

The Sibling Leadership Network: Ethical Considerations and Policy Recommendations Impacting Sibling Caregivers

Banks, Tiffany, PhD¹; DeVries, Lindsey, PhD²; Saxena, Mamta, PhD³; Weaver GracieLee., PhD⁴;
Gregory, Emma., MA.⁵

1. Assistant Professor, School of Social Work, University of Maryland Baltimore County, MD, and Co-chair of Policy and Advocacy, The Sibling Leadership Network. Email: tiffany.banks@siblingleadership.org
2. Assistant Professor, University of Colorado School of Medicine Department of Pediatrics, Aurora, CO
3. Associate Professor, Department of Human Development, State University of New York at Oswego, NY
4. Research Scientist, Prevention Strategies, Greensboro, NC
5. Senior Statewide Trainer, Federation for Children with Special Needs

Table of Contents

<i>Plain Language Summary</i>	3
<i>Introduction</i>	4
<i>Background</i>	4
<i>Who are Family Caregivers?</i>	5
<i>What is Family Caregiving?</i>	6
<i>Impacts of Family Caregiving</i>	9
<i>Theoretical Perspectives</i>	10
<i>Life Course Perspective</i>	10
<i>Push and Pull Theory</i>	11
<i>Policies Impacting Sibling Caregiving</i>	12
<i>Family Medical Leave</i>	12
<i>Home and Community Based Services (HCBS)</i>	13
<i>Discussion</i>	14
Policy Recommendations	15
<i>Family Definition Expansion</i>	15
<i>Paid Family Leave</i>	16
<i>HCBS Reform</i>	16
Other Ethical Considerations	17
<i>References</i>	19

Plain Language Summary

The Sibling Leadership Network (SLN) is a non-profit organization dedicated to supporting siblings of individuals with disabilities. Siblings play an important role as caregivers in the disability community, but also deserve to be recognized as individuals with their own needs, identities, and roles. One area in which we support siblings is through advocacy and support for sibling caregiver roles.

Caregiving is misunderstood. It is providing someone with formal and informal care that may take the form of emotional, physical, or financial support. Caregiving can occur daily or even temporarily, depending on the experience of the individual. There is no one-size-fits-all definition of caregiving, but all care is essential and valued.

The Family Medical Leave Act (FMLA) is a policy that allows employees to take unpaid time from work to care for themselves, their spouse, their parent, or their child. Siblings are not included, unless they are providing caregiving for an individual whose disability prevents them from caring for themselves. We believe that this needs to change to acknowledge the important role siblings play in each other's lives.

Home and Community Based Services (HCBS), funds services that allow people with disabilities to live in their community. HCBS is currently struggling with limited funding and a shortage of direct service providers. Investing in HCBS would decrease demands on family caregivers like siblings.

Introduction

The Sibling Leadership Network (SLN) is a non-profit organization whose mission is *to provide siblings or individuals with disabilities the information, support, and tools to advocate with their siblings and to promote issues important to them and their entire families*. We believe that siblings of individuals with disabilities hold an important and powerful position within the disability community as advocates and allies. Furthermore, our aim is to spotlight the individuality of siblings who fulfill caregiving roles within families. Often depicted as crucial caregiving figures in literature, siblings are frequently overlooked as individuals with diverse identities beyond their familial duties and roles.

To advocate on behalf of ourselves and commit to being allies of those impacted by disabilities, the SLN addresses the community by connecting others with the resources and information needed to effectively advocate for our large and ever-growing community. In 2008, the SLN released a series of white papers highlighting the advocacy and research agenda of the organization (Hellar et al.). One of the areas in which we focus a great deal of self-advocacy in the sibling community is around the concept of family caregiving. This updated white paper seeks to provide ethical considerations for researchers exploring the sibling experience, as well as review the policy and advocacy recommendations our community has prioritized regarding the Family Medical Leave Act (FMLA, 1993).

Background

Before we begin to address the issue of sibling caregiving, it is important to define who is a member of the SLN's sibling community. According to the Centers for Disease Control (CDC; 2023), approximately 1 in 4 individuals in the United States are impacted by disability. The term disability is an umbrella term that includes the 1 in 6 children in the United States diagnosed

with an intellectual and developmental disability (IDD) every year (CDC, 2023), as well as those who are impacted by mental health, chronic health, and acquired disabilities. At the SLN, we recognize that the disability community is vast, complex, and intersectional. We seek to support and advocate alongside the larger disability community and do not limit our scope to any one disability population.

Who are Family Caregivers?

Despite our focus on the greater disability community, the literature on family caregiving is overwhelmingly representative of the IDD community. This is likely a reflection of how the IDD community has prioritized future planning and anticipates caregiving needs earlier in life than families impacted by mental health, chronic health, and other acquired disabilities. It is important to recognize that families impacted by a wide spectrum of disability, including those associated with aging, have caregiving needs and responsibilities that may go unrecognized in peer reviewed literature. This is also reflected in literature that finds sibling caregivers are under researched, even in the IDD community (Lee & Burke, 2018).

Family caregivers are primarily female gendered parents (Anderson & Pettingell, 2023; Santos et al., 2023) but data also shows this group is aging. An estimated 72% of Americans with IDD live with a family member and 24% of these caregivers were over the age of 60 in 2021 (Tanis et al., 2023). Thus, the small number of siblings who are the primary caregiver in current literature is expected to grow. During this transition, siblings are often expected to care for their sibling with a disability, their aging parents, and their own children. This phenomenon is often referred to as the “club-sandwich” generation, a caregiving situation that entails three generations of a family that require support at the same time.

Of those providing caregiving support to a family member, socioeconomics varies. For example, one study showed 36% of caregivers with incomes below \$60,000 (Anderson & Pettingell, 2023) and another found that their sample included 37.3% of caregivers with incomes over \$100,00 (Santos et al., 2023). These variances make it difficult to fully understand the financial burden associated with caregiving and may impact how families access supportive services and funding through IDD organizations.

Finally, the SLN recognizes the diversity within the sibling community. Sibling caregivers have intersectional identities that are impacted by family culture, ethnicity, race, and lived experience. Siblings from differing backgrounds may be impacted by language barriers, cultural beliefs, and family expectations in ways that are unique to that individual. More research is needed to fully understand how marginalization and intersectionality influence the sibling experience.

What is Family Caregiving?

Before reviewing the policies at hand, we must first understand what family caregiving is and how this impacts individuals. Caregiving in the United States is often seen as an obligation with minimal value. This is demonstrated by the lack of policy to support funding family caregiving (Lang and Carlson, 2018), fewer protections for employees needing leave due to non-physical caregiving responsibilities (Bailey, 2017), and low percentages of families who are able to access those supports (Braddock et al., 2015; Tanis et al., 2017). How we define caregiving plays an important role in our understanding of the issues at hand.

The concept of caregiving is narrowly defined in legal literature, often focusing on individuals with high support needs. For example, a common legal term utilized in policies that

impact caregiving is “in loco parentis”. In loco parentis refers to an adult who is acting as a parent on the behalf of a child or an adult with a disability who is incapable of self-care (U.S. Department of Labor [DOL], 2023a). Many individuals who receive caregiving support are not fully incapable of self-care, but still require dynamic and intermittent caregiving support (Setty et al., 2019).

Caregiving demands on siblings may range from physical to emotional support, and everything in between (Lee et al., 2019). This may include formal supports, like therapies, and informal supports, such as natural support from a social or family system (Friedman, 2023). While systems often recognize the need for formal support, the informal support that siblings and other family caregivers provide is often undervalued. In fact, Friedman (2023) found that natural supports are directly tied to quality of life and community participation; stressing the importance of creating systems that allow for these informal caregiving roles to flourish without penalizing the caregiver.

There are several ways in which researchers have defined caregiving. Arnold and Harris (2024), utilize instrumental support as a framework to better understand how families are providing care. Their model found four areas of support that families often provide: physical support, support for healthy living, financial support, and support with the navigation of formal service delivery. Folbre and Wright (2012), on the other hand, define care in three ways: interactive care, support care, and supervisory care. Interactive caregiving refers to caregiving that improves quality of life through hands-on tasks, support caregiving refers to tasks that allow interactive caregiving to occur, and supervisory care is described as “on call” to support should a need arise. Table 1 displays examples of caregiving activities using the interactive, support, and supervisory care model.

Table 1

Examples of Caregiving Tasks

Type of Caregiving	Examples of Continuous Caregiving	Examples of Intermittent Caregiving
Interactive	Supporting a person through their daily physical therapy routine to maintain range of motion.	Supporting a loved one after surgery to complete their physical therapy tasks that may be discontinued once they have recovered.
Support	Being designated as your sibling's representative payee and managing their finances regularly.	Cleaning your loved one's house occasionally.
Supervisory	Needing to be home by 5pm everyday to be present when your sibling comes home from their day program.	Being present during a depressive episode to safeguard your loved one who is temporarily experiencing suicidal thoughts.

Note. Table 1 utilizes the definitions of interactive, support, and supervisory caregiving from Folbre and Wright (2012) and the definitions of intermittent and continuous support from Saxena (2019).

Physical, day to day tasks is not the only care that matters (Bailey, 2017). The concepts of caregiving described above have similarities by acknowledging different levels of intervention and support. This also highlights the disenfranchisement experienced by those providing caregiving outside the narrow legal definition found in policy. Time and effort expended on these tasks can be continuous or intermittent (Saxena et al., 2019), further complicating the definition of caregiving. To further articulate the diverse nature of caregiving, we present three stories from siblings that illustrate different experiences of caregiving.

Sibling Story 1. “When I'm in charge: My sister wakes up very early, so I watch her while she plays. She needs supervision, but not much interference. When it's time, I make breakfast and give her her meds. Sometimes she wants to take a bath, so I help her with that. Then I dress her for day program and pack her lunch and her backpack. If we have time, we play some more. Then I help her onto the bus. When she comes home from

day program, I make her a snack, give her the next set of meds, and then supervise while she plays. Sometimes she gets sleepy and climbs into my lap to take a nap. Then I make dinner and give her a bath. Once she's in her pajamas, she plays some more and falls asleep. I wake her up once more for midnight meds.” (Previously unpublished quote from research participant; Saxena, 2014)

Sibling Story 2. “I generally go to their home every day for about 2 to 3 hours and assist them with bills, home issues (they live with their elderly mom), day program and helper issues, etc. I take them out into the community 2-3 times per week for shopping or eating out.” (Previously unpublished quote from research participant; Saxena, 2014)

Sibling Story 3. “My brother lives in a supportive living environment, so a lot of his day to day care is provided. However, I am always on-call to support my brother’s mental health. I occasionally receive phone calls or text messages from him during periods of high emotions and my ability to respond quickly has reduced the frequent psychiatric hospitalizations he has required. I am his go-to person to reduce negative self-talk and process his emotions outside of the professional caregivers that support him” (SLN member)

Impacts of Family Caregiving

Although many siblings enjoy caring for their sibling, they also report caregiving stress and compassion fatigue (Arc, 2018; Saxena et al., 2019). A lack of opportunity and time constraints to meet their personal and professional goals forces individuals to make difficult choices. Their ability to maintain work-life balance is one reason individuals providing caregiving often face greater health challenges, and increased depression and anxiety (Alnazly & Abojedi, 2019; Mudrazija & Johnson, 2020).

Some family caregivers provide support equivalent to more than a full-time job (Carr & Utz, 2020), whereas others may provide occasional support. In fact, caregivers report spending more than \$7,000 annually (out of pocket) to cover rent, special equipment, and more for the care recipient (AARP, 2021). This explains why, historically, family caregivers have been known to increase their formal work hours to cover expenses (Evercare & National Alliance for Caregiving, 2009). The costs of caregiving, combined with the current unpaid leave options,

means caregivers are often left with difficult decisions between caring for a loved one and making financial ends meet (Lang & Carlson, 2018).

Theoretical Perspectives

To further articulate the sibling experience and the impact the relationship has on individuals with and without disabilities, we present two theoretical frameworks that help to shape our approach to sibling advocacy and research: life course perspective and push pull theory.

Life Course Perspective

From a life course perspective, the development of each member in a family unit has lasting effects on all members of the family (Smith & Hamon, 2016). Life course perspective has four core tenets that help us understand how the experience of disability is shared by an entire family unit (Elder, 1998; Mortimer & Shanahan, 2006). The first tenet, time and place, emphasizes how our lives are shaped by historical context and lived experiences. The second tenet focuses on the timing of life, referring to developmental milestones that shape how we experience our world. This is particularly noticeable in sibling relationships, as milestones for those impacted by developmental delays can become pronounced as children develop at different rates. The third tenet presents the concept of “linked lives”, which is central to this lens. Within the framework of life course perspective, it is understood that we all interact with our support systems and these relationships also impact our lived experiences in ways that cannot be separated. The final tenet, human agency, is a reflection on the importance of self-determination and choice.

Life course perspective is an essential model in understanding the interrelatedness of sibling experiences and importance of recognizing and caring for siblings of individuals with disabilities across the lifespan. For example, family functioning was found to be associated with mental health outcomes for transition aged youth with Autism (Whelan et al., 2023), suggesting that positive family engagement and functioning has positive impacts on mental health during stressful life transitions. When siblings are part of a family unit, the concept of linked lives within life course perspective suggests we examine how all members of the family function together and interact.

Push and Pull Theory

In 1999, Greenberg and colleagues introduced the Push-Pull model to explain the motivations (push in the direction of caregiving) and barriers (pull away from caregiving) to sibling caregiving. This model suggests that factors such as siblings' health, goals, life stages, contextual environment, and relational obligations influence their level of involvement in caregiving (Lohrer, Lukens, & Thorning, 2007).

Saxena (2015) further expanded on this model by identifying factors that can motivate or deter siblings from caregiving at different levels: individual, sibling dyad, family, and community. Some of these factors, such as higher caregiving needs, residential proximity, or the employment status of the sibling, can both simplify and complicate caregiving decisions and the level of involvement.

She further suggested that decision-making regarding caregiving is complex and needs to consider the siblings' specific contexts. For instance, further research could probe into why some siblings do not engage in caregiving despite the intention, how caregiving responsibilities are

divided when there is more than one sibling, and the long-term trajectory of caregiving for both siblings and individuals with IDD (Saxena, 2015). All these inquiries will significantly influence the developmental outcomes of both siblings and individuals with disabilities.

Policies Impacting Sibling Caregiving

There are two primary policies we intend to focus on for this white paper, Family Medical Leave (FMLA) and Home and Community Based Services (HCBS). Studies have shown caregivers have increased financial burden, increased negative health impacts, and increased mental health concerns when compared to non-caregivers. In the following section we will define FMLA and HCBS, while also linking the current literature on their impact on family caregivers.

Family Medical Leave

FMLA has largely remained unchanged since its initial passage in 1993. Current disability advocates are putting pressure on legislators to evaluate the gaps and act quickly to resolve them (Banks, 2019; Setty et al., 2019). For example, federal FMLA policy does not include extended family members or siblings unless they are acting in loco parentis (U.S. DOL, 2023a). Unfortunately, we know that individuals with disabilities are choosing to live with family more often than other adult living arrangements available to them (Tanis et al., 2023). These arrangements don't always require a family member to be acting in a formal caregiving capacity that meets the in loco parentis requirements, making FMLA benefits inaccessible to caregivers providing informal support or supervisory care (Bailey, 2017; Folbre & Wright, 2012).

On the other hand, those who can access FMLA may still find the unpaid leave available to be an unattainable resource due to financial limitations of their family (Lang & Carlson, 2018). Less than 30% of working adults have access to paid leave (U.S. DOL 2023b). Paid leave access also varies by wage and industry, with only 16% of those in the service industry and only 6% of low-wage workers having access to paid leave (U.S. DOL, 2023c).

Unpaid leave is simply not feasible for many workers. Disability advocates support paid family leave efforts because of the financial impacts that unpaid leave has on our community (Leigh & Du, 2015; Setty et al., 2019). Cost of living fluctuations (U.S. DOL, 2023d) may make it more difficult to take unpaid leave for caregiving as well.

Home and Community Based Services (HCBS)

The financial impact of unpaid leave plays a role in the analysis of HCBS utilization as well. HCBS is part of the Medicaid program, which is partially funded by federal and state monies (Patel & Rushefsky, 2006). Under Medicaid, people with disabilities are entitled to Long Term Supports and Services (LTSS; The Autistic Self Advocacy Network [ASAN], 2023). LTSS is the primary funding source for all disability supports and institutionalized care (The Disability Policy Seminar, 2024). Within LTSS, people with disabilities may also receive formal care and support in their own home or their family's home through the optional Medicaid program called HCBS.

Examples of common HCBS supports include home healthcare services, like therapy or case management, and home support services that provide support for activities of daily living, such as transportation assistance and house cleaning (Centers for Medicare and Medicaid Services, 2023). In-home support for daily living skills is often provided by family caregivers

(formal or informal) and direct support professionals or DSPs. In the past few years, however, the United States has felt the effects of a DSP workforce crisis (American Network of Community Options and Resources, 2023). Low wages for DSPs are one of the primary driving factors behind the shortage of providers (Mccall & Scales, 2022). A decrease in the DSP workforce, in turn, increases the demands on family caregivers who are left with limited alternatives.

Discussion

Unpaid labor at home, combined with unpaid leave from your primary employer, means that families have to make choices between family and finances (Lang & Carlson, 2018). In fact, some caregivers have been found to increase their paid work hours to make ends meet and historically caregivers have expressed that they felt uncomfortable considering taking time off work for caregiving tasks (Evercare & National Alliance for Caregiving, 2009). For some, caregiving may be so rigorous that it equates to the same number of work hours as a full-time job (Carr & Utz, 2020).

Caregivers need assistance with work-life balance, respite, and employment benefits such as medical insurance, flexible spending accounts, retirement, flexible policies at work, and paid leave. However, current definitions under the Family Medical Leave Act of 1993 (FMLA) are still limited to caregiving for a spouse, parent, or child. Although there are some exceptions that extend leave to care for someone who acted in the role of parent (i.e. 'loco parentis') and can include care for a sibling (U.S. DOL 2023a), this does not explicitly encompass the diverse caregiving situations throughout the disability community. FMLA eligibility restrictions and compensation create access issues, resulting in unemployment and wage reductions for

caregivers. Without FMLA protection and coverage, caring for siblings with disabilities becomes more difficult to balance for working adults and disproportionately impacts minority females employed in low-paying jobs, who are already struggling with the financial demands of caregiving for an individual with IDD.

To address these inequities, 13 states and the District of Columbia passed Paid Family Medical Leave (PFML) programs (Williamson, 2023). State policies vary in paid leave durations, eligibility, benefit amount, and finance mechanisms (Congressional Research Service, 2023). Additionally, efforts to expand the term “family” to any relationship regardless of biological or legal status, including siblings, have been made at the state and federal level. While this is important progress, disparities in formalized support for caregivers persist.

The COVID-19 pandemic resulted in even greater strain on caregivers of individuals with IDD (Iovino et al., 2021; Wormald et al., 2023; Navas et al., 2021). Research suggests that adult siblings have played a vital role in providing care for their siblings during the pandemic while balancing roles as caregivers for their own children and/or aging parents (Redquest et al., 2021; Dorsman et al., 2023). These recent events have exacerbated the gaps in current FMLA legislation.

Policy Recommendations

Family Definition Expansion

The FMLA has not been updated since its passage in 1993 and must be modernized to meet the needs of 21st century caregivers. The family definition outlined in the *Caring for All Families Act*, introduced to the 118th Congress by Senator Dick Durbin (D-IL) and Representative Jahana Hayes (D-CT-05) in February 2023, is inclusive of multiple types of

family relationships. In this bill, a family member is “a domestic partner, parent-in-law, aunt, uncle, sibling, adult child, grandparent, grandchild, son- or daughter-in-law, and other significant relationships” (Caring for All Families Act, 2023). This act and its previous iterations introduced to the 116th and 117th Congress have failed to gain traction in Congress and have not made it out of committee. Siblings and other caregivers should not have to choose between giving their loved ones the care they need and keeping their job. To support people with disabilities and their families, Congress should prioritize the expanded definition of family as presented in the Caring For All Families Act.

Paid Family Leave

The adoption of a robust federal paid family leave program would provide financial security to all family members in caregiving positions, especially those who cannot afford to take unpaid leave. Recent legislative efforts in paid leave, such as the Comprehensive Paid Leave for Federal Employees Act (2023) have limited eligibility to federal employees. Though this is a step in the right direction, broad coverage is needed. It is encouraging to see the House Bipartisan Paid Leave Working Group, launched in January 2023, which heard from a broad range of stakeholders with the aim of developing bipartisan paid leave policy solutions (Houlahan et al. 2023). We urge legislators to continue these efforts and develop a comprehensive paid family and medical leave program to a wide range of caregivers. States with successful paid leave laws, such as New York, Massachusetts, and Washington, which provide paid leave to a broad range of family members and types of employers, as case studies for a federal paid family medical leave law (National Conference of State Legislatures, 2022).

HCBS Reform

As siblings, we advocate for ourselves, as well as alongside our siblings. While we do not speak for our siblings, we intend to elevate their voices by using our power and privilege.

Several changes to HCBS have been recommended by national disability organizations including making HCBS mandatory and increasing HCBS funding (DPS, 2024). During the 118th Congress, several bills were introduced that model the outcomes desired including The HCBS Relief Act (S. 3118/H.R. 6296), The Better Care Better Jobs Act (S. 100/H.R. 547), and The HCBS Access Act (S. 762/H.R. 1493). By making HCBS mandatory and increasing funding for HCBS services we can contribute to increasing the wages of direct support workers, decrease waitlists, and support sibling caregivers to balance the demands of their caregiving role with other beloved roles they assume.

Other Ethical Considerations

Siblings are more than just caregivers, but individuals with full lives and identities that go beyond their familial relationships. Much of the policy and research that we have discussed consider siblings only in their ability to provide care. While it is important that siblings have access to caregiving resources, such as family leave, it is important that their wellbeing, motivations, and contributions outside the caregiving context be considered in future research and policy discussions, lest siblings be viewed by policymakers simply as unpaid caregiving machines. Theoretical frameworks, such as bioecological theory, may be applied in future research to consider siblings beyond their caregiving role. Bronfenbrenner's (1986) bioecological theory examines the roles a person plays in different contexts of their lives, from their individual characteristics (person), social and family relationships (microsystem), to the political or cultural environment the sibling interacts with (macrosystem; Saxena & Adamsons, 2013). Through

bioecological theory we can understand a sibling's many identities and roles across settings and how their role as a sibling impacts their lives outside of a caregiving context.

People with disabilities are not always represented in policy (Rodgers et al., 2020). In fact, 31.7% of people with disabilities vote, compared to 61.4% in the general public. There are many reasons for this lack of representation including, having your rights limited through guardianship (Association of University Centers on Disabilities, 2020) or not receiving the support you need to prepare for voting (Autistic Self Advocacy Network, 2020). To pass the important policy reforms mentioned previously, the disability community needs allies and support. This will happen when more Americans value the life of a person with a disability, understand how bias is embedded into policies, and work together to advocate for the needs of those in the disability community.

References

- AARP (2021, June). *Caregiving can be costly – Even financially*. AARP Research.
- Alnazly, E. K., & Abojedi, A. (2019). Psychological distress and perceived burden in caregivers of persons with autism spectrum disorder. *Perspectives in Psychiatric Care, 55*(3), 501–508. <https://doi.org/10.1111/ppc.12356>
- American Network of Community Options and Resources. (2023). *The State of America's Direct Support Workforce Crisis: 2023* (pp. 1–12). Ancor. https://www.ancor.org/wp-content/uploads/2023/12/2023-State-of-Americas-Direct-Support-Workforce-Crisis_Final.pdf
- Anderson, L. L., & Pettingell, S. (2023). *Family and Individual Needs for Disability Supports*.
- Arnold, C. K., & Harris, S. P. (2024). Instrumental support: Accounts from adults with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities. https://doi.org/10.1007/s10882-024-09981-5*
- Association of University Centers on Disabilities. (2020). *Guardianship and voting*. AUCD. <https://www.aucd.org/docs/policy/Guardianship%20Chart.pdf>
- The Autistic Self Advocacy Network. (2023). *This Rule Rules: The HCBS Settings Rule and You*. HCBS Settings Rule Resources. <https://autisticadvocacy.org/policy/toolkits/hcbsrule-2/>
- The Autistic Self Advocacy Network. (2020). *Your vote counts: A self-advocate's guide to voting in the u.s.* Autistic Self Advocacy Network. <https://autisticadvocacy.org/policy/toolkits/voting/>
- Bailey, K. (2017). The FMLA and psychological support: Courts care about “care” (and employers should, too). *Michigan Law Review, 115*, 1213–196.

- Banks, T. (2019, December 23). *Family Medical Leave Act of 1993 (FMLA)—A family perspective, an equity issue*. The Latest Disability Policy Updates from the Sibling Leadership Network. <https://mailchi.mp/30e359b4b4b5/policynews-2636147>
- Braddock, D., Hemp, R., Rizzolo, M., Tanis, E., Haffer, L., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities*.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723–742.
<https://doi.org/10.1037/0012-1649.22.6.723>
- Centers for Medicare and Medicaid Services. (2023). *Home- and Community-Based Services*. <https://www.cms.gov/training-education/partner-outreach-resources/american-indian-alaska-native/ltss-ta-center/information/ltss-models/home-and-community-based-services>
- The Disability Policy Seminar (Ed.). (2024). *Community Living*.
<https://disabilitypolicyseminar.org/fact-sheets/>
- Elder, G. H. (1998). The life course as developmental theory. *Child Development*, 69(1).
- Evercare, & National Alliance for Caregiving. (2009). *The economic downturn and its impact on family caregiving* (pp. 1–17) [Survey Report].
- Folbre, N., & Wright, E. O. (2012). Defining care. In N. Folbre (Ed.), *For Love or Money* (pp. 1–20). Russell Sage Foundation. <https://www.jstor.org/stable/10.7758/9781610447904.6>
- Friedman, C. (2023). Natural supports and quality of life of people with disabilities. *Journal of Developmental and Physical Disabilities*. <https://doi.org/10.1007/s10882-023-09922-8>
- Hellar, 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*. (pp. 1–25) [White Paper]. The Sibling Leadership Network.
- Lee, C. E., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities, 15*(3), 237–246. <https://doi.org/10.1111/jppi.12246>
- Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of Autism and Developmental Disorders, 45*(12), 4135–4139. <https://doi.org/10.1007/s10803-015-2521-7>
- Mccall, S., & Scales, K. (2022). *Direct Care Worker Disparities: Key Trends and Challenges*. Paraprofessional Healthcare Institute.
- Mortimer, J. T., & Shanahan, M. J. (Eds.). (2006). *Handbook of the Life Course* (1. softcover print). Springer.
- Mudrazija, S., & Johnson, R. W. (2020). *Economic Impacts of Programs to Support Caregivers: Final Report* (p. 68). Urban Institute.
<https://aspe.hhs.gov/system/files/pdf/263376/EconImpact.pdf>
- Patel, K., & Rushefsky, M. (2006). *Health Care Politics and Policy in America* (3rd ed.). M.E. Sharpe, Inc.
- Rodgers, R., Weintruab, L., & Blachowiak, L. (2020). *Voter Rights and Accessibility* [Webinar].
https://www.aucd.org/template/event.cfm?event_id=8684&id=379&parent=379
- Santos, T., Steinway, C., Mastrogiannis, A., Chen, J., Woodward, J., Riddle, I., Spicer, B., Berens, J., Davis, T., Cornacchia, M., Wright, C., Lindquist, L. A., & Jan, S. (2023). Caregiver support, burden, and long-term planning among caregivers of individuals with

- intellectual and developmental disabilities: A cross-sectional study. *Journal of Applied Research in Intellectual Disabilities*, 36(6), 1229–1240. <https://doi.org/10.1111/jar.13141>
- Saxena, M., & Adamsons, K. (2013). Siblings of individuals with disabilities: Reframing the literature through a bioecological lens. *Journal of Family Theory & Review*, 5(4), 300–316. <https://doi.org/10.1111/jftr.12021>
- Setty, S., Koball, H., Hartig, S., & Sutcliffe, T. (2019). *Disability perspectives on paid leave: A qualitative analysis of leave-taking among workers affected by disabilities or serious health conditions* (pp. 1–55). The Arc and The National Center for Children in Poverty.
- Smith, S. R., & Hamon, R. R. (2016). *Exploring Family Theories* (4th ed.). Oxford.
- Tanis, S., Lulinski, A., Wu, J., Braddock, D., & Hemp, R. (2017). *The state of the states in intellectual and developmental disabilities*. University of Colorado.
<https://stateofthestates.org/create-idd-chart/state-profiles/>
- U.S. Department of Labor (2023a). Fact Sheet #28B Using FMLA leave when you are in the role of a parent to a child.
<https://www.dol.gov/agencies/whd/fact-sheets/28B-fmla-in-loco-parentis>
- U.S. Bureau of Labor Statistics (2023b). Employee benefits survey latest numbers.
<https://www.bls.gov/ebs/latest-numbers.htm>.
- U.S. Bureau of Labor Statistics (2023c). Percentage of civilian workers with access to paid leave by wage category. Graphics for economic news releases.
<https://www.bls.gov/charts/employee-benefits/percent-access-paid-leave-by-wage.htm>.
- U.S. Bureau of Labor Statistics (2023d). 12-month percentage change, Consumer Price Index, selected categories. Graphics for economic news releases.

Whelan, M., McGillivray, J., & Rinehart, N. J. (2023). Using life course theory to explore the association between autistic traits, child, family, and school factors and the successful transition to secondary school. *Journal of Autism and Developmental Disorders*, 54(6), 2333–2346. <https://doi.org/10.1007/s10803-022-05845-z>

Williamson, M. (2023). The state of paid family and medical leave in the U.S. in 2023. *Center for American Progress*.
[https://www.americanprogress.org/article/the-state-of-paid-family-and-medical-leave-in-t
he-u-s-in-2023/](https://www.americanprogress.org/article/the-state-of-paid-family-and-medical-leave-in-the-u-s-in-2023/)