

FUTURE PLANNING FOR SIBLINGS OF PEOPLE WITH DISABILITIES

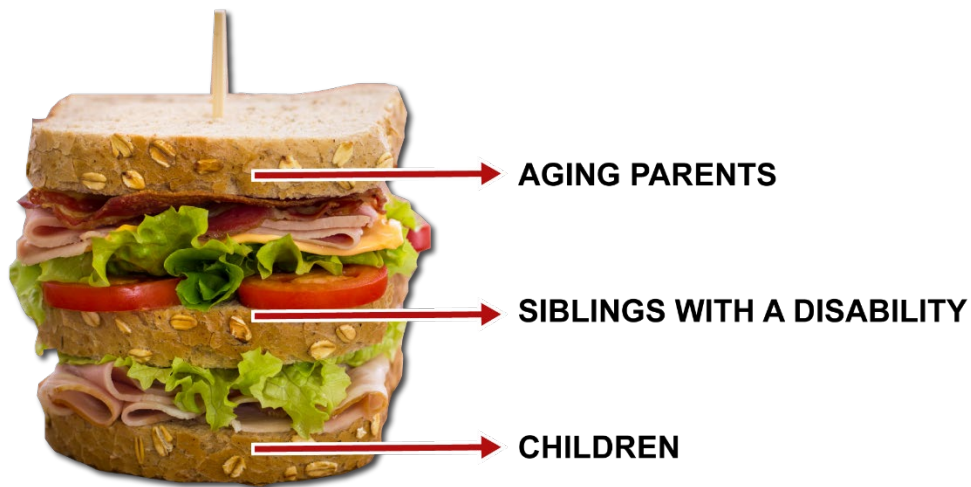
The Important Role of Siblings of People with Disabilities:

- The longest relationship of most people's lives is with their siblings, which provides opportunities for mutual support and care.
- Siblings of people with disabilities play an important role in supporting their brothers and sisters with disabilities throughout life.
- The peer nature of the relationships makes siblings uniquely positioned to support their brothers and sisters with disabilities to lead self-determined lives. This support can include many areas such as voting, employment, transportation, relationships and sexuality, healthcare, housing supports, and more.
- Siblings can advocate with their brothers and sister with disabilities to make change that is important to their entire families

Caregiving Roles of Siblings:

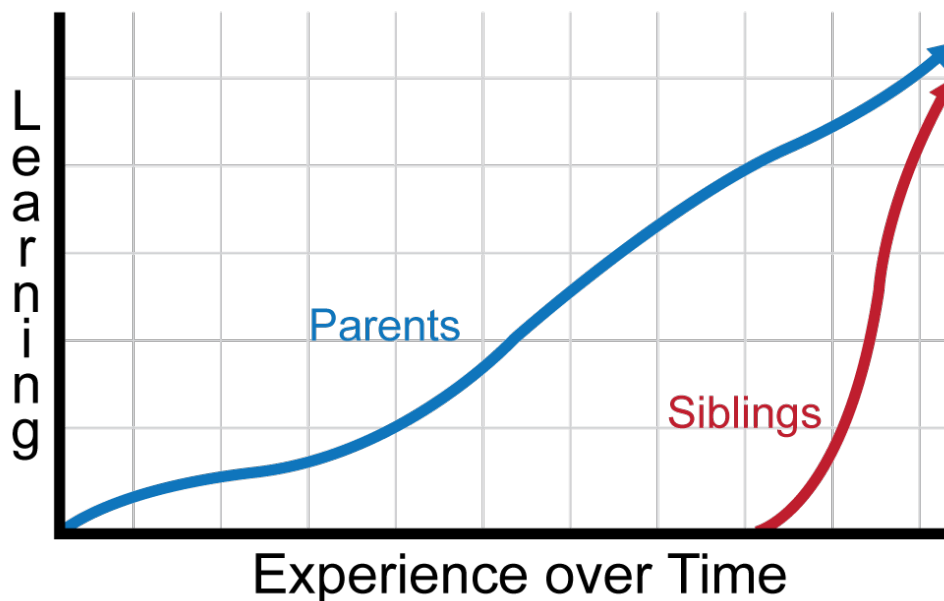
- Siblings often become the next generation of caregivers when parents are unable to provide care.
- As siblings become more involved in the care of their brother or sister with a disability, their own support needs will likely increase.
- When siblings get the support they need, their brothers and sisters with disabilities will have better outcomes.
- Most siblings anticipate fulfilling greater supportive and caregiving roles in the future.
- Siblings of people with disabilities are referred to as the "Club Sandwich Generation" because they often juggle the caregiving of their aging parents, their own children, as well as the extra layer of their brothers and sisters with disabilities. This can be overwhelming and "too big to take a bite out of."

Siblings Juggle Caregiving Roles: The “Club Sandwich” Generation



Learning Curve for System Navigation for Siblings:

- Siblings usually have a lot to learn about the service system and how to navigate it. Parents have often learned how to navigate services and have spent a lifetime building their knowledge of systems as they live and breathe the day-to-day caregiving over a lifetime.
- There is a very steep learning curve when siblings take on a greater caregiving role. And, unfortunately, the transition to caregiving often coincides with a time when their family is in a health crisis. Siblings need to be prepared sooner. Future planning conversations are critical to ensure a smooth transition.



Future Planning:



- Future planning is a process for creating a plan for the future so a person with disabilities can lead a good life.
- Future planning should get the whole family thinking about the future in a person-centered and family-centered manner.
- Future planning helps the family talk about things like where the person with disabilities wants to live and who the person wants to provide support in the future.
- *Future planning gives everyone a choice and a voice!*

What are the Barriers to Future Planning?

- Anxiety about mortality
- Difficulty trusting the system and/or professionals
- Unaware of options and opportunities
- Lack of resources and options
- Parents are afraid to “burden” siblings
- Family disagreements or fear of family disagreements
- Financial costs

What is The Sibling’s Role in Future Planning?

- Identify and share concerns and desires
- Gather helpful information
- Advocate for services and supports
- Network with other siblings and families

Tips to Start The Difficult Dialogue About Future Planning with Your Family:

- Talk to your parents and sibling(s)
- Think about your role
- Think about the people who should be part of the conversation
- Bring resources to share with your family
- Future planning is not a one-time conversation, it is an ongoing process. Think about how you can start the conversation initially and keep the dialogue going.

Components of Future Planning:

1. Financial Planning

- **Special Needs Trusts** are a legal vehicle enabling assets to be held on behalf of someone with disabilities without affecting their eligibility for means-tested public benefits such as Medicaid or Supplemental Security Income. They require an initial financial investment, although in the long run it can also help save money.
Special Needs Alliance: <http://www.specialneedsalliance.org/>
- **ABLE Accounts** (Achieving a Better Life Experience) help people with disabilities have a savings account for money that is to supplement, but not supplant, other benefits a person with disabilities receives.
Save With Able: savewithable.com
- **Social Security Disability Insurance (SSDI)** - monthly benefit paid to the person with disabilities based on their parent's Social Security earnings record.
- **Supplemental Security Income (SSI)** - benefits to disabled adults and children who have limited income and resources. This is based on financial need.
- **Medicaid** - provides health coverage to eligible low-income adults, children, pregnant women, and people who are older or who have disabilities. Many people with disabilities use Medicaid to access social and community supports, including housing supports and other long-term services.
- **Medicare** - health insurance program for people age 65 or older or people younger with certain disabilities. The program helps with the cost of health care, but it does not cover all medical expenses or the cost of most long-term care.

2. Legal Planning

- Supported Decision Making - A process of supporting an adult with disabilities to make his or her own decisions that fosters the person's self-determination and does not take away their rights. Supported Decision Making is an alternative to guardianship.
 - National Resource Center on Supported Decision-Making:
<http://supporteddecisionmaking.org/about>
 - Supported Decision-making and the Sibling Role:
<http://www.supporteddecisionmaking.org/legal-resource/supported-decision-making-and-role-siblings-presentation>
- Surrogate/Substitute Decision Making
 - **Representative Payee** is an individual or organization that serves as a representative to help a person manage his or her government benefits.
 - **Power of attorney** is when someone is given authority to make legal and financial decisions on a person's behalf
 - **Health Care Surrogacy/Proxy** is a document that allows an individual to appoint someone to make health care decisions for them if they are or become unable to make these types of decisions by themselves.
 - **Guardianship** is when someone is designated to make decisions on behalf of someone else. This should be the last option to consider because it can take away rights of people.

3. Residential Planning

- Residential planning is a critical component of future planning. Too often, this conversation regrettably occurs in a rushed manner during a parent's health crisis. Everyone benefits from housing conversations occurring early so there is appropriate time for planning.

- For Home and Community Based supports and services for adults with intellectual disabilities, many states have Medicaid waivers that provide residential services and a lot more: employment services, certain therapies, adaptive aids and more. Every state has different services. Check your State's Department of Disability (the name is slightly different in each state) to see what is available.
- Centers for Independent Living (CILs) are non-residential, community-based organizations, directed and managed by persons with disabilities, which are dedicated to the philosophy that all people with disabilities have the right and the responsibility to make choices to control the direction of their lives and participate fully and equally in their communities

4. Building Relationships and Support Networks

- **Connect with other siblings and pertinent sibling information**
Join the Sibling Leadership Network: siblingleadership.org
Illinois Siblings connect with Supporting Illinois Brothers and Sisters: sibsnetwork.org
Online peer-support networks by Sibling Support Project—Find them on Facebook:
 - Sib20: for sibs in their 20
 - SibNet: for adult sibs
- **The Arc's Center for Future Planning** has a Build your Plan tool that will allow Families to collaborate on Future Planning
 - <https://futureplanning.thearc.org/>
- **Respite** is when you have someone else look after your loved one while you take a short break. It can be provided in your home or a community location. 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.
 - <https://archrespite.org/respitelocator>



This resource was developed by the Sibling Leadership Network in partnership with Supporting Illinois Brothers and Sisters with an investment of the Illinois Council on Developmental Disabilities. This project is supported in part by grant number CFDA 93.630 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.