


What About Me? A Sibling's Perspective

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Family Engagement Partner



Sibling Relationship

- Children spend more time with their siblings than with friends, parents, teachers or even alone.
- By the time children reach age 11, they're spending about 33% of their free time with siblings.
- The longest lasting close human relationship in existence (beginning at birth and lasting until death).
- Can last upwards of 60, 70, even 80 years.
- Typically outlast all other significant relationships in a person's life including relationships with parents, spouses, and friends.


Life Lessons & Siblings...

Vital lessons about socialization and interaction with others within the sibling relationship - among other things, we learn how to:

- Play
- Struggle
- Negotiate
- Cooperate
- Be responsible for others
- Allow others to be responsible for us

Development of our identities takes place within the context of our relationships with siblings.

An estimated 43.2 - 48.6 million Americans have a sibling with a disability.



Question

Are the sibling relationships between a typically developing sibling and their sibling with a disability the same or different than those relationships between two siblings without a disability?

They are both the same AND different.

And because of that, our sibling relationships are often more **COMPLICATED**.

It's complicated because typically developing sibs have:


- Unusual Concerns
- Unusual Opportunities

Unusual Concerns

- Overidentification
- Increased Responsibilities
- Pressure to Achieve
- Embarrassment
- Guilt
- Resentment
- Isolation, Loneliness, and Loss

Overidentification

Overidentification is when a sibling wonders about whether or not they share their siblings' disability or illness.




Increased Responsibilities

- Frequently pushed into surrogate parent role due to increased caregiving needs.
- Siblings often READILY assume the role of manager or caregiver for their brothers or sisters even if they aren't asked to do so.


Pressure to Achieve

Typically developing sibs may feel pressured to make up for their parents' unfulfilled hopes for their sibling with a disability.



Embarrassment

Embarrassment is more common when the problems are mild or invisible as visible disabilities at least provide a reason for unusual behavior.



Guilt

Sibs frequently feel guilty about...

- Their siblings disability – was I responsible for it?
- Their own abilities or health – I am really good at so many things but sometimes that makes me feel bad because so many things are difficult for my sibling.
- Being a caregiver or choosing not to be a caregiver – should I compromise about what I really want to do to help my sib or should I have my own life?
- Typical sibling conflicts they have with their sibling with a disability

Resentment

Sibs often have resentment regarding...

- The amount of care and time their sibling requires
- The perceived unequal treatment
- Being expected to do more around the house and help their siblings with things they cannot do themselves
- Limitations on their and the families' lifestyle due to their siblings' disability.

Isolation, Loneliness, and Loss

Many siblings report feeling...

- A loss of parental attention
- A loss of the "typical" sibling relationship
- Isolated from their peers

Validating and Addressing the Concerns Tips and Strategies

- Provide sibs with a safe environment (both physically and emotionally)
- Pick up on the little things...sibs will give you clues about how they are feeling
- Talk about some of the unusual concerns you have as a parent...just enough to let the sib know that the not so happy feelings they have are normal and definitely okay to share with you
- Ask sibs their thoughts on things (going out in public, having friends over, future stuff) – we think about it a lot sooner than you might realize

Unusual Opportunities

- Maturity
- Insight and Appreciation
- Tolerance
- Advocacy
- Loyalty
- Vocational Opportunities

Maturity

Sibs are mature beyond their years due to...

- Experiencing things different than their typical peers
- Having lost some of their innocence
- Increased responsibilities
- Perspective

Insight and Appreciation

Siblings are very insightful and appreciative of their siblings' abilities, family, and their own health and capabilities



Tolerance

Siblings are more tolerant and accepting of differences because life with their brothers and sisters has made them aware of the consequences of prejudice.

Advocacy

Sibs place a lot of value on their siblings' abilities and contributions, and because they will likely assume an active role in the lives of their siblings, brothers and sisters often become wonderful advocates for individuals with special needs.

Loyalty

Sibs may fight and argue within the family but are often required to defend their brothers and sisters from cruel comments and stares. These incidents give sibs an opportunity to re-examine the relationships they have with their brothers and sisters and reflect upon society's ability to tolerate differences.

Vocational Opportunities

Having a brother or sister with special needs provides sibs with an appreciation the diversity of the human condition. Given their many years of informal education on disabilities, the brothers and sister who seek careers in social services, education, or health care bring a welcome reality check to other professionals in their respective fields.



Tips & Strategies for Celebrating & Maximizing Opportunities

- Make sure sibs have their own interests, and activities that are solely focused on them and their unique skills and talents
- Celebrate sibs accomplishments
- Provide opportunities for sibs to meet and interact with older sibs – especially important for those sibs who do not have another typically developing sibling
- Provide opportunities for sibs to observe individuals who advocate for and work with people with disabilities but don't force it



Providing Sibs with Age-Appropriate Information

Preschool (ages 2-6): Prevent misconceptions, preschoolers need to know that they cannot catch their siblings' disability and that they did not cause the condition. Provide concrete information to these concrete thinkers.

School-Age (7-12): Provide information needed to answer sibs questions about the disability as well as questions that may be posed by classmates, friends, or even strangers.

Teenage (13-18):

- Answer any and all questions teenagers have about their sibling's disability. They may have very specific questions for you. At this stage it is most important for you to be open and honest with sibs about what is happening at the present time as well as future plans.


How is life different for adults who have siblings with developmental disabilities, many who have assumed - or will assume - primary caregiving responsibilities for their brother or sister with disabilities?

- ▶ 80% of survey respondents say they have a close relationship with their sibling with a disability and that this relationship enhances their life;
- ▶ Nearly 50% say their parents currently house and provide caregiving for their sibling with a disability while 14% say their sibling lives with them and another 23% say they are already the primary caregiver;
- ▶ 75% of primary caregivers say caring for their sibling is a full-time job, and 30% say they don't receive support - emotional, physical or financial help - from other friends and family;
- ▶ Of respondents expecting to take on the role of primary caregiver in the future, 80% say they are comfortable taking on this role but they are much more likely to say they are emotionally prepared than financially prepared (60% vs. 33%).

From a Parent's Perspective...

Teach them how to interact and play with their sibling with a disability.

- Continue educating about their sibling's disability as they grow.
- Establish a regular routine for spending time with your children without a disability.
- Find something only you and them share (common interest, special story or song at bedtime).
- Create special ways to celebrate their accomplishments.
- Let them see you advocating for their sibling with a disability.
- Help them form relationships with others.
- Set up time for them to spend time with their friends on their own.
- Find and offer a sibling support group, but don't force their participation.
- **Celebrate National Siblings Day -- April 10!!!**



Remember...

ALL sibling relationships go through phases

ALL sibs need to participate in community and family activities as they feel comfortable

Include siblings in visits with service providers, IEPs, etc...as you feel appropriate (inviting, not requiring attendance)

Provide frequent opportunities for outside support (formal and informal)

What makes you a Supersibling?

- have a desire to be perfect at everything you do
- are very protective of and loyal to others, especially your siblings
- go out of your way not to inconvenience others
- are more independent and mature than most people your age
- have a nurturing personality
- are used to hiding your feelings for the sake of others
- are very intuitive and are very aware of what others around you are feeling
- are extremely empathetic, sometimes to your detriment
- tend to be very patient and tolerant of others
- can easily step into a leadership position


Resources

- **Sibling Support Project:** www.siblingsupport.org
- **Supporting Illinois Brothers & Sisters:** www.sibsnetwork.org
- www.supersiblings.org
- www.spedresource34.wix.com

Sibshops:
Advocate Illinois Masonic Pediatric Developmental Center Sibshops
 Primary Contact: Shella Swann-Guerrero
 Advocate Illinois Masonic Pediatric Developmental Center
 3040 N. Wilton
 Chicago, IL 60657 map
 Phone: 773-298-8127

Forever Sibs
 Primary Contact: Tony Tzoubris at 888-907-SIBS or ttzoubris@foreversibs.org
 1100 N. River Rd. The Villa
 DesPlaines, IL 60016
 888-907-SIBS
www.foreversibs.org


Sibshops



- Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others not-so-good thing, and for many, somewhere in-between.
- They reflect a belief that brothers and sisters have much to offer one another — if they are given a chance.
- Sibshops are a mix of games, new friends, and discussion activities.

SibKids Yahooogroup
 SibKids is the Internet's first listserv for young brothers and sisters of people with special health, developmental, and emotional needs. SibKids members say they enjoy talking about the good parts and not-so-good parts of having a sib with special needs with other kids who "get it!" After all, no one knows what it is like to be a sib of a kid with special needs better than another sib!

SibTeen is a "closed" Facebook group where teenage sibs of people with disabilities can connect with others who get it.



Dear Mr. [Name],

I am pleased to hear from you regarding the [Project Name] and the progress you have made. The information you provided is very helpful and shows a strong commitment to the project's success.

We are currently reviewing the details and will get back to you as soon as possible. Thank you for your patience and understanding.

Sincerely,
[Name]

Dear Mr. [Name],

I have received your letter and appreciate the information you have provided. We are currently in the process of reviewing the details and will get back to you as soon as possible.

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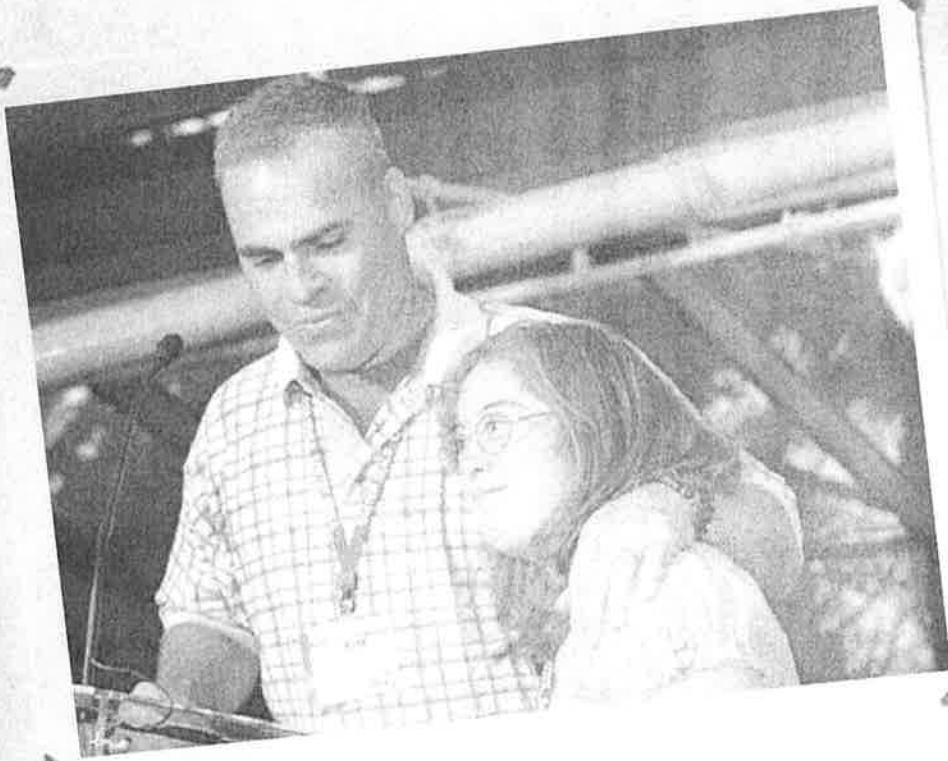
Thank you for your patience and understanding.

Sincerely,
[Name]



Siblings Study

made possible by MassMutual Financial Group



Executive Summary

Easter Seals Siblings Study
Updated 11.12.2012

"From the time they are born, our brothers and sisters are our collaborators and co-conspirators, our role models and cautionary tales. They are our scolds, protectors, goads, tormentors, playmates, counselors, sources of envy, objects of pride. They teach us how to resolve conflicts and how not to; how to conduct friendships and when to walk away from them. Our spouses arrive comparatively late in our lives; our parents eventually leave us. Our siblings may be the only people we'll ever know who truly qualify as partners for life."

Excerpted from Time Magazine's article "The Power of Siblings," July 2006

Siblings: Partners for Life

But what's the experience like for siblings who take on the role of caregiver for an adult sibling with a developmental, intellectual or physical disability? Or who are beginning to prepare for that time in the future when they'll step into that role? What happens to the sibling relationship? And what services and supports – financial, emotional, and otherwise – do they need?

Of the 65 million caregivers in the United States today*, we know many are the primary care provider for an adult brother or sister. Yet far more attention is typically paid to caregivers in the role of spouse, parent or adult child. We don't hear much about the sibling caregiver.

As one of the nation's leading nonprofit provider of services for people living with disabilities, Easter Seals realizes the important role adult siblings play in the lives of their loved ones with disabilities, many assuming primary care for their brother or sister at some point during their sibling's lifetime.

That's why we conducted our *Easter Seals Siblings Study* – to call attention to the experiences of caregivers as well as the services and supports families need. It provides Easter Seals an opportunity to advocate on their behalf and make sure sibling caregivers and adults living with disabilities can access the resources they need to live, learn, work and play in their communities. Easter Seals objective in fielding the Siblings Study was to reach out to sibling caregivers and future caregivers to better understand the implications of taking on this role, as well as contrast attitudes and perceptions of these sibling relationships with those of the general public. Thus, the research was two-fold:

- A more in-depth view of adults who have siblings with a developmental disability
- A parallel, shorter survey among adults in the general population who have a sibling without a disability

Easter Seals thanks [MassMutual](#) for making the Easter Seals Sibling Study possible. As an Easter Seals national corporate partner, MassMutual is committed to serving children and adults with disabilities through its exclusive *SpecialCare*SM program, a solution that gives families living with autism and other disabilities access to information, specialists, and financial strategies that can help improve their quality of life. [Learn more about SpecialCare here.](#)

Easter Seals will use these findings to raise awareness of and advocate for the life-long services and supports families and caregivers desperately need—working to lessen disparities and bridge the gap for people living with developmental disabilities across the country.

Key Findings & Takeaways

By and large, most respondents convey their sibling with a disability had a positive and unique impact on their life – and even the lives of their own children. But, they have also experienced the very real, often challenging negative effects of caregiving, particularly from an emotional and financial perspective.

Many adult siblings are already the primary caregiver for their sister or brother with a disability. Many who aren't yet in a caregiving role expect to take on this role in the future. Yet future caregivers don't feel prepared for the demands of this role, especially when it comes to financial considerations.

And, many siblings aren't taking advantage of the various resources and support groups available to them. Such supports would likely help them better care for their sibling, while juggling their own needs and those of other family members.

Level of Involvement

- Six in ten respondents say they are involved in their sibling's day-to-day life; less than three in ten of the general public respondents say the same.
- Respondents have siblings with an array of disabilities (most commonly an intellectual disability), and report their siblings have various levels of independence.
- Nearly half say their parents currently house and provide caregiving for their sibling with a disability, another 14% say their sibling lives with them and still 23% say they are already the primary caregiver.
- Three quarters of primary caregivers say caring for their sibling is a full-time job, and 30% say they don't receive support – emotional, physical and financial help – from other friends and family.
- Nearly a third of respondents expect to take on the role of primary caregiver in the future. And these future caregivers may be overestimating how much support they will get from other family and friends.
 - Among them, eight in ten say they are comfortable taking on this role, but they are much more likely to say they are emotionally prepared than financially prepared (60% vs. 33%).
 - While more than two thirds (67%) of future caregivers expect to receive emotional, physical and financial help, only 58% of current caregivers say they actually receive this support.
 - Future caregivers are also less likely than current caregivers to see caregiving as a full-time job (55% vs. 75%).



Family Dynamics

- Roughly 80% say they have a close relationship with their sibling with a disability and that this relationship enhances their life; while just 60% of the general public respondents feel the same way about their sibling.
- Approximately 60% say having a sibling with a disability has a positive impact on their quality of life – teaching them patience, understanding, compassion, and providing perspective.
 - This feeling trickles down to the children of the caregiver, too, as four in ten respondents say their kids benefit from having their sibling with a disability (or aunt/uncle) in their lives.
- Respondents also express negative effects as well.
 - At least one in five say having a sibling with a developmental disability has had a negative impact on the cohesiveness of their family, their relationship with their parents, their interactions with extended family, or the quality of their life.

- Many cite increased stress and having a limited social life as some of the additional challenges they face in caring for their sibling with a disability.
- Three quarters of primary caregivers say sometimes their relationship with their sibling puts a strain on their family life and that it's difficult to balance their own needs and those of their family with those of their sibling.

Financial Implications

- Over a third say they provide their sibling with financial support, most commonly those serving as the primary caregiver (81%), those providing housing for their sibling (82%), men (54%) and those 55 and older (43%).
- Two in five respondents say taking care of their sibling with a disability has caused a lot of financial stress for their family.
- 60% wish they knew more about how to plan for their sibling's care and finances, and worry about the cost of caring for their sibling with a disability needs.
 - Those who expect to take over as primary caregiver are even more likely to have these concerns.
 - Similarly, a majority of future caregivers say that they don't feel they are financially prepared to take over this role.
- Just over half of respondents have named a trustee to oversee their sibling's finances, most commonly the respondent themselves (49%), followed by a parent (39%).

Resources & Support

- Respondents are most likely to say other families who have siblings with disabilities are a useful source of information, as well as friends, family and health care professionals.
- Less than a third of respondents are currently involved in a support group, though nearly half say that they would like to know more about local or online support groups.
- While nearly six in ten respondents are aware of people/organizations who specialize in supporting caregivers and siblings with disabilities deal with life issues, just a third report they utilize these services.
 - Those who are unaware of these services are more likely to say having a sibling with a developmental disability has a negative impact on their quality of life, their relationship with their parents, their interactions with their extended family, and their interactions with friends and acquaintances.
 - The top areas of advice respondents receive (or expect to receive) from these support specialists are health and housing, followed by interventions/treatments/therapy, tax/estate planning, and employment.

Methodology

Ipsos conducted two polls on behalf of Easter Seals and the study's sponsor, MassMutual Financial Group:

- A national survey among 1,392 adults age 18 and older who have an adult sibling. Ipsos conducted interviews between July 30 and August 1, 2012 via Ipsos' online omnibus. A survey with an unweighted probability sample of this size and a 100% response rate would have an estimated margin of error of +/- 2.6 percentage points 19 times out of 20 of what the results would have been had the entire U.S. population of adults ages 18+ with an adult sibling been polled.
- A national survey of 351 adults who have a sibling with a developmental disability, including autism, an intellectual disability or a physical disability. Respondents were drawn from a variety of groups and organizations, including Easter Seals, the Sibling Leadership Network, and the Sibling Support Project. Ipsos conducted interviews between July 26 and September 17, 2012. A survey with an unweighted probability sample of this size and a 100% response rate would have an estimated margin of error of +/- 5.2 percentage points.
- All sample surveys and polls may be subject to other sources of error, including, but not limited to coverage error and measurement error.



"Because of Mary, I have greater empathy and a purer childlike joy for the little things in life. I smile more because of my sister, and I never fail to smile when I'm with her." –Joseph

** More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one.*

-- Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009

Books for Siblings of Children with Special Needs

All about My Brother: an Eight-Year-Old Sister's Introduction to Her Brother Who has Autism. S. Peralta, \$19.95 (ages 5-8)

Autism, the Invisible Cord: a Sibling's Diary. Barbara Cain, \$10.95 (novel, ages 12-18)

Autism and Me: Sibling Stories. Ousie Shapiro, photos by Steven Vote, \$21.99

Autism through a Sister's Eyes: a Young Girl's View of Her Brother's Autism. E. Band & E. Hecht, \$16.95 (ages 10-12)

Because ... Someone I Love Has Cancer: a Kids' Activity Book. American Cancer Society, \$13.95 (ages 6-12)

Brotherly Feelings: Me, My Emotions, and My Brother with Asperger's Syndrome. Sam Frender & Dennis Dittrich, \$17.95

Brothers and Sisters of Disabled Children. Peter Burke, \$33.95

Camp Outlook. Brenda Baker, \$14.99 (novel, ages 11-15)

Everybody is Different: a Book for Young People Who Have Brothers or Sisters with Autism. Fiona Bleach, \$11.50

Fasten Your Seatbelt: a Crash Course on Down Syndrome for Brothers and Sisters. Brian Skotko & Susan Levine, \$24.95 (ages 12 +)

French Fries. Lilli Mayerson, \$18.95 (autism)

I Have a Sister, My Sister Is Deaf. Jeanne Whitehouse Peterson, \$9.25 (ages 4-8)

Ian's Walk: a Story about Autism. Laurie Lears & Karen Ritz, \$8.99 (ages 5-8)

I'm Not Her. Janet Gurder, \$11.99 (novel, cancer) (ages 14 +)

Just Because. Rebecca Elliott, \$16.99 (physical/cognitive disorders) (ages 3-10)

My Brother Is Autistic. Jennifer Moore-Mallinos, illustrations by Marta Fàbrega, \$8.99 (ages 3-6)

My Brother Charlie. Holly Robinson Peete & Ryan Elizabeth Peete, \$19.95 (ages 10-14)

My Brother is Different: a Sibling's Guide to Coping with Autism / a Parent's Guide to Help Children Cope with an Autistic Sibling. Barbara Morvay, \$29.50

My Brother Sammy. Becky Edwards & David Armitage, \$12.95 (autism)

My Brother's a World-Class Pain: a Sibling's Guide to ADHD/Hyperactivity. Michael Gordon, \$11.50 (ages 4-9)

My Friend Has Down Syndrome. Jennifer Moore-Mallinos, illustrations by Marta Fàbrega, \$8.99 (ages 3-6)

My Holly: a Story of a Brother's Understanding and Acceptance. Julie Leavitt Wolfe, \$16.99

My Invisible World: Life with My Brother, His Disability & His Service Dog. Morasha Winkour, \$14.95 (ages 8-10)

Nobody's Perfect. Marlee Matlin & Doug Cooney, \$6.99 (novel, ages 9 - 12)

The Normal One: Life with a Difficult or Damaged Sibling. Jeanne Safer, \$15.50

Rules. Cynthia Lord, \$7.99 (ages 10-14)

Russell's World: a Story for Kids about Autism. Charles Amenta, \$11.95 (ages 4-8)

The Sandwich Kid: a Film about Siblings & Disabilities. Created by Keri Bowers, Featuring Jace King, \$36.95 DVD format

The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs. Donald Meyer, editor. \$18.50 (ages 11 +)

Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum. Lynn Stern Feiges, Mary Jane Weiss & Sandra Harris, \$20.95

Siblings and Autism: Stories Spanning Generations and Cultures. Edited by Debra Cumberland & Bruce Mills, \$24.95

Siblings: the Autism Spectrum through Our Eyes. Jane Johnson & Anne van Rensselaer, Editors, \$15.95

Siblings of Children with Autism: a Guide for Families, 3rd Edition. Sandra Harris, \$27.50

Sibshops: Workshops for Siblings of Children with Special Needs, Revised Edition. Don Meyer & Patricia Vadasy, \$41.50

Sometimes My Brother: Helping Kids Understand Autism through a Sibling's Eyes. Angie Healy, \$16.50

Supporting Siblings & Their Families During Intensive Baby Care. Linda Rector, \$32.95

Understanding Brothers and Sisters with Asperger Syndrome. Coulter Video Productions, \$33.95 DVD format

Understanding Brothers and Sisters on the Autism Spectrum. Coulter Video Productions, \$33.95 DVD format

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs. Donald Meyer (ed), \$18.50 (ages 11 +)

We'll Paint the Octopus Red. Stephanie Stuyve-Bodeen & Pam DeVito, \$18.95 (Down syndrome) (ages 3-6)

Why Do You Do That? A Book about Tourette Syndrome for Children and Young People. Uttom Chowdhury & Mary Robertson, \$17.95 (ages 8-16)