

2015 SIBLING POLICY BRIEF



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Providing information and support to siblings of people with disabilities

Many of the estimated 54 million individuals with disabilities in the United States have brothers and sisters. Siblings often have the longest relationship of their lives with each other and can have a powerful, positive impact on each other's experiences. The peer nature of their relationship makes them well suited to support each other throughout their lives. This brief summarizes some key federal legislation that provides support for people with disabilities and their families and illustrates the specific significance for siblings.

The Family and Medical Inclusion Leave Act (FMILA)

The FMILA was last reintroduced in 2013 (H.R. 1751 / S. 846) to reflect the diverse nature of American families and their caregivers' roles. FMILA would update the FMLA of 1993, which permits working individuals to take unpaid, job-protected leave to care for their family members. The new legislation would expand the scope of coverage to include siblings, as well as grandparents/grandchildren, same-sex partners, and adult children with disabilities.

Sibling Significance: For many families today, siblings are the primary caregivers of their brothers and sisters with disabilities. Under the current FMLA, sibling caregivers are barred from the benefits of this statute, which only covers leave to care for one's spouse, child (under the age of 18), or parent. Unfortunately, many siblings mistakenly rely on this statute, believing it currently covers leave to care for their sibling with a disability.¹ The goal of the SLN and like-minded advocacy organizations is to ensure FMLA acknowledges siblings explicitly.

The Older Americans Act (Reauthorization) (OAA)

The Older Americans Act of 1965 supports programs for both older Americans as well as individuals with disabilities. The Act, in recognizing the important role that family caregivers have in our nation's long-term services and supports system, created the National Family Caregiver Support Program under which siblings are eligible to receive caregiver services and supports. It also established Aging and Disability Resource Centers (ADRCs) to provide individuals with a one-stop shop to assist them in discovering the full range of supportive service options available for them to continue living as they choose in their community. Bipartisan legislation was introduced in the Senate in 2013 (S. 1562), but such efforts have since been put on hold. A companion bill has not been introduced in the House.

Sibling Significance: For many family members, planning for their loved ones' future requires knowledge of the multitude of services and supports available to ensure they continue to lead a quality life in the community. As reauthorization efforts continue in the 114th Congress, advocates are seeking to amend the core functions of the ADRCs to assist sibling caregivers and adults with disabilities with future planning.

(Continued...)

¹ Daley, Klerman, & Pozniak (2012). *Family and Medical Leave in 2012: Technical Report*. Cambridge: Abt Associates, Inc.

The Lifespan Respite Care Act (Reauthorization)

The Lifespan Respite Care Act of 2006, last introduced in 2013 (H.R. 4683), increases the availability and coordination of respite services to family caregivers² of individuals with disabilities, regardless of age. Since family caregivers, including siblings, provide the majority of long-term services and supports³, respite services are critical.

Sibling Significance: Respite offers family caregivers a short-term break from the caregiving role in order to stay physically and mentally healthy so that they can in turn provide care to their family members with disabilities. This is particularly relevant for siblings who provide care to their sibling(s) with a disability and their aging parents, whether or not they are formally designated as a caregiver.

The Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD, a United Nations treaty, was signed by President Obama in 2009, but still needs to be ratified by the US Senate. Ratification of the Convention would demonstrate the United States' commitment to ending discrimination worldwide against individuals with disabilities.

Sibling Significance: Recognizing international rights and equality for individuals with disabilities is of great importance to siblings. This treaty will recognize the right of our siblings to freely travel, live, and study abroad and it will serve as a recommitment to disability rights in the United States.

The Sibling Perspective and Federal Law

- Policymakers, researchers, support providers, and advocacy agencies must incorporate siblings into the collective discussion of the rights and supports for citizens with disabilities. Siblings of people with disabilities should be included in policy development, programmatic planning, research, and the delivery of services and supports.
- Due to the aging of adult parent caregivers, siblings are becoming more and more likely to assume greater roles as individuals with intellectual and developmental disabilities (IDD) outlive their parents. Over 71% of adults with IDD in the U.S. live at home with their families, and over 24% of their family caregivers are over the age of 60 years.⁴ However, in 2013 only 7% of the \$61.46 billion in total I/DD spending went to family support.⁵
- State and Federal Laws pertaining to family supports should specifically define the word “family” to include siblings to ensure policies enhance the quality of life of all family members. For example the *Developmental Disabilities Assistance and Bill of Rights Act of 2000* (PL 106-402) currently provides a general definition of “family support services” (Sec. 102(12)) but does not explicitly include siblings in that definition.

For more information on relevant policies visit www.siblingleadership.org



² Family caregiver is defined as an “unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.” Lifespan Respite Care Act (PL 109-442), Sec. 2901(5) (2006).

³ Coughlin, J. (2010). *Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management*, Vol. 2; Issue 1.

⁴ 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.

⁵ Braddock et al. (2015).