

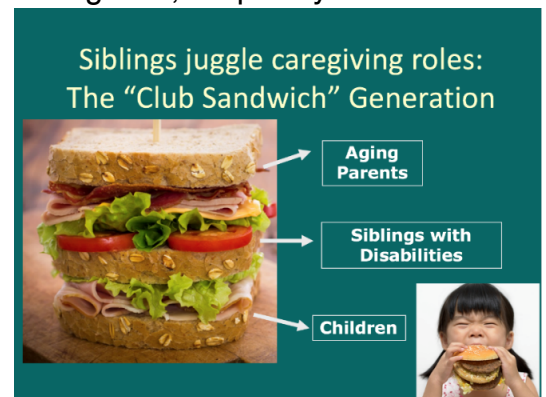
The Important Role of Siblings of People with Disabilities in Texas

Why are siblings of people with disabilities important?

- The longest relationship of most people's lives is with their siblings which provides opportunities for mutual support and care. ⁱ
- 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. ⁱⁱ
- Siblings can advocate with their brothers and sister with disabilities to make change that is important to their entire families. ⁱⁱⁱ

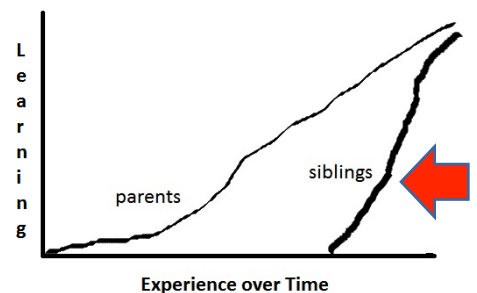
Caregiving roles of siblings:

- Siblings often become the next generation of caregivers when parents are unable to provide care. Typically female siblings become caregivers, frequently the oldest female sibling in the family. ⁱⁱ
- 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. ^{iv}
- Most siblings anticipate fulfilling greater supportive and caregiving roles in the future. ^v
- 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." ^{vi}



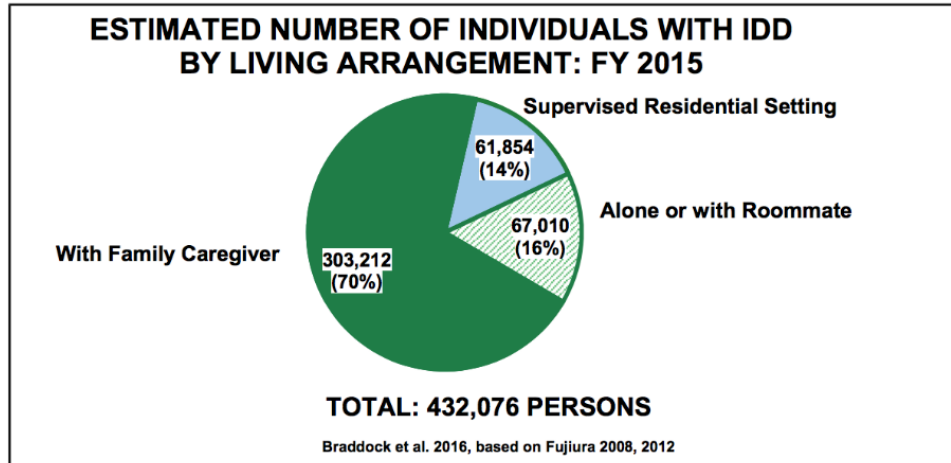
Learning Curve for system navigation for siblings:

- Siblings usually have a lot to learn about the service system and how to navigate it. Parents are often expert service navigators 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.



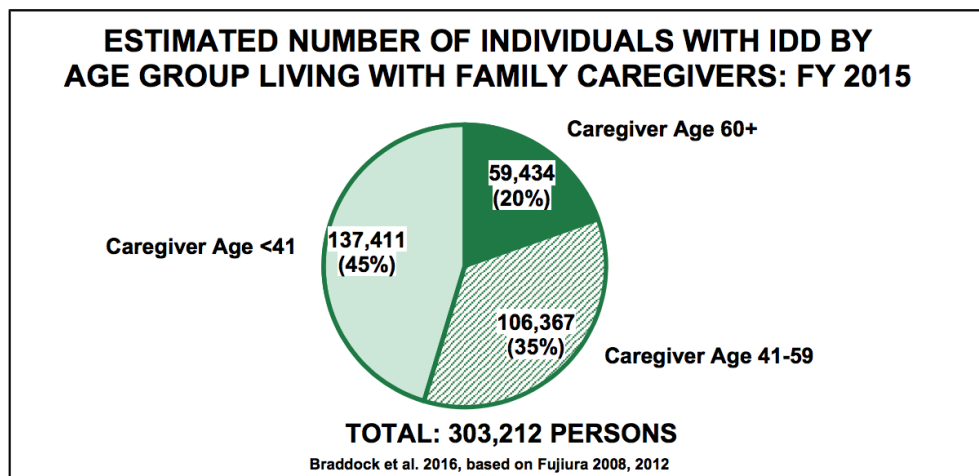
Family Support in Texas: State of the States in Developmental Disabilities^{vii}

Families provide the majority of support for people with I/DD. In Texas, most individuals with I/DD (70%) live with their family caregivers.



However, only 10% of the I/DD funding goes to family support services. There is a disconnect between the support provided by families and the support received by families.

Further, the aging of family caregivers is an important issue in TX that has implications for the service system and family support. Family caregivers are getting older and people with disabilities are living longer. Of the over 300,000 people with IDD living with their family caregivers in TX, 20% are over the age of 60 years. That is 60,000 families in TX that will likely need a caregiver transition in the future. As parents age and are less able to support their adult child with disabilities, sibling involvement becomes more necessary.



Siblings Needs Across the Life Course:

The needs of siblings of people with disabilities are complex varied, and change over time. Some needs include:^{viii}

Childhood:

- Developmentally appropriate information about their sibling's disability.
- Information to respond to questions from other people about their sibling's disability. (i.e. a script that they can use to answer questions that others may be asking about their sibling.)
- Quality time alone with parents.
- To meet peers who are also siblings of people with disabilities who understand their concerns.
- Strategies for addressing bullying of their sibling and/or themselves.
- Parental explanations about potential differences in expectations and rules between themselves and their sibling with disabilities.



Teen Years:

- Opportunities to spend time alone with friends.
- Opportunities to talk to their family about their questions about what the future may hold with their sibling with disabilities.
- Strategies to address peer reactions and bullying.
- An invitation to provide input into the IEP process (if their sister wants them to do this.)
- A safety plan, when appropriate, if their sibling's behavior is violent.
- Space and guidance to plan for life outside of the family (leaving for college, changing living arrangements, or readjusting familial relationships.)



Adulthood and Older Adulthood:

- Spaces to address concerns about future planning and future responsibilities.
- Discussions about raising their own children and considering heritability of disabilities. These conversations are often not only medical but often emotional.
- Guidance on how to navigate the "system" of services and support related to their brother or sister's disabilities.
- To learn how to support their brother or sister with disabilities live a self-determined life.
- Support for the issues of grief and loss – how to support your sibling when parents die; how to support yourself in grief; the loss of a brother/sister.
- Increased support for the transition of caregiver roles shifting.
- Support for managing life across state lines from your brother/sister.



How Can Siblings Connect:

If you are a sibling:

- Sign up for email updates: <https://utexas.us17.list-manage.com/subscribe?u=90c0ef0bff75993466791a079&id=434d67d480>
We'll keep you up to date with statewide events, provide opportunities to connect with others, and send information and resources specific to the unique aspects of the adult sibling relationship.
- Connect with other siblings through our Texas Sibling Network Facebook Group: Chat with siblings across the state in a Facebook group. Swap stories, support others, get advice, and find out about statewide sibling related events. On Facebook: Texas Sibling Network <https://www.facebook.com/Texas-Sibling-Network-155571918496739/>
- Contact us to learn more about the Texas Sibling Network:
Nick Wings-Yanez at nwingsyanez@utexas.edu

If you are a sibling supporter (parent/self-advocate/sib-in-law/professional):

- Invite us to speak to your group about the Texas Sibling Network
- Contact us about making a presentation in your area
- Help us host an event for siblings, families, and/or professionals
- Please contact us to learn more about the Texas Sibling Network:
Nick Wings-Yanez at nwingsyanez@utexas.edu



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*\$83,655, 77% DD funds; \$25,378, 23% non-federal resources.

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