

## Adult Siblings of Individuals with Intellectual/Developmental Disabilities

To date, there has been some research about adults (ages 18 and older) who have siblings with intellectual and developmental disabilities (I/DD). Many factors affect siblings including: characteristics of the brother/sister with a disability, characteristics of the sibling, and family dynamics. The purpose of this document is to share highlights of research about this population.

### Bottom line

Adult siblings tend to have positive and close relationships with their brothers and sisters. They are more likely to assume roles as caregivers; however, they are not usually included in future planning. Brothers and sisters with disabilities may influence the life decisions of their siblings.

**Positive and Negative Experiences:** Most siblings have close relationships with their brothers/sisters with disabilities. Siblings report deriving positive benefits from their relationships with their brothers/sisters. Most siblings seem to do well in life and report good physical health. The negative effects of being a sibling seem to be relatively minor.

**Choicemaking:** Many siblings report that their brothers/sisters with disabilities influence their life decisions. Female siblings of individuals with (versus without) disabilities may be more likely to marry and have kids later in life. Also, female siblings of individuals with (versus without) disabilities may be less likely to divorce. Some siblings report that their brothers/sisters influence their career decisions. Siblings may be more likely to pursue helping professions due to their brothers/sisters.


**Sibling Relationship:** Sibling relationships tend to be very close and positive. Female (versus male) siblings tend to be more involved and closer with their brothers/sisters with disabilities.

**Caregiving Roles:** Siblings tend to anticipate future caregiving roles for their brothers/sisters with disabilities. Indeed, 60% of siblings anticipate fulfilling primary caregiving roles. However, certain siblings are more likely to be primary caregivers. Female (versus males) and lone (versus multiple) siblings are more likely to fulfill future caregiving roles. Furthermore, siblings who are both emotionally and/or physically closer to their brothers/sisters with disabilities are more likely to fulfill future caregiving roles. In Krauss et al., (1996) 19% of siblings expected to live with their brother/sisters. However, while many siblings anticipate fulfilling future roles, many siblings are not included in future planning.

### References

- Heller, T., & Arnold, C.K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 16-25.
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- Seltzer, M.M., Greenberg, J.S., Orsmond, G.I., Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation, 43*, 354-359.

# Resources

 There are some services available to meet the needs of adult siblings. Here, we provide highlights of some of the services available.


## Future Planning Trainings

The purpose of future planning training is to plan for the future of the individual with IDD. One future planning intervention is the "Future is Now" curriculum developed at the University of Illinois at Chicago. The curriculum includes both individuals with disabilities as well as their family members. Participants attend five workshops about legal and financial issues related to caregiving. Families who participate in the training (versus those who do not) are more likely to create a letter of intent, prepare for residential placement, and develop a special needs trust for their family member (Heller & Caldwell, 2006).


## Support Groups

By attending sibling or disability support groups, siblings may have their socio-emotional needs met. Within the disability literature, most of the research about support groups focuses on parents. However, support groups may also help siblings. The SLN has numerous state chapters across the country. Most of these state chapters hold regular outings with siblings. There, siblings can network with one another and feel increased social support.

Another kind of social support is the SLN listserv and Facebook accounts. By connecting with other siblings via social media or electronic resources, siblings may feel less isolated and more able to learn about available services. Research is needed to document the effects of support groups (both in-person and electronic) for siblings of individuals with IDD.

 Sibling Leadership Network: [www.siblingleadership.org](http://www.siblingleadership.org)

Check out the "State Chapters" section of the SLN website to find a chapter near you!

 Sibling Support Project and SibNet: [www.siblingsupport.org](http://www.siblingsupport.org)

Choose "Connect with other sibs" and click on SibNet. Join the Yahoo or Facebook group.

## Reference

Heller T., & Caldwell, J. (2006). Supporting adults with developmental disabilities and aging caregivers in future planning. *Mental Retardation*, 44, 189-202

Suggested citation:

Sibling Leadership Network. (2013). Adult siblings of individuals with intellectual and developmental disabilities. Retrieved from: <http://siblingleadership.org/research/>

Updated June 2013