

## **Our Mission**

The MSSN is committed to supporting siblings of people with disabilities by:

- Creating welcoming communities for siblings across the lifespan;
- Improving the range and availability of sibling support services; and
- Providing education about sibling-related issues.

Adult siblings, policy makers, researchers, and other leaders in the community have examined the impact of disability on siblings and families. By speaking publicly about topics of relevance for siblings – such as accessing services and learning about guardianship – more siblings are now likely to receive the support needed to take on various roles and responsibilities over the course of their lifespan.

### ***Creating Welcoming Communities: Why It's Important***

- Siblings note that they have added responsibilities and family priorities as compared to families raising typically developing children.<sup>1</sup>
- Siblings report that attending workshops or formal gatherings to share information and express feelings with other siblings can be affirming and beneficial.<sup>2</sup>

### ***Improving the Range and Availability of Sibling Support Services: Why It's Important***

- Increased sibling responsibilities, such as transitioning into the role of primary caregiver or legal representative, is a clear pattern as parents age.<sup>3</sup>
  - Responsibilities may include custodial activities such as feeding or dressing, emotional support, and providing advice and information.<sup>4</sup>

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<sup>1</sup> Graff, C., Mandelco, B., Dyches, T. T., Coverston, C. R., Roper, S. O., & Freeborn, D. (2012). Perspectives of adolescent siblings of children with Down syndrome who have multiple health problems. *Journal of Family Nursing*, 18, 175-199. <https://doi.org/10.1177/1074840712439797>;

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, 43, 339-350.

<sup>2</sup> Skotko, B. G., Levine, S. P., Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics Part A*, 155, 2348–2359.

<sup>3</sup> Hall, S. A., & Rossetti, Z. (2017). The roles of adult siblings in the lives of people with severe to profound intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities* 31, 423-434. doi: 10.1111/jar.12421

<sup>4</sup> Graff, C., et al., (2012). Op. cit.; Hannah, M., & Midlarsky, E. (2005). Helping siblings of children with mental retardation. *American Journal of Mental Retardation*, 110(2), 87-99.

- Siblings' responsibilities may not be uniform but may exist across a broad range specific to their brother or sister's functional abilities and support needs.<sup>3</sup>
- Knowledge about the physical, psychological, and behavioral changes that come with age is crucial to prepare siblings for their new role as carers of older adults, especially those with intellectual or developmental disabilities (IDD).<sup>5</sup>
- Even when siblings take on advocacy roles, they report a need to increase the self-determination capacities of their brother or sister with disabilities.<sup>6</sup>

### ***Providing Education About Sibling-Related Issues: Why It's Important***

- Perspectives of adult siblings will most likely change over the lifespan depending on family dynamics and life situations.<sup>3</sup>
- Families are not always in agreement about decisions. Future research needs to focus on ways to promote the positive resolution of disagreements among family members, especially in regard to major life decisions affecting the member with the disability.<sup>6</sup>

### ***What the MSSN does to address our mission goals:***

- **Educational Presentations:**
  - We currently offer two educational presentations to organizations, families, and the broader community:
    - **No Sibling Left Behind:** Geared to parents of young siblings and professionals as well. We address the overall sibling experience (what it's like for siblings to grow up with a brother/sister with a disability), strategies to support siblings, current trends in sibling research, and the growing sibling movement.
    - **Financial Planning is a Family Affair:** Geared to adult siblings, although other family members and professionals can benefit as well. We address how to effectively advocate for an adult brother/sister with disabilities, understanding the legal and financial issues associated with caregiving, and working together as a family to make a plan for future care.
  - **Sibling Panels:** MSSN Board members and members routinely participate in sibling panels to share their experiences and expertise in workshops and other awareness and professional development events for organizations and service providers.

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<sup>5</sup> Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 302-312. <https://doi.org/10.1111/jppi.12094>

<sup>6</sup> Burke, M. M., Lee, C. E., Hall, S., & Rossetti, Z. (2019). Understanding decision making among individuals with intellectual and developmental disabilities (IDD) and their siblings. *Intellectual and Developmental Disabilities*, 57, 26-41. doi: 10.1352/1934-9556-57.1.26



- **Adult Sibling Meet & Greets:** We host meet-ups throughout the year for adult siblings to gather together, share resources and stories, and provide camaraderie and support to each other.
- **Research:** Our Board Members are on the cutting edge of studying the issues that siblings of people with disabilities face across the lifespan. The MSSN supports siblings by studying this population and driving the sibling movement, and the broader disability rights movement, forward.