2025 Texas Focus: Empowering the Future Through Sibling Support

Presenter: Julia Chalker, Director, The Arc of DFW Area
Friday, June 5, 2026
8:30 - 9:45 AM

Opening Thought

- Siblings are often the longest-lasting relationship in a person's life

My Story

- Childhood
- Teacher / Transition Specialist
- Sibshop Facilitator
- Advocate
- Nonprofit leader

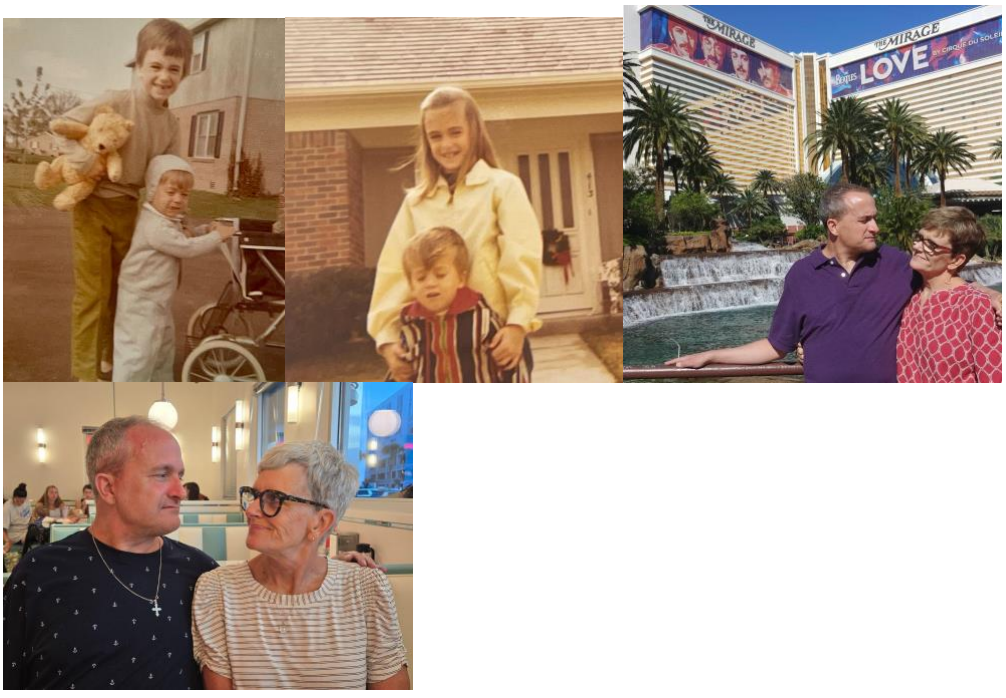

Figure 1
First photo: Speaker as young girl helping younger brother to push a baby buggy
Second photo: Speaker as young teenager with younger brother in front of a house
Third photo: Speaker and her brother as adults together in front of The Mirage Hotel in Las Vegas
Fourth photo: Speaker and her brother as older adults looking at each other

My Identity as Bobby's Sister

- Lifelong advocate
- Protector
- Companion
- Caregiver
- Newly-appointed guardian / decision "guider"

Figure 2
Photo: Speaker and brother as adults on beach

Today's Objectives

- Understand the unique experiences of siblings
- Learn what the research shows
- Explore both the challenges and positive impacts
- Identify practical ways to support siblings
- Recognize the importance of equipping siblings

Terminology for Today

- "Sib" refers to the sibling who has a brother or sister with a disability or special health concern
- "Special sib" refers to the sibling with a disability or special health concern

Why is Sibling Support So Important?

Siblings' Long-Term Involvement

- Likely going to be involved in their sister or brother's lives for the longest amount of time
- Need to increase the likelihood that sibling will desire to voluntarily stay involved through lifetime
- Providing support to siblings will better equip them for their future involvement with sibling in whatever role they are in
- Supporting siblings subsequently helps the entire family system

When siblings are supported, the entire family system becomes stronger!

What the Research Tells Us

Research Highlights - Young Sibs

- Exhibit more empathy and understanding toward those with disabilities
- Some studies indicated that sibs may have increased behavior problems, anxiety, and depression
- Siblings tend to spend a lot of time with special sibs, have warm relationships

Research Highlights - Young Sibs

- Even in youth, found to take on more caregiving roles than those without special sibs
- Effects of this extra caregiving (mixed research) -
    - Developing greater understanding of others
    - Increased anxiety and less time to spend time with own friends
- Involvement in service coordination - most family plans as well as transition plans don't include siblings

Research Highlights - Adult Sibs

- Most report close relationships with their special sibs and positive benefits from the relationship (negative effects minimal)
- Many report their special sibs influence their life decisions such as marriage and family and careers (much more likely to enter a helping profession)

Research Highlights - Adult Sibs

- Adult sibling relationships tend to be very close and positive - females more involved and closer
- Adult sibs tend to anticipate future caregiving roles for their special sibs
    - 60% anticipate fulfilling primary caregiving roles
    - Female and lone sibs more likely
    - 19% expect to live with their special sibs

Yet, many siblings are not included in future planning!

Important Research Takeaways

- The disability itself is usually NOT the strongest predictor of sibling well-being . . .
- Family communication, support, and coping patterns matter more!

Challenges for Siblings

Factors Affecting Sibling Relationships

- Age, gender, type of disability
- Family's coping strategies
- External support systems
- Financial resources
- Personal and cultural beliefs

Social Challenges

- Embarrassment - special sib's appearance or behavior (may be more prevalent if mild or "invisible" disability)
- Difficulty explaining disability to peers
- Isolation from friends who "don't understand"

Guilt or Grief

- Feeling responsible for the disability - irrational but real
- Survivor's guilt / guilt over own abilities
- Guilt over typical sibling conflicts or having negative feelings
- Grief related to unmet expectations

Figure 3
Photo: Pre-teen boy sitting on a round swing and looking upset

Stress or Anxiety

- Demands of caregiving responsibilities
- Concern for parents' stress
- Concerns for the future: adult roles, financial planning

Figure 4
Photo: Teenage boy with his head in his hands looking stressed

Isolation

- Feeling invisible or overlooked
- Parents may be too overwhelmed or stressed to recognize sibling's call for attention
- Sib might not go to parents when they need them because they see the stress caused by the special sib

Figure 5
Photo: Young girl sitting away from others with her head on her hands on her desk

Isolation from Information

- Sibling's disability often not discussed with them as means of protecting them
- Insufficient information about sibling's problems leads to unique loneliness

Isolation from Peers

- Hard to share feelings of frustration and loneliness with friends who cannot relate

Figure 6
Photo: Young boy walking ahead of other classmates looking sad

Resentment

- Attention sibling receives
- Amount of care and time sibling requires
- Perceived unequal treatment
- Increased responsibilities
- Limitations on family lifestyle

Figure 7
Photo: Teen girl standing with her arms crossed looking annoyed

Pressure to Achieve

- Common for siblings to excel in academics, sports, music, or even behavior
- Conscious or unconscious pressure from parents to compensate
- Many sibs place the pressure on themselves
- Could be vulnerable to internalizing issues rather than seeking help from parents

Figure 8
Photo: Graphic of an A+ report card with "Over-Achiever" printed on it

Positive Impacts on Sibling Relationships

Strengths Sibs Often Develop

- Emotional intelligence, empathy, resilience
- Increased maturity, patience, flexibility, and a deep sense of responsibility
- Advocacy skills

Strengths Sibs Often Develop

- Insight
- Appreciation for sibling's abilities, pride
- Compassion, humor, loyalty, and unconditional love
- Greater understanding of diversity and inclusion

Unique Perspectives Developed
Siblings often:

- Become strong community leaders

- Enter helping professions
- Advocate for inclusion and accessibility
- Build deep and meaningful relationships

Influence on Future Vocations

- Sibling experiences often lead to pursuing caregiving-related professions (i.e., medicine, special education, psychology)
- Siblings often cite their upbringing as a driving factor of career choice

Communication / Providing Information

How Families Provide Info to Sibs

- HOW info is given greatly affects a sib's adjustment to it
- May assume the worst when left in the dark
- Often excluded from traditional sources of info (i.e., teachers, doctors, therapists, and other providers)
- May hesitate to ask questions, not wanting to upset parents

Information Needs - Preschoolers

- Cannot catch it / didn't cause it
- Concrete thinkers - explanations as clear as possible
- Describe in terms of differences in behavior and routine
- "Our eyes are like a camera taking pictures for our brain – sometimes our eye camera doesn't work right"

Information Needs - Older

- School-Aged Children - need information to answer their questions as well as those of peers or strangers
- Teenagers - may have specific questions about sibling's needs

Provide Educational Resources

- Age-appropriate books and publications for sibs
- Many disability-specific organizations have resources for sibs

Figure 9

Photo: Mother reading a book to a little boy and a little girl

Open Communication

- Keep the sibling's special needs an open topic and encourage questions
- Answer questions about the disability/condition
- Provide with written materials, age-appropriate media
- Include siblings with service providers
- Practical Strategies Families Can Start Today

Create One-on-One Time

- Plan for special time with sibling
- Even brief intentional moments matter
- Use your network to help with logistics
- Helps siblings feel seen and valued

Promote shared activities

- Include siblings in learning activities such as braille or orientation and mobility games
- Adapting parts of activities that a visually impaired child can do alongside their sibling prevents exclusion
- Include Siblings in Learning Activities

Involve Siblings but Monitor Caregiving Expectations

- Involve siblings in daily activities but be aware of expecting excessive caregiving duties
- Allow choice whenever possible

Simple but Powerful Actions

- Check in regularly with siblings
- Ask open-ended questions
- Add to their knowledge of sibling's disability over time with gains in maturity
- Encourage outside interests and friendships
- Celebrate each child's unique accomplishments
- Give equal responsibilities to all siblings (based on skills), fostering fairness and teamwork

Encourage Identity Outside of Being a Sib

- Provide sib with space to find personal interests, achieve goals, and develop positive self-identify outside of disability/sibling support

Transition / Future Planning

Prepare for the Future Gradually

- Discuss future planning over time

- Include siblings in conversations at their level of understanding (i.e., school, therapies, medical – they often have valuable input
- Long-term planning benefits siblings
- Knowing there is a plan reduces stress and anxiety

Figure 10
Photo: Pre-teen boy wearing glasses and trying to look at a question mark taped to his forehead

Transition as Part of the IEP

- Does parent/family assessment include sibling voice?
- Postsecondary goals (do they involve sibling in some way?)
- Coordinated Set of Activities (include sibling supports, resources, long-term planning, etc.)
- Include sibs in person-centered planning when old enough to understand/contribute

Important Conversations to Have Over Time

- Guardianship and alternatives
- Financial planning
- Housing options
- Support networks
- Emergency planning
- Expectations for involvement

Future Planning Should be Collaborative

- Encourage shared decision making
- Have realistic expectations
- Support systems beyond one sibling if possible
- Respect sibling's own life goals

Connecting Sibs with Support

Once again . . .

- Sibs will likely have the longest-lasting relationship with their special sibs in the family
- Yet they have far fewer opportunities to gain access to programs, services, and professional support

Opportunities to Meet Other Sibs

- Develop supportive relationships with others in similar circumstances
- Sibling support groups
- Camps and other activities that include siblings
- Online connections

Figure 11
Photo: Speaker with approximately 10 smiling children and one other adult appearing to be having fun together

Other Connections

- Counseling or therapy if needed
- Mentors such as adult sibs
- Let counselors, mentors, teachers, etc. know of individual situations, current issues

Sibshops - General

- Sibling Support Project - since 1990
- Don Meyer, M.Ed., pioneer in sibling movement
- Targets children 8-13 years of age
- Must become a certified Sibshop facilitator in order to use the Sibshop name/logo

Figure 12
Image of national Sibshop logo

Goals of Sibshops

- Opportunity to meet other sibs
- Discuss common joys and concerns
- Learn how to handle different situations common to sibs
- Learn more about implications of their siblings' special needs

Sibshop Activities

- Alternate between fun, lively recreational activities and those that allow them to share their experiences (but are still fun!)
- Sibshop book has many ready-to-implement activities
- Sample Sibshop schedule

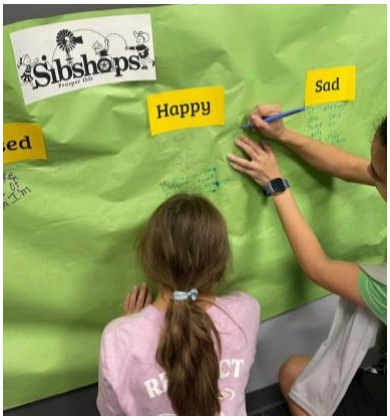

Figure 13
Photo: Children writing on the "Graffiti wall" under different feeling labels

Possible Sibshop Outcomes

- Increase the chances that brothers and sisters will elect to remain lovingly involved as adults
- Study showed that 75% said that Sibshops had an impact on their adult lives)
- Creates bonds of support and friendship for sibs that can last into adulthood

Find or Start a Sibling Support Group!

- Find a Sibshop
- Sibshop Facilitator Certification training
- Different models (i.e., school district, agency, hospital)
- Contact Julia if you need support from someone who has started Sibshops

Sibling Support Resources

- Sibling Support Network
- APH ConnectCenter
- Online Sibling Connections
- Sibshop Resources

Sibshop Videos

- My Sib Video

World Changers Video

Final Thoughts

- Siblings will be there after parents are gone and special education services are a distant memory
- If provided with support and information, they can help their sibs live dignified lives from childhood into their senior years

Thank you for attending!

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