



# **Siblings: Too Important to Ignore**

**Chattanooga Autism Conference**

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# The Longest Lasting Relationship in a Family...

the Sibling Relationship



# If we support typically developing sibs as they grow up



We increase the chances they will elect to remain lovingly involved as adults



# **Sibling Research Don Meyer**

Unique Opportunities

Unique Concerns

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

# Embarrassment



(It happens to everyone)

# Guilt

Feeling responsible for the disability

Survivor's guilt

Guilt over abilities or health

Guilt over typical sibling conflicts

Guilt regarding caregiving

# Maturity

Experiences different from your peers'

Loss of innocence

Increased responsibilities



# Insight

Appreciation for their siblings' abilities

Appreciation for their family

Appreciation for one's health and capabilities

# Isolation, Loneliness, and Loss

Isolation from parents' attention

Isolation from information, the process

Isolation from peers

# Loyalty



# Tolerance and Advocacy

Greater tolerance, compassion, and  
understanding of people

Understanding of the consequences of  
prejudice

Ardent advocates for people with special  
needs

# Resentment

Loss of parental attention

Unequal treatment and excessive demands

Resentment regarding failure to plan for the future

# Avoiding Misconceptions About the Condition



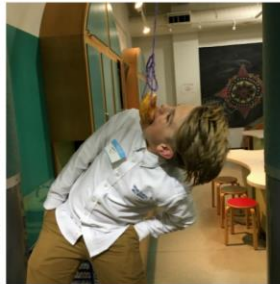
# What Sibshops are... And are not...

Sibshops are “events” – a time to celebrate  
being a sib

A time to acknowledge the good, not-so-good,  
and in-between times

Are not therapy, although the effect may be  
therapeutic





# Sibling Support Project Goals

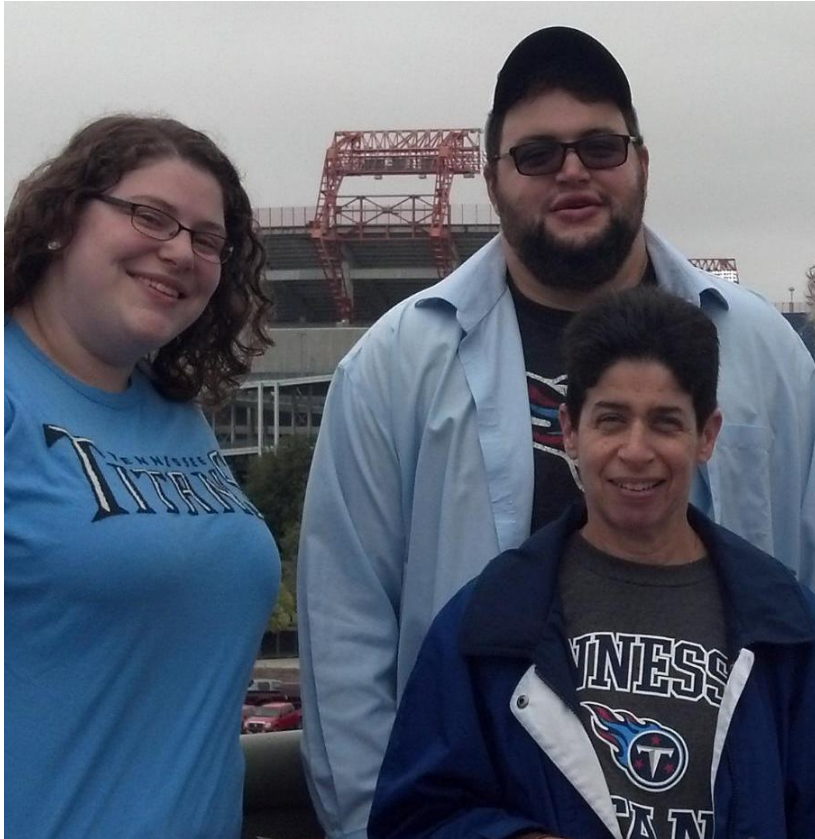
To provide brothers and sisters of children with special needs an opportunity to:

- meet other siblings in a relaxed recreational setting
- discuss common joys and concerns with other siblings
- learn how others handle situations commonly experienced by siblings of children with special needs
- learn more about the implications of their brothers' and sisters' special needs

To provide parents with an opportunity to learn more about common concerns of brothers and sisters



# University of Washington Study on Impact of Sibshops



- **90%** Said Sibshops had a positive effect on their feelings toward their siblings.
- **2/3** – Said Sibshops taught them coping strategies
- **3/4** - Reported Sibshops affected their adult lives.
- **94%** - Said they would recommend Sibshops to others



# Tennessee Adult Brothers and Sisters



Remember...if we support typically developing sibs as they grow up...



We increase the chances they will  
elect to remain lovingly involved as adults...  
but they still need support

# Tennessee Adult Brothers and Sisters

## **MISSION**

To be the premier organization in Tennessee that empowers siblings to lead fulfilling lives as they advocate for their brothers and sisters with disabilities.

## **VISION**

Provide information, support, and networking opportunities for adult siblings of individuals with disabilities in the state of Tennessee.

# TABS Membership



TABS comprises a statewide and local network of 100+ adult sibs of individuals with intellectual and developmental disabilities (I/DD), special healthcare needs or mental diagnoses.

Interested in starting a TABS group in your city? Contact us!

# Why do we need TABS?

Sibling relationships have unusual challenges and rewards

- **Families feel strain of long-term support.** In the U.S., 71% of the 4.9 million people with I/DD live with their families, yet only 7% of funding goes to family support services.
- **Siblings are peer advocates.** While they are in a unique position to support their brothers & sisters with I/DD (with perspectives different from parent caregivers), their needs are often overlooked.





# Why do we need TABS?

Sibling relationships have unusual challenges and rewards



- **“Club Sandwich” generation:** Siblings often have to care for multiple generations of their families (aging parents, brothers & sisters with disabilities, children).
- **Connect with others who understand:** Share your experience and get needed resources, including assistance with planning for your and your sibling’s future.

# Why do we need TABS?

Sibling relationships have unusual challenges and rewards

- There are more than 100,000 adults and children in TN that have intellectual & developmental disabilities.
  - 75% of these individuals live with and are supported by their families and are not receiving paid long-term services and supports.
- When “disability” is defined more broadly, more than 975,000 Tennesseans have a disability.\*
- It is safe to assume MANY of these individuals have siblings who offer varying levels of support to their brothers and sisters across the lifespan.

Source: \*Based on 1.55% prevalence of 6.6 million population of TN, US Census (2015);

<http://www.stateofthestates.org/documents/Tennessee.pdf>;

\*\* American Community Survey data table search for “disability characteristics” and “Tennessee”

# Affiliates

Partners in education and empowerment



**VANDERBILT**  
**KENNEDY CENTER**  
for Research on Human Development



Council on  
Developmental Disabilities



Sibling Support Project

**SIBLING**   
**LEADERSHIP**  
**NETWORK**

# Programs and Activities

## Supporting young sibs through Sibshops

- Events for younger siblings (ages 8-13) that allow them to connect with other sibs, play games and have fun, and learn that they're not alone.
- Aug. 2016 – Hosted a Sibshop facilitator training to grow the number of TN Sibshops.
- Hope to promote more opportunities for SibShops in TN.



# Programs and Activities

## Sibling Meet-Ups



Some TABS chapters host informal meetings or dinner get-togethers to socialize and discuss a variety of topics.

# Programs and Activities

## Conferences

We convene workshops and statewide conferences. The first statewide conference was in 2009; hosted 5 more since then. Topics include...

- Employment
- Financial and legal planning
- Healthcare
- Housing
- Long-term services and support
- Planning for the future
- Self-care/caregiver stress





# National Resources for Siblings

- Sibling Leadership Network - <http://siblingleadership.org>
- The Arc US Center for Future Planning:  
<https://futureplanning.thearc.org/pages/learn/who-are-you/sibling>
- Sibling Support Project - <https://www.siblingsupport.org/>
- Online communities – led for siblings by siblings:
  - SibNet [Yahoo listserv & Facebook group]
  - SibTeen [Facebook group]
  - Sib20 [Facebook group]



# In their own words...

TN Siblings share thoughts on their experiences at our conferences and workshops.



*"This is such a valuable resource for an under-served population. I come away each year with renewed energy, new information - and new friends!"*

*"I really like hearing people's personal stories. That to me is more helpful than anything. I like learning where other siblings are now, and how they felt/are feeling when they were dealing with similar situations."*

*"Great opportunity! Sibshops are extraordinary and every sibling should have the chance to join one and feel a part of the 'sib' community!"*

*"I really learned a lot and will recommend this program to my other siblings who are co-caregivers for our sibling who has a disability."*

# How can you support TABS?

- Share info about TABS with other brothers, sisters and families in the disability community.
- Let us know if you are interested in launching Sibshops in your community.
- Involve us in your disability conferences, events or projects so siblings can have a “seat at the table” and TABS can recruit more sibling members!



# Join Us In Supporting Tennessee Siblings



**Contact:** *Emma Shouse, TN Council on Developmental Disabilities*



615-253-5368



[info.tabs@vanderbilt.edu](mailto:info.tabs@vanderbilt.edu)



[@tabs.siblings](https://www.facebook.com/tabs.siblings)



[vkc.mc.vanderbilt.edu/vkc/tabs](http://vkc.mc.vanderbilt.edu/vkc/tabs)



# Save the Date!

**SIBLING**   
**LEADERSHIP  
NETWORK**

## 2017 National Conference

June 24 & 25  
Hartford, Connecticut

For updates on details: [siblingleadership.org](http://siblingleadership.org)

<http://siblingleadership.org/2017-sln-conference/>



**Thank You!**