Turnbull & Turnbull, 1990); this may result in affective (anxiety and depression) consequences for the sibling without disabilities, particularly as many with DD retain a lifelong reliance upon their families (Wolfe, Song, Greenberg, & Mailick, 2014). The characteristics of the type of DD can also affect sibling outcome, with, for example, siblings of individuals with Down's syndrome (DS) usually having better overall health, including fewer reported depression symptoms than those who have siblings with autistic spectrum disorder (ASD) (e.g., Hodapp & Urbano, 2007). Research to date has usually focused on sibling affective outcomes in childhood; consequently, there is relatively little information available on adult sibling affective outcome, and in particular, if it is the characteristics of the disability or if it is the interactive effect of demographic factors that account for the outcomes.

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### 1.1. Influences of disability types on sibling affective outcome

Adult siblings of individuals with DS, in comparison to ASD, have better sibling relationships, health, affective health and more contact with their sibling with intellectual disabilities (Hodapp & Urbano, 2007). This is a trajectory that appears to be continued from childhood because, as children, siblings of individuals with DS can emerge as better adjusted than normative control samples (Hastings, 2007). Conversely, 40% of children whose siblings have ASD report scores on affective disorders that place them on the at-risk or clinical range, compared to between 6 and 13% in typically developing samples (Ross & Cuskelly, 2006). Smith and Perry (2005) found that 36% of children and adolescents whose sibling had ASD reported borderline or clinically significant internalising problems. Siblings of children with ASD and an intellectual disability have more emotional problems than children whose siblings have only an intellectual disability or a control sample (Petalas, Hastings, Nash, Lloyd, & Dewey, 2009). Possible reasons for this increased vulnerability include the increasing age of the child with autism, being younger than the child with autism and the possibility of phenotypic similarities. However, when Orsmond, Kuo, and Seltzer (2009) specifically compared adolescents and adults whose sibling had ASD there was no difference in depressive symptoms found between adolescence and adulthood; noticeably, neither age group reported symptoms near to the cut-off point for clinical depression. The differences in these findings may be due to comparing children with adolescents and adults and possibly some ameliorative affective mechanism occurs as the sibling ages.

Similar to individuals with ASD, those diagnosed with Prader-Willi syndrome (PWS) are characterised by maladaptive behavioural tendencies (Dimitropoulos & Schultz, 2007; Veltman et al., 2004), often associated with mild mental retardation (Cassidy & Driscoll, 2009). PWS is caused by a sporadic chromosomal disorder and tends to be diagnosed in infancy (Cassidy & Driscoll, 2009). However, despite many disabilities such as DS, ASD and PWS having a clear diagnosis, in approximately 40% of individuals who have moderate to severe intellectual disability there is no known diagnosis (Knight et al., 1999). This can be particularly stressful because, without a diagnosis, there can be no realistic prognosis. It also limits participation in specific support groups, which can be isolating for the family.

### 1.2. Demographic influences on sibling affective outcome

There is a greater general propensity for females to report higher affective symptoms than males (e.g., McLean, Asnaani, Litz, & Hofmann, 2011); however, research has been inconsistent in reporting gender outcomes for siblings. Hannah and Midlarsky (1999) reported that sisters of children with disabilities scored higher on affective disorders than brothers, possibly because they play a larger part in their sibling's caretaking; however, a meta-analysis found no gender differences in affective disorders (Rossiter & Sharpe, 2001). Conversely, Hastings (2003) reported that brothers of children with ASD had more adjustment difficulties than sisters.

Higher parental educational attainment and levels of household income can help family adjustment and ameliorate stress, due to a greater ability to access and pay for support (Bramlett & Mosher, 2002; Hastings, 2003). However, decrements in mathematical and language achievements were witnessed as early educational experiences for siblings, alongside an increased likelihood to have to repeat a grade (Fletcher, Hair, & Wolfe, 2012). Conversely, Wolfe et al. (2014) found normative levels of education and employment in adult siblings. Lower levels of socio-economic status (SES) tend to be associated with increased adjustment problems in children whose siblings have disabilities but this risk can be ameliorated by lower levels of parental stress (Giallo & Gavidia-Payne, 2006; Macks & Reeve, 2007). Hartley, Barker, Baker, Seltzer, and Greenberg (2012) found in families who have a child with ASD that household income significantly affected maternal marital satisfaction, which general studies show can impact upon the whole family (e.g., Gudmunson, Beutler, Israelsen, McCoy, & Hill, 2007).

### 1.3. Familial influence on sibling affective outcome

In addition, being older than the sibling with disabilities is associated with better adjustment scores (Hastings, 2003). Younger siblings often worry about overtaking their older sibling with disabilities either academically or physically (Turnbull & Turnbull, 1990), they may suffer from more emotional problems (Petalas et al., 2009), and, due to extra care giving responsibilities, may be more likely to have elevated rates of affective disorders (Gold, 1993). Conversely, Macks and Reeve (2007) report siblings' emotional adjustment patterns were more at risk when older than their sibling with ASD.

### 1.4. The present study

Research into the affective condition of adult siblings of individuals with disabilities is relatively limited and conflicting. It is known that adult homo- or heterotypic patterns of affective issues are best predicted by previous disorders, often from childhood or adolescence (Copeland et al., 2013). The majority of studies that have taken place to date have mainly focused on childhood adjustment (e.g., Cuskelly & Gunn, 2006; Petalas et al., 2009); however, with the progression of medical technology, it is now common for individuals with disabilities to have much longer lifespans (Seltzer, Greenberg, Orsmond, & Lounds, 2005). Consequently, there is a requirement to examine the long-term outcomes for these siblings because in many instances adult siblings will assume responsibility for their sibling with disabilities once the parents are no longer able to do so (Davys, Mitchell, & Haigh, 2015b). It is of paramount importance that the siblings are psychologically healthy in order for them to be able to cope with the undertaking of responsibility for their sibling with disabilities, while potentially

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