Sibling Support and the Importance of the Sibling Relationship

Katie Foley
kfoley@thearcnepa.org
Mandy Colville
mcolville@thearcnepa.org
Roseann Polishan

rpolishan@thearcnepa.org



What makes the Sibling Relationship most important?

- Brothers and sisters will likely be the longest relationship that the person with special needs will have
- ▶ They will be there long after the parent relationship is gone
- Special education services are gone
- They need support as much as parents

Important things to remember

- Siblings require their own time and space
 - ► They should have their own interest
 - They need their own time with you
 - It is important to acknowledge their concerns
 - Siblings are also the most important and influential role model

Some struggles as a result of being the sibling

- > Typically developing siblings set high expectations for themselves.
 - They feel the need to be perfect and carry the expectations for the family hopes and fears
- Siblings lack support of peers
- > Siblings can feel resentful, guilt, shame and many emotions that are never addressed and can cause a very dysfunctional or nonexistent relationship as a result
- Siblings often suffer high levels of anxiety
- Most siblings that take care of their brother or sister with a disability are more likely to live in poverty
 - Family caregivers are the largest source of Long-term care available –Opinion research corporation 2005
 - Caregivers, especially women are 2.5 times more likely to live in poverty. -Rice University
 - > 76% of Sibling Caregivers make less than 50,000 a year.
 - Sisters are more likely to be caregivers and this position is usually permanent

Struggles of Siblings continued:

- Effects of having siblings with disabilities on women and girls
 - > 3 times more likely to have functional impairment
 - ► Feel sad and nervous
 - Have difficulties at school
 - American Association of Intellectual and Developmental disabilities. 2015

Why the typically developing sibling needs support?

- Siblings share many of the same concerns that parents of children with special needs experience,
 - isolation
 - a need for information
 - guilt
 - concerns about the future
 - caregiving demands

How to make siblings feel equally important

- Make special one on one time for the sibling:
 - My mom especially would make time to take me to places that she and I only enjoyed (like the art museum). That was always very special.
 - My mom and I had "dates" and did something that I wanted to do. I know planning this was sometimes difficult for her, especially if my brother was having a bad day. But she always made it happen one way or another.

Siblings need information too.

- Throughout their lives siblings will have ever changing need for information about their siblings disability.
- ▶ Siblings are often left out of the planning and support that is given to the parents to help support the child with special needs and the services intended to help the child learn to succeed and support his or her self. Service providers typically do not include siblings although they are an important part of the "functional family" relationship Family decisions are often made without the sibling despite the lifelong role that they will play.
- Siblings have concerns about the future too.
- Many brothers and sisters worry about what they will need to do for their siblings as they get older. It can help the typically developing sibling make plans and prepare for the future, consider back up plans and bring them into the loop.
- Include both sons and daughters in the planning an caring.
- Communicate with your children Actively listening can be extremely helpful to a child with a lot of worry on their mind.

Why the need for support for Siblings?

Parent often find an irreplaceable benefit to befriending other parents who have children with special needs. It is just as important for siblings to find support among their peers.

It is important to assure our siblings that they have the right to pursue their own dreams. They will have an ever evolving relationship and it is better to allow the choice instead of obligations to the sibling. For their own good and that of the sibling with special needs

Siblings have concerns about the future too.

- Many brothers and sisters worry about what they will need to do for their siblings as they get older. It can help the typically developing sibling make plans and prepare for the future, consider back up plans and bring them into the loop.
 - Some siblings start thinking about how they will care for their brother or sister as young as 5
 - Many siblings don't know anything about their sibling's care, supports or needs until the parent passes away.
 - Parents often wish to prevent their children from worry but the typically developing child will worry regardless.
 - Siblings will often carry a large financial burden without knowing where to get help to care for their brother or sister.

Siblings should be included in decisions and heard

- Include both sons and daughters in the planning an caring.
 - Caregiving is more often left to the female sibling but all brothers and sisters should be included in understanding and planning for the future.
- Communicate with your children "Actively" listening can be extremely helpful to a child with a lot of worry on their mind.
 - Children who have felt heard (according to The siblings Support Project) were less likely to feel resentment and more likely to have a positive relationship with their sibling
 - ► Children who attended Sibshops were 90% more likely to have positive feelings about their sibling relationship.

What are some of the significant voids in sibling resources?

- Siblings are often left out of the planning and support that is given to the parents to help support the child with special needs and the services intended to help the child learn to succeed and support his or her self.
 - Service providers typically do not include siblings although they are an important part of the "functional family" relationship
 - Family decisions are often made without the sibling despite the life long role that they will play.

Celebrate each child equally for their own accomplishments

- Just as it is important to acknowledge the accomplishes big and small of the child with special needs, it is equally important to acknowledge the typically developing child's successes as well. Each child is unique!
 - " My parents made sure to celebrate my sister's and my achievements separately and equally. I celebrated my sister's milestones and it was expected that my sis would celebrate mine."
 - " My mom often complemented me on my accomplishments, skills, and spirit—and still does. That helped a lot!"

Acknowledge the Specialness of the sibling

- ▶ I liked when they acknowledged that I knew as much about my brother as my parents did.
- Our parents were proud that each of us was unique and had our own skills and abilities.

Siblings have a right to Autonomy

- It is important to assure our siblings that they have the right to pursue their own dreams. They will have an ever evolving relationship and it is better to allow the choice instead of obligations to the sibling. For their own good and that of the sibling with special needs
 - Siblings who feel they have no choice will often grow to resent their sibling and, or parent and are less likely to be a strong advocate.
 - ▶ Siblings who feel supported in their life are more likely to return of their own volition and more often than not will carry on in advocacy roles in their careers as well.

Sibling Resources

- Sibling Leadership Network:
 - ► http://siblingleadership.org
 - Katie.Arnold@siblingleadership.org
- Sibling Support Project:
 - www.siblingsupport.org
 - bit.ly/sibshopnearyou
- Books and Publications for all ages

Sibling Support Social Media

- Sibnet (adultsiblings) bit.ly/adultsibnet
- Sib20 (18-30) bit.ly/sib20
- SibTeen (until age 18) bit.ly/sibteen

Family Medical Leave

► The U.S. Department of Labor (DOL) clarified when an adult (18+) sibling may be eligible to take job-protected leave under the <u>Family and Medical Leave Act</u> (FMLA). The DOL now includes siblings among those eligible for FMLA job-protected leave under certain circumstances.

How are siblings covered?

- You the employee are providing care to someone who acted in loco parentis for you when you were a child. Your eligibility is based on the fact that this person acted "in the place of a parent" in the past.
- ➤ You the employee are providing in loco parentis In this case, your eligibility is based on the fact that you are acting "in the place of a parent" right now.

It's important to have more than just special needs that connects the family

Some families are sports fans, some are travelers, readers, or love board games but sibshops have found that children who grew up in families that were connected by more than just special needs were more successful and happier.

What is the Sibling Support Project

- Founded in 1990 It is the first National program dedicated to the life-long and ever changing concerns of the Millions of brothers and sisters of people with special needs.
- SibShops understand the Key role of Siblings and help support them throughout their lifetime

https://youtu.be/qyz5Ds1m0q4

Sibshops

- Sibshops. Sibshops are lively events for school-age brothers and sisters of kids with disabilities and health concerns. Sibshops exist throughout most US states and Canadian provinces, and in several countries around the world.
- Online Communities for Brothers and Sisters. The Sibling Support Project hosts the largest and longest- standing social networking groups for siblings and other family members, including SibNet, SibTeen, Sib20 and GKSN (Grandparents of Kids with Special Needs).
- Publications. Our books and publications for and about siblings include Thicker Than Water, The Sibling Survival Guide, Views from Our Shoes, The Sibling Slam Book, Living with a Brother or Sister with Special Needs, and Sibshops: Workshops for Siblings of Children with Special Needs.
- Workshops and Training. Since 1990, we have presented hundreds of workshops and trainings on Sibshops and sibling issues across the country and around the world.

https://youtu.be/S6icBUpGkxs

Sibshops and their benefit

- Sibshops give children the opportunity to connect to other children that understand them and their siblings
- ▶ In a survey conducted by the University of Washington in 2005:
 - Over 90 % of respondents had a positive effect on the feelings toward siblings.
 - ▶ Sibshops taught coping strategies to over 67%.
 - ▶ 75% reported SibShops affected their adult life.
 - ▶ 94% said they would recommend Sibshops to others.
 - ▶ The biggest beneficiaries of the of Sibling Support are the Siblings with Disabilities
 - ▶ Sibshops helped siblings to remain lovingly engaged throughout their life.

The Arc Sibshop's Schedule

- > 3/26/23 (Sunday) 11:30
- > 5/27/23 (Saturday) 11:30
- > 7/30/23 (Sunday) 11:30
- > 9/23/23 (Saturday) 11:30
- ▶ 12/10/23 (Sunday) 11:30

Resources:

- ► <u>file:///C:/Users/arcgu/OneDrive/Desktop/New%20folder/Impact-of-sibling-on-sisters-Wisconsibs.</u>
- https://autismcenter.org/sibshops
- https://siblingsupport.org/sibshops/
- https://www.thearcfamilyinstitute.org/spceial-campiangs/siblingresources/sibshops.html
- https://thearc.org/get-involved/siblings/

Thank You!!

Questions ??

