

Sibling Relationships: Barriers and Strategies for Success



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The impact of having a child with a disability on the family

Family Impact

- Areas which *may impact* family functioning when a child has a disability
 - Family relationships strained: Parent-child, child-siblings, caregiver-caregiver
 - Social Difficulties with peers including being rejected by peers, not invited to playdates/ parties
 - Financial Difficulties related to seeking medical and/or therapeutic treatments

** NOTE: Not all families will experience all areas of impact*

Family Impact

- Areas which may impact family functioning (con't)
 - Community relationship strains
 - Family outings can be very challenging for the parents and siblings of some children due to the behaviors that these children might display
 - Increased levels of parental stress especially for children who have behavioral challenges
 - Feeling less effective as a parent

** NOTE: Not all families will experience all areas of impact*

Sibling Impact: Reports

- Over-identification: Feeling as though they may have the same diagnosis or develop the diagnosis
- Feelings of embarrassment or isolation
- Feelings of resentment and guilt
- Pressure to Achieve
- Need for Accurate Information
- Concerns about the Future
- Caregiving
 - Taking on extra responsibilities
 - Protectors of their siblings

What siblings would like parents and service providers to know

- Discussion on Sibnet, listserve for adult siblings of people with disabilities, regarding the considerations that the siblings want from parents, family members or other service providers.
 - The right to one's own life
 - Acknowledging siblings concerns and needs
 - Expectations for typically developing children (e.g. worry about over compensating)
 - Expect typical behavior from typically developing siblings (sibling rivalry)
 - Expectations for the family member with special needs
 - The right to a safe environment
 - Opportunities to meet peers and obtain information

What siblings would like parents and service providers to know

- Discussion on Sibnet, listserve for adult siblings of people with disabilities, regarding the considerations that the siblings want from parents, family members or other service providers.
 - Good communication
 - One-on-one time with parents
 - Celebrating every child's achievements and milestones
 - Addressing siblings concerns about the future
 - Including both sons and daughters in family planning

Quotes from Kids

- “Even if you feel bad for your sick brother or sister, you still want your parents too”- 12 year old girl
- Sometimes I feel as though my parents don't care about what I do or don't do. They are so preoccupied with my brother and all his friends that I don't really seem to matter. Almost all my times is spent in my room watching my TV, listening to music, doing homework or talking on the phone. You would think somebody would notice that I spend all my times in my room away from everyone else and all the problems that surround our lives” -18 year old
- I get made when I get into trouble for things my sister gets away with. I try not to get mad because I know that she doesn't know any better about something, but sometimes I just lose it!” – 10 year old

Sibling Impact

Most Significant Problem = Family Challenges due to disruptive behaviors

- Feelings of Victimization: Physical violence, verbal aggression, manipulation and control
- Differential Parental Treatment: Feeling that the focus of the family is on the child with disability
- Feelings of discrepancies in discipline
- Negative Feelings
 - Loss of typical sibling relationship
 - Anxiety, worry, sadness, resentment, guilt

Sibling Impact: Positive Reports on having a sibling with a disability

- Independent
 - Accepting of others or those that are different
 - Protective and Loving
 - High levels of Self-Control and Cooperation
 - Higher academic performance
 - Demonstrate less aggression
 - Patient and Resilient
 - May have more family cohesion; Can have a decrease in sibling rivalry
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- **Sibling Report:** Having a sibling with a disability improved their lives by making them more understanding and more appreciative of the positive things in life.

Why some siblings respond differently

Potential Internalizing Symptoms in Siblings of children with disabilities

- Anxious and Depressive Symptoms
- Perfectionism
- Emotional lability- lots of ups and downs
- Physical complaints
- Anger

Potential Externalizing Symptoms in Siblings of children with disabilities

- Delinquent and aggressive behaviors
- Inattentive and hyperactive behaviors
- Potential Difficulties in social relationships

Theoretical Perspectives: Why people may have different responses in the same situation

Irrational Thoughts: Associated with poorer adjustment

- I think it's **awful** that my sibling has a disability
- It is **unbearable** that my sibling has certain behaviors (tantrums, not being able to do things)
- My sibling's disability **absolutely** must not affect me.

Rational Thoughts: Associated with better adjustment

1. I really don't want my sibling to have a disability, but I realize and accept that things don't always have to be that way I want them to be.
2. It is unpleasant and unfortunate that my sibling has a disability, but it is not terrible.
3. I can stand to be a bad sibling

Additional risk and protective factors associated with sibling adjustment

How children adjust and respond to stressors can be impacted by a number of variables:

- **Demographic factors:** Ethnicity, socioeconomic status, and size of family
- **Family factors:** Family functioning, parent stress, parent and sibling functioning, parent coping strategies, and family relationships
- **Child factors:** Sibling characteristics, perceived sibling social support, knowledge about their siblings disability
- **Sibling factors:** presence of other disorders (comorbidity) and level of symptoms

Supporting Siblings

Healthier ways of responding among children with a sibling with a disability

Need for Intervention

- The siblings of children with Neurodevelopmental Disorders are 3 times more likely to have social, emotional, behavioral and school difficulties
- Siblings report 4 main areas of discontent
 1. Not enough attention from other family members
 2. Limited opportunities for affective expression
 3. Isolation from peers
 4. Lack of information about their siblings' disabilities

Need for Interventions

- Knowing that siblings are at an increased risk for emotional/ behavioral concerns provides support for prevention and intervention services
- Need for Interventions that target sibling factors such as:
 - Social support
 - Knowledge
 - Problem Solving
 - Coping Skills

What you can do as a parent to support siblings

- Keep an open communication
 - Understanding and validation that the sibling may have questions, concerns or negative feelings about their sibling and their diagnoses
- Education on misperceptions and fears through discussions and books
- Special time/ day/ activity with parent and non-disabled sibling
- If the child has a sticker chart, consider one for the sibling as well to increase positive attention
- Embrace differences and highlight strengths/ interests in all children
- Informing your children about their siblings:
 - Diagnosis
 - Services
 - Medications

Talking to your sibling child about disability

- If your child is noticing differences, expressing concern over differential treatment, or has asked questions about why their sibling acts a certain way, it is likely a good time to start to explain a sibling's disability
- Why it's important
 - Maintains trust
 - Improves understanding
 - Helps siblings relationships

<https://www.sibs.org.uk/supporting-young-siblings/parents/explaining-disability-to-your-sibling-child/>

Talking to your sibling child about disability

- What makes it harder for siblings
 - Finding out about their brother or sister from a friend or neighbor.
 - Being told that everything is going to be OK when they know that it isn't.
 - Worrying that they may also get the same illness or condition as their brother or sister.
 - Not having anyone to talk to about it.
 - Feeling guilty about getting on with their own lives.
 - Feeling left out of conversations about their brother or sister.

<https://www.sibs.org.uk/supporting-young-siblings/parents/explaining-disability-to-your-sibling-child/>

Talking to your sibling child about disability

- First assess your own understanding of your child's disability
 - Do you have all the facts on what the causes/ symptoms are?
 - Do your family members have all the facts they need? (e.g. spouses, extended family living with the family)
 - Who can you ask for clarification
 - Not always a “clear cut” answer, especially in young children

Providing information according to age

- **Preschoolers to early elementary:**

- Understanding that they did not cause their sibling's disability and they can not “catch” it
- Simple explanations about things the sibling does well and needs help with

- **School aged:**

- May have questions from peers that come up about their sibling
- May have their own theories about the sibling's disability and the cause.
- Can be more direct and informative about the sibling's diagnosis

- **Teenage years and young adulthood**

- Can speak even more openly. Peer concerns may be present and new challenges may arise (e.g. how to cope if your sibling is bullied, social media concerns).
- Concerns about the future.

Sibling Support Groups

- Common Objectives
 - Comfortable and supportive environment
 - Psycho-education
 - Shared experiences
 - Fun activities
- Designed to:
 - Decrease feelings of isolation
 - Increase knowledge
 - Increase opportunities to discuss feelings
 - Increase coping and problem solving skills
- May include a social media page
- Research is emerging

Sibshops

Sibshops are high energy events where siblings (Sibs) will meet other Sibs (usually for the first time), have fun, laugh, talk about the “good and not-so-good” parts of having a sib with special needs, play some great games, learn something about the services their brothers and sister receive, and have some more fun!

Sibshops may be “therapeutic”, but they are NOT therapy.

A celebration of the many lifelong contributions made by the brothers and sisters of people with special needs.

Sibshops Goals

To Provide Siblings the Opportunity to:

1. Meet other siblings in a relaxed, recreational setting
2. Discuss common joys and concern with other siblings
3. Learn how others handle situations common to the siblings of children with special needs
4. Learn more about the implications of their sibling's disability

To Provide Parents the Opportunity to:

5. Provide parents and professionals with an opportunity to learn more about sibling concerns.

Resources

- **Sibling Support Project:** www.siblingsupport.org

Yaphank

N.I.S. Sibshop- Betsy Kaplan

<http://www.niskids.org>

Sachem

Sachem SEPTA- Patti Waszkiewicz

Millennium Children's Therapy

<http://www.sachemsepta.com>

NYC Sibshops

AHRC- Annette Spallino, LCSW

<http://www.ahrcnyc.org>

Huntington

Millennium Children's therapy- Faith katzman

Www.mmctherapy.com

Oyster Bay

One Step Further Center Center- Nancy Weiss

www.onestepfurthercenter.org

Islandia

Breakthrough Intensive Physical Therapy-

Christine Astarita- <http://breakthroughptli.com>

Syosett

Syosett SEPTA

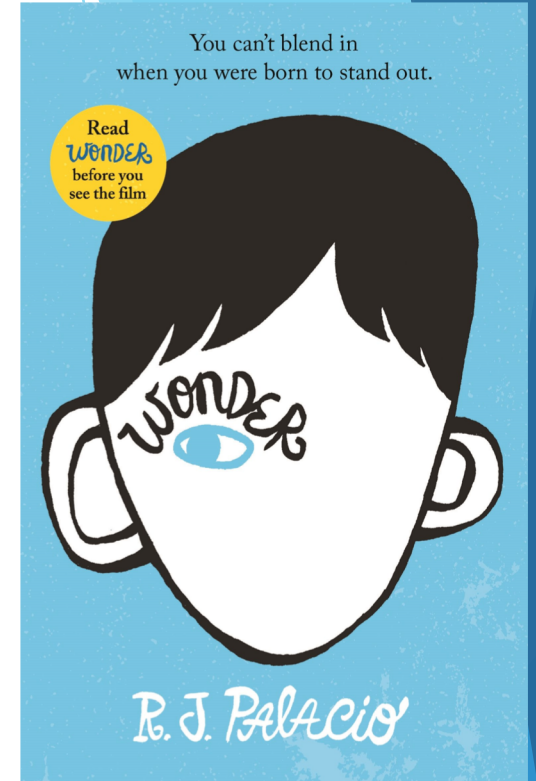


Resources: Books for Parents

- [Sibshops: Workshops for Siblings of Children with Special Needs.](#) Meyer & Vadasy
- [Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs.](#) Meyer
- [Living with a Brother or Sister with Special Needs: A Book for Sibs.](#) Meyer & Vadasy
- [The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities.](#) Meyer & Holl
- [The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs.](#) Meyer
- [Thicker Than Water: Essays by Adult Siblings of People with Disabilities.](#) Meyer
- [Uncommon Fathers: Reflections on Raising a Child With a Disability.](#) Meyer

Resources: Books for Young Readers

- [Tru Confessions](#). Janet Tashjian
- [Are You Alone on Purpose?](#) Nancy Werlin
- [Al Capone Does My Shirts](#). Gennifer Choldenko
- [Rules](#). Cynthia Lord
- [Wonder](#). R. J. Palacio
- [Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters](#) Brian Skotko and Susan Levine



Connecting with Other Sibs

Websites:

- [SibNet](#)-for adult brothers and sisters
- [Sib20](#)-for young adult sibs, 18 to early thirties
- [SibTeen](#)-for teen brothers and sisters

Sibling Leadership Network: a national organization that provides siblings of people with disabilities the information, tools, and guidance to advocate for—and with—their brothers and sisters.

- **SibsNY-** <http://sibsny.org/>
 - Meet and connect, fundraise, learn information, volunteer, conferences, resources.

Support for Caregivers

- There is research documenting increased levels of stress in caregivers of people with disabilities (e.g. parents)
- The importance of self care
 - “Putting your oxygen mask on first before helping others”
- Seeking help and support when you need it
 - Parent support groups
 - Therapeutic Support
 - Hobbies/ interests
 - Exercise other activities

Take Home Messages

- Research on siblings of children with neurodevelopmental disorders shown that:
 - Siblings can be impacted both positively and negatively.
 - Siblings can feel a sense of resentment (e.g. of attention provided to child with a disability) and the guilt for having those feelings
 - Siblings may not share their concerns/ fears/ frustrations due to not wanting to worry or overburden their parents
 - Sibling support groups help to decrease the negative impacts and may help prevent future difficulties.
 - Providing siblings with information about the child's disability can be helpful
 - Keeping an open dialogue is important

What we can do to support siblings

- Keep an open communication
 - Understanding and validation that the sibling may have questions, concerns or negative feelings about their sibling and their diagnoses
- Provide siblings with opportunities for psycho-education and social support
 - Diagnosis, Services, Medications
- Education on misperceptions and fears through discussions and books
- Embrace differences and highlight strengths/ interests in all children
- Additional activities
 - Special time/day activity with parent and non-disabled sibling
 - If child has a behavior system at home, consider one for the sibling to to increase positive attention
 - Outside resources and books
 - Sibling support groups

IF YOU WANT
TO KNOW HOW
TO TREAT A
CHILD WITH
SPECIAL NEEDS,
LOOK AT THEIR
SIBLING...

THEY
WILL
SHOW
YOU.



Thank you! Questions?

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