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Adult siblings of people with intellectual disabilities and/or a diagnosis of autism

An evidence review

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Introduction

This evidence review summarises current research about adult siblings of people with intellectual disabilities (i.e., learning disabilities in the UK context) and/or autism (a developmental disability). Much of the sibling research in the intellectual and developmental disability field assumes that siblings of people with intellectual or developmental disabilities may have different experiences and outcomes compared to their peers without a brother or sister with intellectual or developmental disabilities. This assumption is supported by family systems perspectives, whereby family members are understood to exert a reciprocal, continuous influence on one another. Siblings may be expected to take on caring and support roles for their disabled siblings when their parents are no longer able to. This expectation may become increasingly important due to medical advances leading to the increased life expectancy for people with intellectual disability (Hodapp & Urbano, 2007). Therefore, services and governments may be particularly interested in the wellness of siblings due to their potential roles as future caregivers. Even when siblings are not care providers, there is still the need to consider their wellbeing and, if needed, provide appropriate supports.

Previously Davys et al. (2011) and Heller & Arnold (2010) have investigated the literature on adult siblings who have a brother or sister with an intellectual or developmental disability respectively. The available evidence included in these reviews on siblings' psychological outcomes and relationships includes mixed findings, with some studies showing worse outcomes for siblings of people with intellectual or developmental disabilities, or similar outcomes, and some showing better outcomes (Davys et al., 2011; Heller & Arnold, 2010). The reason for these differences in study findings is likely due to methodological differences or limitations. For example, adult sibling studies tend to use small, convenience-based samples of individuals who have opted to participate, which may influence the results and make them less applicable to all adult siblings. These differences may also be due to the nature of studying complex social phenomena such as the family. Family experiences and psychosocial outcomes are complex and dynamic almost by nature – ambivalence, contradictions and changeability are potentially the hallmark of any familial experience. Sibling research, therefore, inevitably over-simplifies the experiences of siblings of people with intellectual or developmental disabilities.

When selecting the literature to include in this review, we prioritised studies with more robust methods. For example, we have prioritised research on population-based (likely to be more representative) samples and systematic reviews. The quality of research about adult siblings, however, is not as robust as the child sibling literature. For example, we have found no randomised control trial evaluations of adult sibling supports. Given the limited amount of high-quality evidence, we have also included other studies that are relatively robust including: studies with larger sample sizes; studies with more robust sampling methods; and studies with control or comparison groups.

This evidence review seeks to provide a response to the following questions about adult siblings of people with intellectual and developmental disabilities:

1. Are adult siblings at risk of increased psychological or social problems?
2. Are there any positive sibling experiences or outcomes captured in the literature?
3. What are the relationships between individuals with intellectual disability and/or autism and their adult siblings like?
4. What caregiving expectations and experiences do adult siblings face?
5. Are adult siblings' life choices and decisions influenced by having a disabled brother or sister?
6. What support is available for adult siblings and are these effective?
7. What gaps are there in the research evidence?

These questions were developed collaboratively between the authors and staff members of the UK charity Sibs. Three of the authors and the Sibs staff members are also adult siblings of disabled people.

1. Are adult siblings at risk of increased psychological or social problems?

Many studies that explore psychological and social outcomes in adult siblings use small samples of convenience, without a comparison group. This limitation has resulted in mixed and contradictory findings to the question of whether adult siblings of disabled people are at an increased risk of more psychological or social problems in comparison to adult siblings of people without a disability.

We have identified one population-based study, drawing on Swedish cohort study data (Rai et al., 2018). Population-level data benefit from more robust and representative sampling techniques, making them ideal for answering questions about how the outcomes of a specific sub-population compare to the general population. Rai et al. (2018) found that young adult siblings of autistic individuals were more likely to experience depression even when other factors, such as age, sex, and family income, were controlled for in the analyses.

As we identified no further adult-focused population-based studies about siblings, we will now consider other larger-scale studies. A recent survey conducted in collaboration with the UK charity Sibs recruited the largest UK-sample of adult siblings of people with intellectual and developmental disabilities (*N* = 911). Drawing on a subsample of 851 adult siblings of people with intellectual and developmental disabilities, Hayden et al. (2022) found that adult siblings experienced statistically significantly worse outcomes compared to other adults on all four outcomes: mental distress (large effect size), mental wellbeing (medium effect size), quality of life (small effect size), and health (small effect size). When comparing the outcomes for adult siblings who were carers for their brothers and sisters with intellectual and developmental disabilities to adult siblings who did not have a caring role for their brothers and sisters, Hayden et al. (2022) found that adult sibling carers had statistically significantly worse outcomes across the four measures (mental distress, mental wellbeing, quality of life, and health; effect sizes were all small). Further analyses found that adult siblings of people with Down syndrome and siblings of people with degree-level qualifications generally experienced better outcomes. Siblings who were especially at risk of worse outcomes were siblings who were experiencing socio-economic deprivation/poverty.

The Wisconsin Longitudinal Study is a large study that follows the lives of a group of individuals (*N* = 10,317) who graduated in 1957 from high schools in Wisconsin, USA throughout their lives (Herd et al., 2014). Selected siblings were incorporated into the study in 1977, 1994, 2005 and 2011. Drawing on data from the Wisconsin Longitudinal Study, Taylor et al. (2008) considered the wellbeing and life course outcomes of adult siblings of people with mild intellectual disability (*n* = 268) or mental illness (*n* = 83) and compared their findings with data from adults with a brother or sister without a disability (*n* = 791). Taylor et al. found that adult siblings of people with mild intellectual disability had similar scores on the psychological wellbeing or distress measures and the personality measures when compared to a sample of adult siblings of a people without a disability. It was the group of adult siblings who had a brother or sister with a mental illness who were at risk of worse outcomes.

Other large-scale data examining the psychological outcomes of siblings have been collected in the USA. Hodapp et al. (2010) used a national, online survey of male and female adult siblings of disabled people (*N* = 1,160). Hodapp et al's (2010) findings suggest that male siblings may report slightly fewer physical and mental health issues than women, but overall, most siblings reported good physical and mental health. Some siblings may also be comparing their health to the health of their disabled brothers and sisters. Hodapp and Urbano (2007), used a sub-set of the same data to compare the self-perceived health and depressive symptoms of adult siblings of autistic people (*n* = 176) in comparison to adult siblings of individuals with Down syndrome (*n* = 284). They identified slightly poorer outcomes in adult siblings of autistic people compared to adult siblings of people with Down syndrome. However, as there was no comparison made to the general population it is difficult to contextualise the findings.

Overall, research studies suggest that there may be a small sub-population of adult siblings who may be experiencing elevated mental health problems (Rai et al., 2018; Hayden et al., 2022). These findings differed in Taylor et al. (2008), where middle-aged siblings of people with mild intellectual disability had similar mental distress scores compared to other adults. This difference may be due to the age of the sample, as Rai et al., (2018) was about young adult siblings, and Hayden et al., (2022) found that the young adult siblings had worse mental distress scores than the older-in-age siblings in their sample. Overall, siblings reported good physical health (Hayden et al., 2022 – small effect size for health; Hodapp et al., 2010).

2. What positive sibling experiences or outcomes are captured in the literature?

Although we have just discussed that there are a small group of adult siblings who are at risk of experiencing slightly worse outcomes compared to other adults, it is important to highlight that many of the adult siblings in these samples are not experiencing elevated mental health problems, and adult siblings' physical health seems to be similar to other adults' physical health. Hodapp et al. (2010) found that many of the 1,160 adults siblings surveyed, self-identified as having developed various positive personal attributes from having a brother or sister with a disability, including stating that they had/were 'somewhat or much more of the following: empathy (90%), understanding differences (94.4%), opportunities to learn (86.7%), compassion (87.2%), aware of family dynamics (84.7%), responsible person (83.2%), and aware of injustices (87.8%)' (Hodapp et al., 2010: 56). These data suggest that a large proportion of the siblings in this sample perceived that they had developed positive personal attributes due to having a brother or sister with a disability.

Other sibling studies that focus on positive experiences tend to be qualitative (e.g., using interview methods) and small-scale. A larger-scale qualitative study that employed a qualitative survey methodology drew on data from 224 adult siblings of people with intellectual or developmental disabilities (Mauldin & Saxena, 2018). Young adult siblings described the ways in which their brothers and sisters with intellectual or developmental disabilities had enhanced their lives through 'mutual exchange'. These positive factors included boosts in self-esteem when they helped their brother or sister, and through fun and enjoyment with their brother or sister. Siblings also described developing personality characteristics because of their relationship with their brother or sister with intellectual or developmental disabilities, for example, being more 'loving and respectful', 'more compassionate and accepting of others' differences' and being 'kinder' (Mauldin & Saxena, 2018: 2252-3).

3. What are the relationships between individuals with intellectual and developmental disabilities and their adult siblings like?

Sibling relationships are relatively under-studied in the intellectual and developmental disabilities sibling literature in comparison to siblings' outcomes, with no population-based studies and few large-scale studies in this area. Sibling relationships are important because they are potentially the longest relationship a person will have, typically lasting across the lifespan and arguably helping to form the basis of many social behaviours (Mandleco & Webb, 2015). For disabled people, their relationships with their siblings may be even more important, as siblings may offer friendship, care, support, and advocacy (Richardson & Jordan, 2017). A systematic review found that closeness in the sibling relationship was an important predictor of adult siblings being caregivers for their brothers and sisters with intellectual or developmental disabilities (Lee & Burke, 2018). Therefore, those interested in the future care and wellbeing of disabled adults should perhaps be interested in ways of improving and fostering the relationship between siblings and their brothers and sisters with intellectual and/or developmental disabilities.

Hodapp et al (2010) surveyed 1,160 adult siblings and included data on wellbeing (as previously described) and sibling relationships. Most of the siblings (88-95.5%) stated that they "very much or extremely" understood, could trust, respected, felt affection, and were fair towards their disabled brother or sister. Hodapp et al. (2010) also found a small advantage in sibling relationship quality in families where the sibling had at least one other non-disabled sibling. Furthermore, the study found that female siblings spent more time with their disabled brother or sister compared to male siblings. A study of 406 adolescent and adult siblings of autistic people also found that siblings reported that the sibling relationship was more positive when they are the same sex as their autistic brother or sister (Orsmond et al., 2009). Evidently, different family compositions and dynamics are likely to result in different experiences for siblings. Orsmond and Fulford (2018) found in their study of 207 adult siblings from 125 families, that there was greater variation *within* families with multiple sibling pairs than *between* families in terms of the relationship quality between typically developing siblings and their autistic brother or sister. Factors related to the brother or sister with intellectual or developmental disabilities are also salient, for example sibling relationship quality when one sibling has Down syndrome have been found to be more positive than when one sibling is autistic (Orsmond & Seltzer, 2007; Hodapp & Urbano, 2007). A closer sibling relationship has been reported when the autistic brother or sister had fewer behavioural and emotional problems, higher social skills, and fewer behaviours that challenged (Orsmond & Seltzer, 2007; Hodapp & Urbano, 2007).

There have also been a couple of relatively large-scale maternal report studies examining sibling relationships. For instance, a large-scale survey asked mothers (*N* = 838) aged 50 or over who have a child with either a developmental disability or schizophrenia about the relationship between their children (Pruchno et al., 1996). The disabled children included in this study were aged between nine and 60 years (thus, the study included both child and adult siblings). Most mothers in the sample perceived the relationship between their child with a disability and at least one of their typically developing siblings as “excellent” or “good” (84.6%).

Overall adult sibling relationships appear to be fairly positive where one is typically developing and one has an intellectual or developmental disability. Several of the mentioned negative aspects of the sibling relationship are also found amongst siblings where neither is disabled. There are a few factors associated with more positive adult sibling relationships including, being from a larger family (Hodapp et al., 2010), having a brother or sister with fewer challenging behaviours (Orsmond et al., 2009), or having a brother or sister with Down syndrome (Orsmond & Seltzer, 2007; Hodapp & Urbano, 2007).

4. What caregiving expectations and experiences do adult siblings face?

Adult siblings of disabled people are often considered to be potential providers of caregiving once parents are no longer able to. A population-based study by Sonik et al. (2016; *n* of sibling caregivers = 78) described the characteristics of sibling caregivers of people with intellectual or developmental disabilities. The data used were from the Survey of Income and Program Participation and the data were nationally representative of the USA population. The caregivers in this study were living with their brother or sister with intellectual or developmental disabilities as a head of the household – so they do not represent other forms of sibling caregiving and support. Sonik et al. found that moderate material hardship was common amongst sibling caregivers. They also estimated that sibling caregivers were more likely to be Black, older, women, and poorly educated in comparison to other adults. Although women are represented in sibling research and sibling supports, Sonik et al. (2016) highlights that sibling research and support services have significant work to do with regards to representing and including Black siblings and siblings experiencing socio-economic deprivation or who have lower levels of education.

Large-scale adult sibling survey data from the USA have examined what factors may be associated with current caregiving amongst siblings (Lee et al., 2019). Drawing on data from 429 adult siblings of people with intellectual or developmental disabilities, Lee et al. found positive associations between current caregiving and, for example, sibling relationship quality; advocacy; future planning; and their brother and sister with intellectual or developmental disabilities having lower levels of independence. Large-scale data drawing on 757 adult siblings in the USA from Burke et al. (2012) showed that adult siblings who were female, reported closer sibling relationships, reported living closer to their brother or sister with intellectual or developmental disabilities, and were the lone sibling without a disability, were more likely to expect to take on a caregiving role in the future.

In terms of overall sibling caregiver experiences, a systematic review by Lee and Burke (2018) highlighted that the findings about sibling caregiver experiences have a degree of variability. This variation is in part due to differences in the definition of caregiving, but also related to the way studies are designed and positioned. For example, Lee and Burke (2018) only identified two studies that examined ‘caregiving rewards’, such as personal growth (McGraw & Walker, 2007). Close sibling relationships and strong sibling bonds were predictors of both current and future caregiving (Burke et al. 2015). Lee and Burke's (2018) systematic review also summarised caregiving challenges highlighted in the sibling caregiver literature, including the demands of caregiving, conflict between mothers and siblings, ageing, and challenges navigating services.

5. Are adult siblings' life choices and decisions influenced by their disabled brothers and sisters?

Siblings' life decisions, such as marriage, having children, and careers, may be associated with having a brother or sister with an intellectual disability. Hodapp et al., (2010; *N* = 1,160) examined whether having a disabled brother or sister may have influenced people's decision to get married or have children. Findings from the study suggested a delay in marriage amongst siblings of disabled people, with about 40% of siblings never having been married. When these differences were compared to U.S. Census data by sex, the data suggested that the difference was driven by female siblings marrying later in life. However, these female siblings were also slightly less likely than their peers to divorce. Controlling for race, ethnicity, and education levels, female siblings, especially at the youngest age levels, were also less likely than their peers to have children. However, this finding may relate to the later age of marriage. In a study using data from the Wisconsin Longitudinal Study, researchers found differences depending on whether brothers or sisters were diagnosed with mental illness compared to developmental disabilities (Wolfe et al., 2014). Siblings of people with mental illnesses were just as likely to be married as siblings of people without mental illnesses. Siblings of people with developmental disabilities were significantly less likely to be married, and more likely to be divorced, than siblings of people without developmental disabilities. The authors suggested that these differences may reflect family stress as well as potential shared genetic health vulnerabilities.

Two studies investigating whether having a brother or sister with a disability affected siblings' career choices reported no differences between siblings of disabled people and siblings of people without disabilities on career choice or involvement in helping vs. non-helping professions (Burton & Parks, 1994; Konstam et al., 1993). However, the Wisconsin Longitudinal Study was also used to investigate this question using a large sample of siblings of people with mild intellectual disability; finding that female siblings were more likely to have a career in a caring profession than male siblings (Taylor & Shivers, 2011). Amongst siblings of people with intellectual disabilities, women were also more likely to be involved in volunteering activities than were men. Data from the Wisconsin Longitudinal Study have again indicated differences depending on whether brothers or sisters were diagnosed with mental illnesses versus developmental disabilities (Wolfe et al., 2014). Siblings of those with mental illnesses were less likely to be employed than siblings of people without mental illnesses, but siblings of those with developmental disabilities were equally likely to be employed as siblings of people without developmental disabilities.

6. What supports are available for adult siblings, and are these effective?

There are few interventions and supports for adult siblings that have been robustly evaluated (e.g., no randomized control trials), although studies have identified the need for support for siblings of disabled people (Arnold et al., 2012). Suggestions for support for non-disabled adult siblings have included more disability-related information, support in caregiving roles, and improving formal support from services and professionals. Much of the existing support provided for adult siblings is linked to their potential caregiving roles for their brother or sister with a disability. Although caregiving support is a need, there may also be support needs to foster non-disabled siblings' own wellbeing. Support related to caregiving tends to be targeted at parents rather than specifically at adult siblings who may also take on this role. Online supports were described by Hasman and Zafron (2010) for individuals who provide care for adults with intellectual disability which included both siblings and parents. The support explored was provided in majority by caregiver organisations, such as "Care Community" and the "Caregiver Resource Network".

Heller and Schindler (2009) considered a range of support provided to families of adults with intellectual disability and identified that there are few evaluative data on any interventions that target adult siblings. Support services identified included conferences, support groups (both online and in-person), and the provision of information across a range of countries (Heller and Schindler, 2009). Meltzer (2021) recently examined national-level sibling support services for both children and adults in the USA (*n* = 5), UK (*n* = 2), Canada (*n* = 2), New Zealand (*n* = 1), and Australia (*n* = 2), via qualitative interviews with staff in support services. The support that these organisations offered focused on: Siblings' individual needs, such as a focus on recognition and validation, social-emotional wellbeing, and developing siblings' knowledge and skills; Relationships

– at the sibling pair level, but also with the wider family; Connection and community building amongst siblings; and Advocating for siblings.

Qualitative studies have further highlighted that some siblings feel excluded from decision making by parents and also feel invisible to care organisations. This exclusion results in siblings feeling that they lack support, information, and advice (Tozer et al., 2013). Most interventions that are supported or evaluated by research data are targeted at the family more broadly (particularly at parents). More research in this area is needed; in particular the development of interventions for adult siblings based on research and the use of randomised control trials to measure the effectiveness of these and already existing interventions.

7. What gaps are there in the research evidence?

As discussed, there have been various studies examining adult siblings' experiences and outcomes. In terms of future research priorities, the following gaps should be examined:

1. Where available, population level data about adult siblings should be examined. These types of studies benefit from being large-scale, having normative samples to compare the findings to, and being more representative of the population of adults in a particular country. Being more representative of a population is important since these data may lead to less biased findings than most of the current adult sibling literature.
2. We acknowledge, however, that population level data about adult siblings is uncommon. Furthermore, these data are limited in the sense that the variables and measures are selected by the original study team – without a focus on intellectual or developmental disabilities. Therefore, researchers should seek to collaborate with practitioners and other researchers to recruit sibling samples at a larger scale. Recruiting normative samples can be onerous on participants and is not always necessary. Where possible, researchers should select measures and questions that are used in national population studies or where population norms are published, so that adult sibling results can be compared to normative samples to contextualise the findings.
3. We need to understand siblings' experiences over time and through key transitions, such as when young people transition to adulthood, when adult siblings become parents, or when adult siblings take on primary care roles for their brothers and

sisters with intellectual or developmental disabilities. Large-scale longitudinal data would be required to examine these factors. Longitudinal data also help us to further understand associations between different factors – allowing us to more accurately predict which siblings are likely to need what supports, or which siblings are likely to take on care roles in the future.

4. Sibling studies using qualitative methods that advance our understanding about siblings' experiences and further contextualise statistical findings have value, particularly where they illuminate the experiences of specific sibling groups researchers know less about, such as those from lower socio-economic status backgrounds, siblings from Black, Asian and Minority Ethnic communities or those siblings who take on additional primary caring responsibilities for their disabled brothers or sisters. Research co-produced with siblings, as advanced by Kramer and Meltzer (2016), have the potential to further improve our understanding of sibling experiences – and co-production should be extended to quantitative as well as qualitative research.
5. Research about adult sibling relationships tends to exclude the perspectives of disabled siblings (Meltzer & Kramer, 2016; Richardson & Jordan, 2017). This exclusion marginalises disabled people and limits sibling research methodologically. Understanding sibling relationships is important for siblings' social wellbeing and may be a key factor in enhancing sibling care for their disabled brothers and sisters.
6. Further, although there are some supports in place for adult siblings, these have not been evaluated robustly using, for example, randomised control trials, so this is also a research need.
7. There is a notable and controversial emphasis currently in medical research related to intellectual and developmental disabilities about understanding the genetic carrier status of family members, including siblings. How this societal narrative affects adult siblings, both physically and psychologically, needs to be further explored. For example, are siblings of people with intellectual or developmental disabilities concerned about their own carrier status, and what are the implications of being made aware of carrier status?

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