

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. The following are highlights of federal legislation that provide support for people with intellectual and developmental disabilities and their significance for siblings.

The Family Medical Leave Inclusion Act (FMLIA)

The FMLIA was reintroduced in 2013 (S. 857/H.R. 1757) to reflect the diverse nature of American families and their caregivers' roles. FMLIA would update the Family Medical Leave Act of 1993, which permits working individuals to take unpaid, job-protected leave to care for their family members. The new legislation would permit leave to care for siblings, as well as grandparents/grandchildren, parent/son/daughter-in-laws, domestic partners and/or their children, 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 Older Americans Act (OAA) Reauthorization

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.

Sibling Significance: For many family members, planning for their loved ones future requires knowledge of the multitude of services and supports available to ensure (s)he continues to lead a quality life in the community. As reauthorization efforts continue in the 113th Congress, advocates are seeking to amend the core functions of the ADRCs to assist sibling caregivers and adults with disabilities with future planning.

The Lifespan Respite Care Act

The Lifespan Respite Care Act of 2006 (H.R. 3248) increases the availability and coordination of respite care services for family caregivers of individuals with disabilities, regardless of age. Congress needs to prioritize this legislation, which was last reauthorized in 2011. Research shows family caregivers, including siblings, provide the majority of long-term care and therefore respite serves as a critical support.

Sibling Significance: Family caregivers, many of whom are siblings, experience significant financial, physical, and psychological stress due to the care they provide on a daily basis. This legislation is crucial in supporting siblings in their role as caregiver, especially in families with aging parents.

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

The Achieving a Better Life Experience (ABLE) Act

Reintroduced in February 2013, the ABLE Act (S. 313/H.R.647) would give individuals with disabilities and their families access to tax-free savings accounts that would allow for asset development and future planning while protecting eligibility for Medicaid, SSI, and other important federal benefits for people with disabilities. This Act would allow family members to save for disability expenses the same way that families save for college, including those related to education, housing, transportation, employment supports, and health and wellness. Since reintroduction in the 113th Congress, the ABLE Act has gained momentum as well as bipartisan support.

Sibling Significance: The savings by families under this legislation can reduce the financial costs to siblings who will support their brothers or sisters in the future.

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

The CRPD, a United Nations treaty, was at the forefront of the disability advocacy agenda last year. The U.S. signed on to the Convention in 2009 and the Obama Administration submitted it to the Senate for advice and consent in May 2012. Ratification, which requires a 2/3 vote in the Senate, would showcase the U.S. commitment to ending discrimination worldwide against individuals with disabilities. Though the Senate rejected ratification of the CRPD on December 4th, by a vote of 61-38, strong advocacy efforts have continued in the 113th Congress.

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 U.S.

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.
- Many siblings have indicated that they will assume primary care of their brother or sister with disabilities at some point during the sibling's lifetime. However, it must be noted that this should not be considered the expectation, but rather a choice made by the entire family unit.
- Due to the aging of adult parent caregivers, siblings are becoming more and more likely to assume greater roles, including co-residence with their siblings, as individuals with intellectual and developmental disabilities (I/DD) outlive their parents. Over 70% of adults with DD in the U.S. live at home with their families, and over 25% of their family caregivers are over the age of 60 years.²
- While the majority of long-term services and supports for persons with I/DD are provided in the family home, in 2011 only 7% of the \$52.6 billion in total I/DD spending was allocated to support individuals in the family home. Thus, there is a great need to increase funding for community living, supporting individuals to live in their own home or with their families.³
- 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 Braddock, et al. (2013). *State of the States in Developmental Disabilities* Based on Fujiura 2012.

³ Braddock et al. (2013).