**Research in Developmental Disabilities**

**Special Issue: Sibling Relationships in Developmental Disabilities**

**Editors: Katie Cebula & Hanna Kovshoff**

The journal [Research in Developmental Disabilities](https://www.journals.elsevier.com/research-in-developmental-disabilities) have recently published a special issue on sibling relationships in developmental disabilities. The issue, edited by [Dr Katie Cebula](https://www.ed.ac.uk/profile/katie-cebula) (University of Edinburgh) and [Dr Hanna Kovshoff](https://www.southampton.ac.uk/psychology/about/staff/hk.page) (University of Southampton) includes research studies exploring a range of issues concerning the lives of children and adults with developmental disabilities and their siblings – from playing together, to feelings of school belonging, to relationship quality. Summaries of the articles are included below. You can access the special issue here and can contact the editors or authors for further details:

<https://www.sciencedirect.com/journal/research-in-developmental-disabilities/special-issue/106X577CZ7Z>

**Article Title: Perspectives about adult sibling relationships: A dyadic analysis of siblings with and without intellectual and developmental disabilities**

**Article authors: Zachary Rossetti, Chung eun Lee, Meghan Burke, Sarah Hall**

Adult sibling relationships tend to be long lasting, and are characterized by reciprocity and changes over the life course. Adult siblings of individuals with intellectual and developmental disabilities (IDD) may assume unique roles such as advocate, legal representative, and especially caregiver, whether directly or indirectly. Most adult siblings of individuals with IDD report positive relationships characterized by warmth and support. However, existing research often only examines the perspective of the nondisabled sibling; it is unclear whether siblings with IDD report close sibling relationships. Thus, the aim of this study was to understand adult sibling relationships from the perspectives of both siblings with and without IDD.

This study’s research question was: How do adult siblings with and without IDD describe the context and quality of their sibling relationships? Eight sibling pairs participated in three interviews on the same day: 1) interview with the nondisabled sibling, 2) interview with the sibling with IDD, and 3) interview with both siblings. Overall, siblings with and without IDD shared similar information about the context and quality of their relationships, and their perceptions of their sibling relationship. Most relationships were characterized by close physical proximity, daily or weekly contact, shared social activities (e.g., talking together, going to restaurants, seeing movies and shopping together), and emotional closeness. The findings suggest that contextual factors, such as physical proximity and life stage, are critical to perceptions of sibling relationships. Family support services should include siblings with and without IDD to maintain or strengthen sibling relationships over time.

**Article Title: Empathy and perceptions of their brother or sister among adolescent siblings of individuals with and without autism spectrum disorder**

**Article author: Carolyn M. Shivers**

One of the potential positive outcomes for siblings of individuals with disabilities, including autism spectrum disorder (ASD) is that these siblings are more understanding of differences and may be more empathetic. Our study used data from an online survey to determine if siblings of individuals with autism (ASD-Sibs) had different levels of empathy than siblings of individuals without disabilities (TD-Sibs). A total of 26 ASD-Sibs and 48 TD-Sibs completed the survey. All participants were between the ages of 12 and 18, and each only had one brother or sister.

We found that ASD-Sibs, on average, reported higher levels of perspective taking than TD-Sibs, a skill in which people try to understand someone else’s side of the story. This skill was related to positive feelings toward their brother or sister. That is, siblings who were better at perspective taking reported more happy and loving feelings about their brother or sister. No other types of empathy were related to feelings in the sibling relationship. Also, when asked what they would wish for if they had three magic wishes, ASD-Sibs were more likely than TD-Sibs to make wishes for their brother or sister.

These findings show the importance of empathy in the sibling relationship for siblings of individuals with disabilities. It is possible that teaching siblings perspective-taking skills can help foster healthy sibling relationships.

**Article Title: Academic self-concept and sense of school belonging of adolescent siblings of autistic children**

**Article authors: Alexandra Gregory, Richard P. Hastings, Hanna Kovshoff**

Children and young people spend a large proportion of their time in school, however there have been relatively few studies of siblings of children with disabilities that have been conducted in the school setting. We measured school-related outcomes for siblings of autistic children including sense of school belonging (e.g. feeling accepted, included, respected, and supported at school) and academic self-concept (e.g. the identity, perceptions, and beliefs of learners within school). Sibling wellbeing/behavioural adjustment was also explored.

In total, 65 siblings of autistic children and 57 siblings of children without autism, aged 11 to 16 years and attending mainstream secondary schools, completed online questionnaires. Relative to siblings of non-autistic children, siblings of autistic children self-reported lower feelings of belonging at school and poorer academic self-concept, in addition to lower self-, parent- and teacher-reported wellbeing. We also found that the more severe the young person’s emotional and behavioural difficulties were, the lower their school belonging and academic self-concept.

Despite these findings, there were larger differences in the school outcomes of the group of children with an autistic sibling compared to the group of children without an autistic sibling. Accordingly, researchers and practitioners should avoid automatically presuming that siblings of autistic children will experience difficulties at school, but there may be a group of children that are at greater risk. Professionals should take a systemic view, as well as a person-centred approach to understanding the varying needs of, and providing support to, siblings of autistic children.

**Article Title: Siblings of children with Williams syndrome: Correlates of psychosocial adjustment and sibling relationship quality**

**Article authors: Katie Cebula, Amanda Gillooly, Laura K. Coulthard, Deborah M. Riby, Richard P. Hastings**

Children with Williams syndrome can also have intellectual disabilities. They are often very sociable, but may also have anxiety and health difficulties. How does this affect their siblings? To find out, we gave 41 parents/caregivers some questionnaires about the behaviour, emotional difficulties and relationship quality of their child with Williams syndrome and the ‘typically developing’ sibling (both 4 – 18 years old). In 31 families the siblings themselves also took part.

We found that siblings of children with Williams syndrome are, overall, similar to the general child population, in terms of behaviour problems and emotional adjustment (including anxiety). We also found that siblings sometimes reported having more difficulties than parents thought they had. However, siblings also said that they had high levels of positive support, particularly from friends and family. There were also differences between families. Behaviour problems and emotional difficulties were more common in siblings when there was conflict in the sibling relationship.

The findings show that having a child with Williams syndrome does not necessarily cause major difficulties for their siblings. However, it also shows that it is important for support services to listen to the siblings themselves about their experiences. Finally, it shows that a ‘one size fits all’ approach to family support is not useful for families with a child with Williams syndrome.

**Article Title: A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection**

**Article authors: Alexandra T. Leedham, Andrew R. Thompson, Megan Freeth**

Diagnosis of Autism Spectrum Condition (ASC) can have an impact on an entire family, including siblings. Sometimes the experiences of siblings can go unnoticed. However, some recent research has asked siblings about their experiences. This review aimed to look at the recent research investigating the experiences of brothers and sisters (both children and adults) of autistic people. This included using searching for relevant research using a structured search process. Eighteen studies were found to meet the guidelines for the review. An analysis method called Thematic Synthesis was used to analyse and combine the research articles to look for themes.

Results showed that there were four main themes. Some siblings had extra responsibilities in the home and for caring, more than may be expected, especially of a child. It was particularly difficult when behaviours that could be challenging affected siblings both physically and emotionally. Many people talked about connecting with their autistic siblings and learning about their unique skills and needs and feeling protective of them.

There was a lot of love and compassion described by siblings. However, several siblings also had difficulties with their mental health because things could be difficult for them. When brothers and sisters had some control over what they learnt about ASC and what they had to do in the home they found it easier. They also coped best when they got to spend dedicated time with their parents and with other siblings with similar experiences.

**Article Title: Using Administrative Data to Examine Variables Affecting the Mental Health of Siblings of Children who have a Developmental Disability**

**Article authors: Sandra Marquis, Kimberlyn McGrail, and Michael Hayes**

This study used mental health data from the province of British Columbia, Canada. A group of over 45,000 brothers and sisters of children who have a developmental disability were studied.

The study found that sisters of children who have a developmental disability had higher odds of depression compared to brothers of children who have a developmental disability. However, there was no difference between sisters and brothers in other mental health problems.

Sisters and brothers of children with Autism Spectrum Disorder (ASD), Fetal Alcohol Syndrome (FAS) and other rarer developmental disabilities had higher odds of depression or other mental health problems compared to sisters and brothers of children who had Down syndrome. Siblings of children with FAS had the highest odds of both depression and other mental health problems.

Sisters and brothers from very low income families had higher odds of depression and other mental health problems compared to brothers and sisters from high income families.

The results from this study are important for planning programs and services for siblings of children who have a developmental disability. Particular attention should be paid to low income families and to siblings of children with FAS.

**Article Title: The Quality of the Relationship between Typically Developing Children and their Siblings with and without Intellectual Disability: Insights from Children's Drawings**

**Article authors: Anat Zaidman-Zait, Miri Yechezkiely, Dafna Regev**

Having a child with a disability in a family places unique demands on all family members, including siblings. Although challenges exist, they are often accompanied by both short- and long-term positive contributions. In the current study we examined the relationships of typically developing (TD) children and their siblings with and without intellectual disabilities (ID) and the associations between sibling relationships and children’s social-emotional adjustment. Mothers and their children aged 8-11, with TD siblings and with siblings with ID participated in the study. Following the assumptions that artistic creation allows internal content to be expressed visually and the added value of children’s self-reports, we asked children to draw themselves and their siblings and to complete a questionnaire regarding their sibling relationship. Drawings were assessed using several set criteria (e.g., the physical distance between the figures). In addition, mothers completed questionnaires about their children’s sibling relationship and on their TD children’s social-emotional adjustment. Findings revealed that children with siblings with ID showed increased positive aspects of sibling relationship (e.g., empathy, closeness) and decreased negative aspects (e.g., conflict, rivalry) in comparison to children with TD siblings. Also, increased in positive qualities of sibling relationship were associated with enhanced children's social-emotional adjustment. The current study suggests that children's drawings may be a useful way to deepen our understanding of unique aspects of sibling relationships that are not revealed in verbal reports. In addition, having a family member with a disability makes the rest of typically developing children more attentive to the needs of others.

**Article Title: In their own words, in their own photos: Adolescent females’ siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister**

**Article authors: Dr Georgia Pavlopoulou, Dr Dagmara Dimitriou**

The aim of this paper is to report a series of sisters’ led collaborative efforts with academic researchers and representatives of the sisters’ local community including educational, clinical and disability sectors.

11 sisters growing up with an autistic sibling with additional learning disability, as experts of their own experiences, worked together by i) collecting photo data by themselves, ii) determining the content of the data and iii) categorising, analysing and interpreting the data that consisted of their observations, experiences and reflection.

Sister-driven content analysis identified six major categories: 1. Sleep, bath, lunch and homework routines 2. Awareness is not enough-Acceptance is the key 3. Love is in the air 4. Sisters want to have fun 5. Sensory Journey- Finding out what works together 6. Today my mum-tomorrow who? The findings highlighted the feelings, needs and thoughts that the sisters may experience at home but also as students and young females in the community.

Then, they co-produced a photo exhibition, provocative discussions, workshops, and video screenings. Panel discussions raised questions such as “What is it like to grow up with an autistic brother or sister?”, “Can we democratise family research and family intervention in families caring for a disabled person?”, and ‘What do siblings wish you know?'. These community-based activities got delegates to think about what does it mean to grow up with an autistic sibling and how we can democratise our services by codesigning and co-delivering support schemes embedded within the siblings’ local communities.