

# The Massachusetts Sibling Support Network

## 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.

## WHY IT'S IMPORTANT TO...

### *Create Welcoming Communities*

- 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>

### *Improve the Range & Availability of Sibling Support Services*

- 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>
  - 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 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>



### *Provide Education About Sibling-Related Issues*

- Perspectives of adult siblings are likely to 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 WE DO

### *Educational Presentations*

- **No Sibling Left Behind:** Geared to parents of young siblings as well as professionals. We discuss what it's like for siblings to grow up with a brother or sister who has 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, useful for all family members and professionals. We address effective advocacy for an adult brother or sister with disabilities, understanding legal and financial issues associated with caregiving, and working together as a family to make a plan for future care.

### **Sibling Panels**

MSSN 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.

### **Adult Sibling Meet & Greets**

We host periodic meet-ups for adult siblings to gather, 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.

Contact the MSSN to  
schedule presentations  
or trainings  
for your organization

[www.masiblingsupport.org](http://www.masiblingsupport.org)

**For more information consult these sources  
or contact the MSSN at  
[www.masiblingsupport.org](http://www.masiblingsupport.org)**

<sup>1</sup> Graff, C., Mandleco, 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.

<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

# THE MASSACHUSETTS SIBLING SUPPORT NETWORK



Supporting siblings  
of persons with disabilities  
across the Commonwealth  
& across the lifespan

[www.masiblingsupport.org](http://www.masiblingsupport.org)