

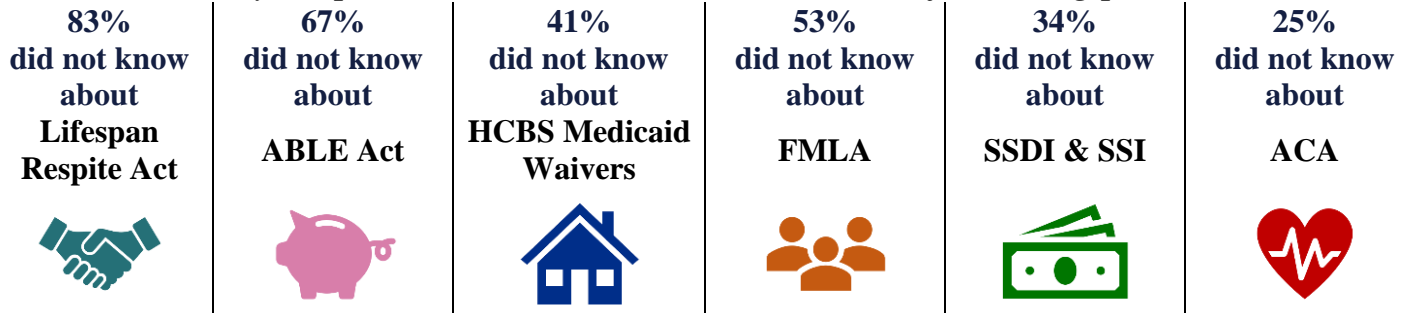
Sibling Leadership Network (SLN) Policy Brief

Disabilities Policies for Siblings of People with Disabilities in Texas

A Sibling Survey was conducted in Texas by the Sibling Leadership Network and 108 siblings of people with disabilities completed the survey. Respondents were asked about their extent of knowledge about disabilities policies which showed the need for more information on disability policies being shared with siblings. The survey results indicate that many siblings of people with disabilities had not heard or did not know much about a number of disability policies.

Knowledge Gap:

Survey respondents did NOT know about the following policies:



These policies impact the lives of people with disabilities and their families. The results above indicate the need for more information about disability policies for siblings and their families so they can understand how to access the services and supports their families need.

This Policy Brief highlights the following Federal policies along with the relevance in Texas:



Achieving a Better Life Experience (ABLE) Act: Allowing families to develop savings account for their family members with disabilities that does not negatively impact their benefits.



Family and Medical Leave Inclusion Act (FMLA): Unpaid leave for individuals to take care of family members, including individuals with disabilities.



Patient Protection and Affordable Care Act (ACA): Allowing individuals with preexisting conditions to access health insurance and allows states to expand Medicaid to more low-income families.



Lifespan Respite Care Act Increasing the availability of respite care for family caregivers of individuals with disabilities, regardless of age.



Social Security Disability Insurance and Supplemental Security Income (SSDI & SSI): Providing financial assistance to people with disabilities.



Home and Community Based Services (HCBS) Medicaid Waivers: Funding to help individuals with disabilities access community supports.



Achieving a Better Life Experience (ABLE) Act

The Achieving a Better Life Experience (ABLE) Act is a Federal law passed in 2014 to help people with disabilities create a savings account for money that is to supplement, but not supplant, other benefits a person has. It is an important way for people with disabilities to save more money without it negatively impacting their benefits. For more information visit the ABLE National Resource Center: <https://www.ablenrc.org/what-is-able/what-are-able-accounts/>

- The Texas ABLE Program was established to encourage and assist individuals with disabilities and their families in saving funds to pay for many disability-related expenses critical to maintaining the individuals' health, independence, and quality of life. The Texas ABLE Program is established and maintained by the Texas Prepaid Higher Education Tuition Board with assistance from the Texas Comptroller of Public Accounts.
- The Texas ABLE (Achieving a Better Life Experience) Program helps people with disabilities set up savings accounts that will not negatively impact benefits: <https://www.texasable.org/>
- The Texas Sibling Network did a training that has great information about ABLE accounts and is video recorded. Watch it at the link below: <https://www.facebook.com/155571918496739/videos/174208893299708/>



Family and Medical Leave Act (FMLA)

Family and Medical Leave Act (FMLA) became law in 1993 and allows eligible employees to take up to 12 work weeks of unpaid leave during any 12-month period to provide care for a parent, spouse, or child with serious health conditions. While siblings have not been explicitly included in FMLA, the Department of Labor updated their guidance in 2015 to clarify that some siblings could be covered under FMLA when a sibling is “in loco parentis” or acting like a parent. A factsheet about FMLA can be found at: <https://siblingleadership.org/wp-content/uploads/2015/08/FMLA-Fact-Sheet.pdf>



Patient Protection and Affordable Care Act (ACA)

The Patient Protection and Affordable Care Act (ACA) was passed in 2010 and has provisions that can improve the health care experiences of people with intellectual and developmental disabilities (I/DD). Most notably, the ACA allows individuals with pre-existing conditions to access health insurance and also allows states to expand Medicaid to more low-income families.

- The Affordable Care Act and the I/DD Community An Overview of the Law and Advocacy Priorities Going Forward: <https://autisticadvocacy.org/wp-content/uploads/2013/09/ACA-ASAN-policy-brief.pdf>
- Affordable Care Act Toolkit for Self-Advocates: <https://autisticadvocacy.org/policy/toolkits/aca/>



Lifespan Respite Care Act

Lifespan Respite Care Act was authorized in 2006 to help increase the availability of respite care for family caregivers of individuals with disabilities, regardless of age. Many people with disabilities live with their families and their families provide care and support. Respite is when you have someone else spend time with your loved one while you take a short break for things such as being able to go to the gym or grab coffee with a friend or do errands or attend meetings or just to get a little rest to be rejuvenated for the caregiving role. Respite can happen in your family home or at a community location. There are different types of respite providers and some are free and low-cost and there is some funding available for some possibilities. All people providing care for a loved one need and deserve a break at some point, and it can help the person continue to provide great care and be beneficial to the person they are caring for and their whole family.

- ARCH National Respite Network and Resource Center <https://archrespite.org/> has a National Respite Locator (<https://archrespite.org/respitelocator>), a service to help caregivers and professionals locate respite services in their community.
- Get connected with a National Respite Coalition (<https://archrespite.org/national-respite-coalition>), a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the
- Get more information and resources from the Lifespan Respite Technical Assistance Center (<https://archrespite.org/ta-center-for-respite>.)
- Take Time Texas has resources about respite specific to Texas: <https://apps.hhs.texas.gov/taketimetexas/what-is-respite.html>



Social Security Disability Insurance and Supplemental Security Income

The Social Security Disability Insurance and Supplemental Security Income programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program. For more information visit <https://www.ssa.gov/disability/>

- Social Security Disability Insurance (SSDI) pays a monthly benefit that to the individual with disabilities when a parent has paid Social Security taxes. The SSDI program pays benefits to adults who have a disability that began before they became 22-years-old. The benefits are paid to the person with disabilities based on their parent's Social Security earnings record. So, if your parents paid into social security and your sibling was born with or acquired his or her disability before the age of 22 years old, they may be eligible to receive SSDI.
- SSI stands for Supplemental Security Income (SSI) and pays benefits to disabled adults and children who have limited income and resources. This is based on financial need and looks at income, assets, and living arrangements to determine eligibility.
- For information specific to the specifics of these benefits in Texas, visit Your Texas Benefits: <https://www.yourtexasbenefits.com/Learn/Home>





Home and Community Based Services (HCBS) Medicaid Waivers

The Medicaid Home and Community Based Services (HCBS) waiver program provides supports and services for eligible people with disabilities in their home and community. Nationally, the Social Security Act authorized the HCBS program under Section 1915(c) and allows states to provide services to people in their home and community instead of moving into a facility for care. Each state develops waiver programs to provide these supports and services. Texas has the longest waiting list for services in the country and is ranked 48th out of 50 states and the District of Columbia in terms of spending for supports and services for people with intellectual and developmental disabilities according to the State of the States in Developmental Disabilities.

Texas currently has five HCBS waivers to provide services and supports to different populations in the state:

- ❖ **Home and Community-based Services (HCS)** - Provides services and supports that are individualized to people with intellectual disabilities living with their family, in their own home or in another community setting such as a small group home. This program supplements, rather than replaces, other services being provided.
 - The Texas Health and Human Services Commission (HHSC) contracts with public and private entities to provide HCS services.
 - Contact the local intellectual and developmental disability authority (LIDDA) that serves the county where the person lives. Your local LIDDA can be found at <https://apps.hhs.texas.gov/contact/la.cfm> or email HCSPolicy@hhsc.state.tx.us
 - <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/home-community-based-services-hcs>

- ❖ **Texas Home Living (TxHmL)** - Provides selected essential services and supports so people with intellectual and developmental disabilities can continue to live in the community. This program is for people living with their families or in their own homes. These services are supposed to supplement other services someone is receiving.
 - The Texas Health and Human Services Commission (HHSC) contracts with public and private entities to provide HCS services.
 - Contact the local intellectual and developmental disability authority (LIDDA) that serves the county where the person lives. Your local LIDDA can be found at <https://apps.hhs.texas.gov/contact/la.cfm> or email TxHmLPolicy@hhsc.state.tx.us
 - <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/texas-home-living-txhtml>



- ❖ **Community Living Assistance and Support Services (CLASS)** - Provides services for people with a disability, other than an intellectual disability, that originated before 22 years old and impacts function in daily life. Services are based on a person's specific needs related to their disability. Services must be cost effective and not available through another program or resource.
 - The Texas Department of Aging and Disability Services (DADS) contracts with public and private entities to provide CLASS services.
 - For more information contact: 877-438-5658 or CLASS@dads.state.tx.us
 - <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/community-living-assistance-support-services-class>

- ❖ **Deaf-Blind with Multiple Disabilities (DBMD)** - Provides services for people who are deaf-blind and have other related disabilities. Services are provided to increase opportunities for people to communicate and interact with their environment.
 - For more information contact: 877-438-5658 or DBMD@dads.state.tx.us
 - <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/deaf-blind-multiple-disabilities-dbmd>

- ❖ **Medically Dependent Children Program (MDCP)** - Provides services to support families of medically fragile children and young adults to reduce placement in nursing facilities.
 - Texas Health and Human Services employees provide case management services.
 - <https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/medically-dependent-children-program-mdcp>

RESOURCES IN TEXAS



Texas Sibling Network (TSN) aims to create a community for adult siblings of people with intellectual and developmental disabilities. TSN provides support, resources, leadership and advocacy skill building opportunities for siblings. TSN is a community *for* siblings of people with disabilities *by* siblings of people with disabilities.

Website: <https://disabilitystudies.utexas.edu/TSN>

Facebook: [Texas Sibling Network](#)

Twitter: <https://twitter.com/TexasSibling>

Instagram: <https://www.instagram.com/texassiblingnetwork/>



The Arc of Texas promotes, protects, and advocates for the human rights and self-determination of Texans with intellectual and developmental disabilities.

<https://www.thearcoftexas.org/>

The Arc of Texas has a Master Pooled Trusts which is a pooled special needs trust managed by The Arc of Texas with approval from the Social Security Administration and the Texas Health and Human Services Commission. <https://masterpooledtrust.org/>



Disability Rights Texas has sample supported decision-making agreements:

<https://www.disabilityrightstx.org/resources/supported-decision-making>



Coalition for Texans with Disabilities (CTD) is the largest and oldest member-driven cross-disability organization in the state. "Cross-disability" refers to all types of disabilities and different functional needs, rather than a particular disability or subset of disabilities.

<https://www.txdisabilities.org/>