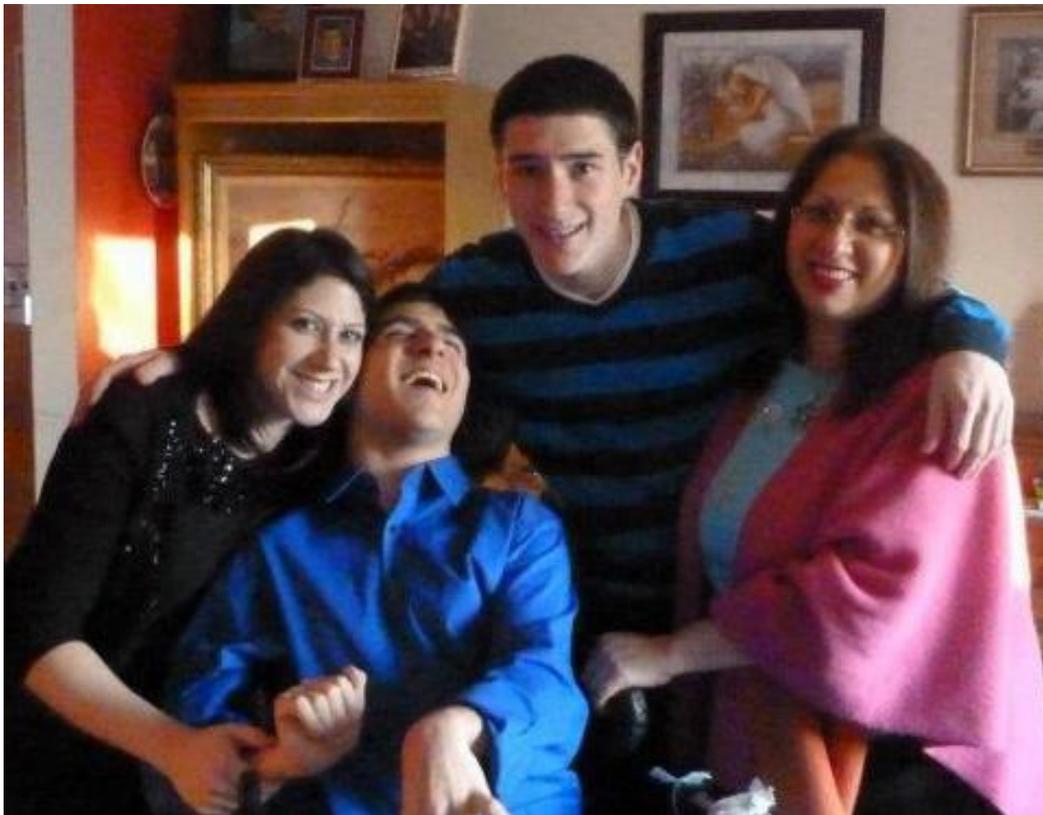




Recommendations for Policy Advocacy  
Relating to Siblings of  
People with Developmental Disabilities

June 5, 2014

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# Acknowledgments:

Sibling Policy Forums were held in March 2014 by the Institute on Disability and Human Development at the University of Illinois at Chicago (UIC). Thanks to the community partners on this project including:

- ❖ The Sibling Leadership Network
- ❖ Supporting Illinois Brothers and Sisters, Inc.
- ❖ The Arc of Illinois
- ❖ The Autism Project of Illinois

The Sibling Policy Forums were funded by the Institute for Policy and Civic Engagement at the University of Illinois at Chicago.



The content of this document is not meant to reflect the views of the funder or partners.

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# Introduction

This white paper provides recommendations for policy advocacy relating to siblings of people with disabilities. In 2008, the leaders of the Sibling Leadership Network (SLN) developed a series of white papers (Heller et al, 2008) that have guided the SLN throughout its considerable growth within the last 6 years. In March 2014, Sibling Policy Forums were held across the state of Illinois that helped provide updates to the policy and advocacy section of the previous whitepaper. The Forums engaged siblings in a policy discourse and attendees learned about current disability policies relevant to siblings of people with disabilities and their families. The Sibling Policy Forums emphasized the multi-layered nature of advocacy and highlighted the unique roles that siblings can play within advocacy. From fighting for services, to connecting with other siblings for change, to visiting with legislators, siblings offer perspectives that have not always been included in traditional forms or methods of advocacy.

***Sibling Advocacy Toolkit:*** A toolkit of strategies for civic engagement was developed for siblings to use to engage in policy debates. Tools include research and policy briefs, sample letters to policymakers, sibling talking points, and steps to share one’s story. The Advocacy Toolkit for siblings has been put online by the Sibling Leadership Network so siblings across the country can access it at: <http://siblingleadership.org/sibling-policy-forum/>.

***Sibling Policy Videos:*** Two policy videos on sibling perspectives were created from the stories of participants in the Sibling Policy Forums. Using a “hook, line, and sinker” process, siblings shared their stories for these videos. The two videos can be found on the SLN website: <http://siblingleadership.org/sibling-policy-forum/>.

- ❖ Employment First Policy: Sibling Perspectives (3:27 minutes)
- ❖ Policy Video by Siblings on Future Planning (4:43 minutes)

# Siblings as Advocates: Unique Roles and Opportunities

## Purpose

The purpose of this white paper is to provide a summary of policies related to siblings of people with disabilities and their families. Policies that are intended to support families often overlook siblings of people with disabilities. Many of the estimated 3.7 to 4.9 million individuals with developmental disabilities in the United States (Fujiura, 1998; Larson et al., 2001; U.S. Census Bureau, 2010) have brothers and sisters. Siblings often have the longest relationship of their lives with each other and they are an untapped constituency for policy advocacy (Arnold, Heller, and Kramer, 2012). The peer nature of their relationship makes them well suited to support their brothers and sisters with disabilities to lead self-determined lives. Also, siblings of people with disabilities often become the next generation of caregivers when parents are no longer able to fill this role (Burke, et al., 2012; Heller & Arnold, 2010). Although siblings often play a key support role in the lives of their brothers and sisters with disabilities, they are frequently overlooked in policy discussions (Arnold, Heller, & Kramer, 2012). The brothers and sisters of people with disabilities are a key constituency of interested and essential allies. Siblings of people with disabilities can serve as resources for agencies and policymakers in the movement toward full inclusion and participation of all individuals with disabilities. This updated white paper reflects the most current policies that are relevant to people with disabilities, their siblings, and their families.

## Principles Guiding Policy and Advocacy

The guiding principles in this white paper were developed by Cathy Allen, John Kramer, Emily Marino, Shea Obremski, and Anna Zendell for the SLN 2008 White Paper (Heller et al) and are still relevant and meaningful. These principles continue to ground the policy advocacy efforts in which the SLN engages for siblings of people with disabilities.

1. *The term “family” should include siblings.* Federal law generally allows states to define “family” as they interpret various statutory provisions. But where a state defines family as

“parents and guardians,” or fails to define family at all, brothers and sisters are left without an opportunity to participate in planning and care.

2. *Siblings have a unique and under-represented voice in advocacy for and with their brothers and sisters with disabilities.* The sibling relationship is considered the longest-lasting relationship of the human experience, providing the greatest opportunity for reciprocal support and care. Adequate representation of brothers and sister in the lives of people with disabilities can lead to more balance in regards to independent living, personal freedom and self-sufficiency.
3. *Policymakers and agencies must incorporate siblings into the collective discussion of the rights and supports of citizens with disabilities.* Including siblings will enhance the quality of life of individuals with disabilities and ensure quality services, support and long-term care for people with disabilities
4. *Siblings should be included in policy development, programmatic planning, services and supports.* While many state and local regulations require family representation on policymaking boards and committees, parents have consistently been the identified family representatives. With the aging of American society, it is prudent to start investing in the next generation - siblings. Many siblings are already providing support with little or no input in shaping public policy, services or supports.
5. *Family support policy must enhance the quality of life of all family members.* The focus of federally funded family support is the child with the disability and their parents. The current policy omits brothers and sisters who can also benefit from an enhanced quality of life. We believe it is time to strengthen family support policy by explicitly including brothers and sisters of people with disabilities in federal family support program guidelines.
6. *There are millions of siblings who are an untapped resource who can, with the proper support and encouragement, make a positive impact in the lives of their brothers and sisters and others with disabilities.* When given the opportunity to meet other brothers and sisters of individuals with disabilities, people often note their sense of comfort and relief to know they are not alone. With support and information, an increasing number of brothers and sisters are capable and willing to play significant roles in the lives of people with disabilities.

## Sibling Advocacy

Over the past five decades, policies related to people with developmental disabilities and their families have evolved. After a long history of isolation and institutionalization, today the focus for people with disabilities is on self-determination and creating lives in communities of their choosing. The social revolution that created this change was led by loving family members and determined self-advocates as well as concerned professionals, and courageous legislators. However, there is still much work to be done.

Siblings are an untapped constituency for policy advocacy with the potential to exponentially increase the power of the disability advocacy movement. Policymakers, advocates, and professionals are beginning to understand the unique potential that siblings possess. Understanding siblings as a distinct group, while related both to family, parental and self-advocacy, will have implications for increasing sibling engagement in all levels of advocacy.

## Key Policy Recommendations

The SLN strongly supports the following legislation and initiatives, in alliance with groups of self-advocates and other disability organizations across the country.

The SLN's Policy & Advocacy Committee works to educate policymakers by providing sibling perspectives on policies that will impact people with disabilities and their families. The Policy & Advocacy Committee also partners with disability groups to advocate for federal policies that advance the opportunities for full inclusion and participation of people with disabilities. Comprised of nationally recognized experts in the policy arena, the SLN Policy & Advocacy Committee members have created the Sibling Policy Brief (available for online download at <http://siblingleadership.org/policy-advocacy/>). Below are the policies that the SLN focuses on, and each policy or initiative's respective significance to siblings.

### Employment First

Employment First is a national initiative to more fully realize the goal of inclusion for people with disabilities through employment. Employment First initiatives, which are state-based, are focused on integrated and community employment for people with disabilities as the first option. Thirty-three states have Employment First initiatives of some kind, but several states, including

California, Kansas and Delaware have signed Employment First Legislation. Several states, such as Arkansas, Ohio, Tennessee and Oklahoma have signed Executive Orders and other states are in the process of passing more formal legislative measures.

**Sibling Significance:** Increasing employment for people with disabilities has long been a target by self-advocates, families, and professionals in the field. Employment is good for people with disabilities, but it can also have an impact on sibling relationships. Meaningful and gainful employment for people with disabilities can open up a variety of new experiences, including more opportunities for the give and take relationships we expect from our sibling relationships. Dr. John Kramer has created a series of short videos that are available on the SLN website at: <http://siblingleadership.org/research/employment/>. These videos, in addition to the interviews that Dr. Kramer has done, provide perspective on the unique ways in which siblings can support their brother or sister with a disability.

## Older Americans Act 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 one's 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.

## Family and Medical Leave Inclusion Act (S. 857/HR 1757)

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.

### Lifespan Respite Care Act (P.L. 109-442)

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.

### 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 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.
- 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.
- 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.

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For more information, visit [www.siblingleadership.org/policy-advocacy/](http://www.siblingleadership.org/policy-advocacy/)



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