

FASD and Siblings: A Review of Current Knowledge

Madeline Mantler, MSc (in progress)^{a,b}; Maggie Cumming, BSc (in progress)^{a,c}; Celisse Bibr, PhD^a, Hannah Denberg, MSc^{a,d}

^aCanada FASD Research Network, ^bBrock University, ^cUniversity of Guelph, ^dUniversity of Galway

KEY MESSAGES

Siblings of individuals with FASD are underrepresented in FASD research, despite having unique experiences and perspectives that are important to understand. Relationships between siblings are extremely meaningful and offer developmental opportunities; at the same time, siblings of individuals with FASD may experience risk of parentification, sibling separation, similar adverse childhood experiences, and lower parental attention. These experiences must be recognized in support systems and policies in order to meet their specific needs, benefitting siblings, individuals with FASD, and those around them.

Issue:

Children with FASD experience unique challenges that require specialized support from caregivers and families. Although much research has focused on living experiences of individuals with FASD and their caregivers, there has been little research focused on the experiences of their siblings. This gap is important to address, given the distinct strengths, challenges, and perspectives of siblings of individuals with FASD.

Several authors of this issue paper are siblings of people with FASD. Blending both scientific evidence and living experience wisdom, this paper describes the experiences of siblings of people with FASD, emphasizing recommendations for siblings and those with in-body and in-home living experience of FASD.

Background:

Knowing the full impact of FASD on individuals, siblings, and families is crucial in designing comprehensive family supports. Currently, most FASD research focuses exclusively on the diagnosed individuals and their caregivers. The exclusion of sibling experiences from research can result in policy and practice overlooking the developmental impacts of growing up with a sibling with FASD. Exploring the living experiences of siblings of individuals of FASD can help

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build awareness of the unique difficulties they face, as well as their successes and strengths, which can help guide supports for siblings and families in the future. This paper outlines the current state of research on siblings of individuals with FASD. Because of the limited amount of literature focused specifically on FASD, this paper draws upon broader research on neurodevelopmental disorder experiences from siblings.

Unique Challenges and Positive Impacts of Sibling Relationships

Sibling relationships are long lasting and play a significant role in the lives of many people: this is also true for siblings of individuals with FASD. However, these relationships may also involve unique challenges. Researchers working with people with neurodevelopmental disorders (NDDs) have identified experiences such as conflict, aggression, emotional strain, and parentification among siblings, particularly when siblings take on caregiving roles within the family context (Bastiaansen et al., 2022). Similarly, in the context of FASD, siblings have described navigating complex emotional and behavioural challenges within their relationships (Bélanger, 2017). These responsibilities may shape family dynamics and impact sibling well-being over time (Bastiaansen et al., 2022; Bélanger, 2017).

Despite these challenges, sibling interactions contribute to important developmental and relational outcomes. Researchers suggest that navigating sibling dynamics can help children develop emotional understanding, conflict resolution, and emotional regulation skills extending beyond the home environment (Kramer 2014; Sang & Nelson, 2017). For example, siblings who learn to manage disagreements at home may be better equipped to apply these skills in broader social contexts, such as at school (Kramer 2014; Sang & Nelson, 2017).

In families of children with NDDs, sibling involvement in developmental interventions has been associated with positive outcomes for both children, including opportunities to develop empathy, leadership, and communication skills (Beffel et al., 2022). Similarly, siblings of people with FASD value these relationships, reporting their familial experiences contributed to personal growth, and strengthened their empathy and interpersonal skills (Bélanger, 2017).

Aggression and Violence in the Home

In some cases, individuals with FASD may engage in aggressive behaviour as a result of difficulties with executive functioning and increased impulsivity (Joseph et al., 2022). Additionally, early environmental adversities such as verbal/physical abuse, neglect, and substance use in the home are common for children with FASD, and may increase the risk of aggressive behaviour (Champagne et al., 2023; Joseph et al., 2022). Overall, these elements can create volatile home environments. In some extreme cases, this can present as Child and Adolescent-to-Parent Violence and Abuse (CAPVA). Positive parenting tactics have been shown to be successful at reducing and de-escalating aggressive behaviour to avoid CAPVA (Gibbs, 2024). However, witnessing CAPVA still has detrimental effects on siblings in the family home such as increased levels of fear/distress, depression, and anxiety (Baker & Bonnicks, 2021). CAPVA can result in the aggressive sibling being removed from the home due to concerns of safety, which can be traumatizing for siblings and can bring up complex emotions (Baker & Bonnicks, 2021). Given the elevated rates of aggression in the home for some people with FASD (Champagne et al., 2023), having parental support and education for managing and de-

escalating aggressive behaviour is vital—for the individual with FASD, their sibling(s), and the whole family system. Maintaining safety in the home while supporting sibling relationships is an important consideration for many families.

Sibling-Focused Parentification

Parentification occurs when a child takes on parental duties for their sibling with a disability. Often, siblings of someone with a disability such as autism, Down Syndrome, or FASD have greater caregiving responsibilities than is usually expected for siblings (Tomeny et al., 2017). Family structure may further influence the extent of these responsibilities. For example, the likelihood of taking on caregiving doubles for lone siblings compared to families with multiple siblings who can share caregiving responsibilities (Burke et al., 2012). As a result, siblings may feel like they had to grow up too fast or like they hold responsibilities that are inappropriate for their age and role as a sibling (Levante et al., 2023). Sibling experiences of parentification are mixed, with some expressing pride in their helping role, while others report feelings of frustration (Hayden et al., 2019). Being parentified can cause siblings to feel high levels of anxiety and lower levels of wellbeing, as well as strain sibling relationships (Levante et al., 2023). Sibling-focused parentification often stems from parents needing additional support due to illness, crisis, physical or mental health needs, or parental loss (Dariotis et al., 2023). The unintentional abdication of parental responsibilities onto a child could also occur during periods of family stress, such as unemployment, eviction, or circumstances stemming from parental disability (Dariotis et al., 2023). This issue may be further compounded given that caregivers of children with FASD report they often experience stress over having a lack of resources to support their family (Kautz et al., 2021). Although parentification can have detrimental impacts, it is often an unintended result of overextension of caregivers struggling to meet family needs as a result of gaps in supports (Dariotis et al., 2023).

Siblings in Caregiving and Advocacy Roles

Caregiving responsibility often extends into adulthood for siblings of someone with a disability. In the autism literature, individuals report feeling burdened knowing they will have to take care of their sibling with autism when their parents can no longer do so (Levante et al., 2023). Similarly, adult siblings of individuals with developmental disorders, including FASD, report feeling worried for their siblings' future, including concerns about homelessness, substance use difficulties, or involvement with the law (Hughes, 2017). As a result, many neurotypical siblings describe feeling unprepared to take on a caregiving role. Importantly, it is the lack of support and resources that results in siblings feeling worried, not that they view their siblings as a burden (Hughes, 2017).

Many siblings of individuals with FASD engage passionately in advocacy. Sometimes they focus on case advocacy working to ensure their sibling secures services they need, whereas other times their work extends to cause advocacy, championing large systemic changes that benefit all individuals with NDDs (Burke et al., 2015). Additionally, siblings often find identity and purpose in advocacy, such as rewarding careers in disability-specific helping professions, more often than individuals who do not have a sibling with a disability (Beffel, et al., 2023).

Gender and Sibling Caregiving

Within many Western and North American contexts, gender norms continue to shape family caregiving roles, with girls and women more frequently expected to assume caregiving roles within the family (Jacobson et al., 2025; Sharma et al., 2016; Statistics Canada, 2023). In Canada, 52% of girls and women over the age of 15 years provide some form of care to children and care-dependent adults, compared to 42% of men who provide care (Statistics Canada, 2022). Female siblings of children with learning disabilities are also known to take on more caregiving roles throughout their childhood than their male siblings (Dyson, 2010). Similarly, among siblings of children with FASD, female siblings often get involved in FASD advocacy along with their mothers, but similar advocacy is not seen in male siblings (Bélanger, 2017). It is likely that children witness emotional and physical caretaking responsibilities of their guardians, which are often heavily gendered, then repeat their learned behaviours (Dyson, 2010). The gender caregiving gap for siblings starts early and is rooted in gendered expectations formed in childhood.

In long-term caregiving roles, female siblings are often expected to take on a greater share of responsibilities than their male siblings (Burke et al., 2012). However, caregiving roles are shaped by a range of social, cultural, and familial factors rather than being inherently tied to gender. Positive caregiving practices within the family may encourage siblings to take on supportive roles for their sibling with an intellectual disability (Burke et al., 2012). Family members without disabilities who share a physically and emotionally close relationship with their sibling may be more inclined to take on supportive roles within the family.

Lower Parental Attention

Caregiving for someone with FASD can come with significant challenges, given the complex nature of the disability. Caregivers often report feeling under supported, isolated, with intense levels of stress (Flannigan et al., 2024), which can result in reduced attention and emotional availability for other children in the household (Philips et al., 2022). Children who have siblings with FASD are reported to display anger and frustration when they feel parental attention is unequally divided (Phillips et al., 2022). In broader disability research, receiving lower parental attention as a result of having a sibling with a disability and high needs can be described as the 'glass child phenomenon', where, because their sibling requires high levels of attention, other children may feel overlooked and invisible (Hanvey et al., 2022). Perhaps related to these lower levels of attention, siblings of children with a developmental disorder experience increased odds of depression and other mental health needs (Marquis, et al., 2019). Given these impacts on the whole family system, supports should include parental guidance on how to engage and care for neurotypical siblings to avoid the impacts of low parental attention. Research in this area is newly emerging and needs to be investigated further.

Family Financial Strain

For siblings of people with disabilities, family financial strain has been associated with poorer health outcomes, increased behavioural difficulties, and lower academic performance compared to peers not experiencing financial strain (Samuel et al., 2025). The financial cost of raising a child with a disability for families can be great, however the full estimate of the cost

for raising a child with FASD is difficult to quantify. The financial impacts on families can stem from direct care costs like out-of-pocket therapies, indirect costs like loss of income due to requiring more caregiving time, or intangible costs such as the impact on mental health (Tait et al., 2025). Additional research is needed to understand the sibling and family financial impact within the specific context of FASD.

Sibling Separation

Historically in Canada many children with intellectual disabilities were institutionalized in the hopes of providing them with adequate care (Brown & Radford, 2015). However, institutionalization was a traumatic system for both the individuals who were sent to live there, and the siblings left at home (Burghardt, 2023). Siblings of institutional survivors report that being separated from their sibling has had profound effects on their lives and leaves a haunting trauma (Burghardt, 2023), feeling their sibling's absence everyday (Freeman, 2019). Today, Canada has shifted away from institutionalization for those with intellectual disabilities, but siblings more commonly become separated when children are placed in the child welfare system (Burghardt, 2023; Sheppard, 2017). Although many Canadian jurisdictions prioritize maintaining sibling relationships and co-placement when entering care, separation may still occur in practice due to system-level constraints (Gardner, 2022). Globally, research has shown that children with FASD are disproportionately represented in child welfare and foster care systems (Popova et al., 2019), with one recent scoping review estimating that approximately 31% of children with FASD experience foster care placement (Engesether et al., 2024).

Disability plays a role in determining if it possible to keep siblings together in a foster care placement (Font & Kim, 2022). Children entering the child welfare system with a disability such as FASD often require additional support and resources, which can further complicate efforts to identify placements able to accommodate sibling groups while meeting each child's needs (Font & Kim, 2022; Fuentes-Peláez et al., 2022). is difficult to determine the impact of sibling separation in foster care as placing siblings together and apart can come with its own positive and negative consequences (DiGiovanni & Font, 2021). For example, while experiences of parentification or sibling abuse may cause siblings to benefit in some ways from separated placements, keeping siblings together can also lead to stronger relationships and/or preventing additional loss and grief (DiGiovanni & Font, 2021).

Conclusion:

Siblings of individuals with FASD are an untapped strength within the family system. Siblings have a unique role within the family and face both challenges and opportunities for growth. However, even with the clear importance of siblings, the perspectives of these individuals remain largely unexplored in FASD research. Sometimes siblings may experience adversities such as verbal or physical aggression from their sibling, inappropriate caregiving burden at a young age, and reduced parental attention and resources. However, siblings of individuals with FASD can also gain the opportunity to be a supportive role model for their sibling and grow their own empathy, resilience, and interpersonal skills. For children with FASD, siblings are an important driver in positive socialization and often play an advocacy role, supporting individuals with FASD throughout their life.

Recommendations:

Policy and support recommendations:

- Greater understanding of FASD and sibling experiences is required among policymakers, service providers, educators, and child welfare professionals to support informed decision-making and family-centred service delivery.
- Family-centred FASD supports that recognize siblings as important members of the family system should be developed and expanded, providing opportunities for education, emotional support, and involvement in care planning. Professionals working in healthcare, education, child welfare, and community services should routinely consider the wellbeing and support needs of siblings when assessing and supporting individuals with FASD.
- Services and programs tailored to siblings of individuals with FASD should be developed, evaluated, and promoted to address unique support needs. These initiatives could include peer support opportunities, educational resources, and counselling supports, designed to enhance understanding of FASD, promote sibling wellbeing, and strengthen sibling and family relationships. Access to respite, counselling, and community-based supports for families should also be increased, while promoting awareness of the caregiving responsibilities that may be placed on siblings. Family-centred services should help support sibling wellbeing and educate parents on the potential risks of sibling parentification.
- Decisions surrounding sibling separation require careful consideration of the potential benefits and harms for each family. Policies and practices should recognize that sibling relationships can serve as important sources of support and stability, while also acknowledging that safety, wellbeing, and individual needs may change over time and require ongoing assessment.

Recommendations for future research:

- Researchers should place greater emphasis on examining the lived and living experiences of siblings of individuals with FASD to better understand their strengths, challenges, support needs, and family roles. Greater understanding of sibling perspectives can help guide the development of more responsive and informed supports.
- Additional research is needed to examine and short- and long-term impacts of having a sibling with FASD on wellbeing, family relationships, educational outcomes, caregiving responsibilities, and quality of life across the lifespan.
- FASD researchers should adopt a greater strengths-based focus by examining resilience, coping strategies, positive sibling relationships, and factors that contribute to wellbeing among siblings and families of individuals with FASD, helping to balance the historical emphasis on challenges and adverse outcomes.

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