



# Siblings of Individuals with Disabilities

## *Why are sibs important?*

- Siblings often have the longest-lasting familial relationships.<sup>1</sup>
- Many of the estimated 4.9 million individuals with developmental disabilities (I/DD) in the United States have brothers and sisters.<sup>2</sup>

## *Family caregivers*

- Family caregivers are the largest source of long term care services in the U.S; from 2000 to 2015, the number of family caregivers is estimated to increase by 80%.
- In the United States, 71% of the 4.9 million people with I/DD live with their families, yet only 7% of funding goes to family support services.<sup>3</sup>

## *Sibling roles*

- Siblings often become the next generation of caregivers when parents are unable to provide care. Frequently, the oldest female sibling becomes the caregiver.<sup>4</sup>
- Most siblings anticipate fulfilling greater supportive and caregiving roles.<sup>5</sup>
- The peer nature of the relationship makes siblings uniquely positioned to support their brothers and sisters with disabilities to lead self-determined lives. This support can include many areas such as employment, voting, transportation, relationships and sexuality, healthcare, housing supports, and more.<sup>6</sup>
- Even though siblings have unique roles and are likely future caregivers, the needs and perspectives of siblings are often overlooked. By addressing the needs of siblings, their brothers and sisters with disabilities will have better outcomes.<sup>7</sup>
- Siblings are called the “club sandwich generation” because they often juggle the caregiving of their aging parents, their own children, as well as their brothers and sisters with disabilities.<sup>8</sup>



## Sibling Needs

- While support programs and services have been developed for individuals with I/DD and their parents, supports for siblings have been limited.<sup>9</sup>
- There is a specific need for information on future planning. Future planning is critical because it helps start an important dialogue among families and helps break up the planning process into manageable steps. Future planning programs should include both the siblings with and without disabilities in the entire process.<sup>10</sup>



<sup>1</sup> Cicirelli, V. G. (1995). Sibling relationships across the life span. New York: Plenum Press.

<sup>2</sup> Fujiura, G. T. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225-235.

Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106(3), 231-252.

U.S. Census Bureau. (2010). Data finders: Population clocks. Retrieved May 19, 2010, from <http://www.census.gov>

<sup>3</sup> Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

<sup>4</sup> 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.

<sup>5</sup> Burke, M.M., Taylor, J.L., Urbano, R.C., & Hodapp, R.M. (2012). Predictors of future caregiving by siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117,33-47.

<sup>6</sup> 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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<sup>7</sup> Arnold, C.K., Heller, T., and Kramer, J. (2012). Support Needs of Siblings of People with Developmental Disabilities, *Intellectual and Developmental Disabilities*, 50(5), 373-382.

Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D. (2008). The Sibling Leadership Network: Recommendations for research, advocacy, and supports relating to siblings of people with developmental disabilities. Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, University of Illinois at Chicago.

<sup>8</sup> Arnold, C.K., Heller, T., and Kramer, J. (2012). Support Needs of Siblings of People with Developmental Disabilities, *Intellectual and Developmental Disabilities*, 50(5), 373-382.

<sup>9</sup> 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.

<sup>10</sup> Arnold, C.K., Heller, T., and Kramer, J. (2012). Support Needs of Siblings of People with Developmental Disabilities, *Intellectual and Developmental Disabilities*, 50(5), 373-382.

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