

# Helping Siblings Understand Autism and Encouraging Positive Relationships

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## 1. Understanding My Sibling's Disability

- **"Telling" does not Guarantee Understanding**

The process of sharing information has two components, telling and understanding. As a child's ability to understand changes significantly as he/she grows and matures, the "telling" process must involve determining the child's level of understanding at their particular stage of development and representing the same information in different ways over time.

- **Misconceptions and Misinformation**

Research indicates that siblings often do not understand or have misinformation regarding the definition and cause of their brother or sister's disorder. Additionally, it has been indicated that parents often overestimate siblings' understanding of the implications of their brother or sister's disorder.

## 2. My Perspective as a Sibling

- **Things to Know**

Siblings are likely to spend more time with the child in their family who has special needs than any one else, other than the mother or primary caregiver. In addition, because the sibling relationship is the longest lasting relationship in the family, sibling issues are lifelong issues and change throughout the lifespan.

- **Of Concern or to be Expected?**

Many situations that arise around sibling relationships can be attributed to typical sibling concerns. However, having a sibling with a disability or disorder

impacts a child in many ways. Sibling concerns can be compounded by their level of understanding of their brother or sister's disorder and its implications, as well as the coping abilities and strategies exhibited by parents (so be sure to take care of not only your children but of yourself and your other significant relationships!!). It is also important to remember that factual understanding and emotional acceptance are different processes.

- **Other Impacting Factors**

- Type and Severity of the Child's Disorder
- Number of Children in the Family
- Age Differences between Siblings
- Family's Child-rearing Practices
- Family's Lifestyle
- Other Stress-producing Conditions existing in the Family
- Parental/Family Coping styles and Interaction Patterns
- The Resources, Support Services and Networks available to the Family

### 3. Developmental Stages

- Depending on the sibling's developmental stage or level of understanding, his or her concerns are likely to focus on the cause of their brother or sister's disorder, their brother or sister's thoughts and feelings, whether or not he or she will get better, what is expected of them as a sibling, treatment and supports, and what the future holds for everyone involved.

#### UNDERSTANDING AUTISM

#### SIBLING'S PERSPECTIVE

##### Early Childhood

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|---|--|
| <ul style="list-style-type: none"> <li>▪ Autism is understood in terms of isolated behaviors that are specific, observable and concrete (i.e., understanding is based on what the sibling sees rather than on logic)</li> <li>▪ Believes "illness" or disability can be almost magically</li> </ul> | <ul style="list-style-type: none"> <li>▪ Will notice differences between self and brother or sister but expects typical sibling interactions and relationships</li> <li>▪ May be fearful of unpredictable behaviors (e.g., fearful for own safety, fear possessions will be taken or destroyed)</li> </ul> |
|---|--|

- transmitted
- The sibling has not yet devised logical strategies to relate observations and does not yet have the capacity to reason or understand on an abstract level what "autism" means or what the related implications may be
  - Focus on concrete strategies and simple explanations that are specific, factual, and concrete (e.g., if the child is scared by tantrum behaviors, remove him/her from the immediate area and provide reassurance and comfort; explain that brother Billy waves his hands because he is excited)
  - May take on caregiver or teacher role
  - May believe something is wrong with them since they feel they receive less parental/adult attention; may attempt to become the "perfect" child
  - The sibling is unable to articulate his/her feelings and may do so using behavior
  - May regress or mimic his/her brother or sister's behaviors in order to gain the same attention
  - May develop jealousy and resentment toward parent for giving more attention to brother or sister, leading to feelings of rejection

### Middle Childhood

- Autism is understood in terms of physical events; the concept of "contamination" results in the sibling understanding "illness" or disorder as being transmitted through physical contact
- The sibling is developing the ability to draw meaningful connections between current and past experiences and consider the connection between multiple symptoms, behaviors and/or events; develops understanding that the disorder is enduring
- However, understanding may be based on mistaken assumptions and "magical thinking" (e.g., the
- May worry that their brother or sister's "illness" or disorder is contagious or can be "caught"; may believe that their "bad" behavior or thoughts resulted in their brother or sister's "illness" or disorder
- May feel guilt for having negative feelings toward sister or brother; May feel "survivor's guilt"
- May feel hurt or take brother or sister's behaviors personally
- Develops awareness of parents as "flawed" and may be critical of their efforts in addressing both their and

- sibling might believe that Billy's autism came from getting sick, because he once heard the disorder described as an illness)
- The sibling is not yet able to consider "possibilities" or implications of his brother or sister's disorder (e.g., parents may assume the sibling understands that the family can not attend the parade due to the sister or brother's inability to sit and attend, but the sibling may not yet have the cognitive abilities to relate the two)
  - The sibling is able to understand concrete definitions of their brother or sister's disorder and explanations of related needs described in familiar terms they understand; understands and becomes a "storehouse" of "facts"
- their brother or sister's needs
- Is becoming aware of differences among people in the "outside" world; may develop feelings of isolation and embarrassment or shame
  - May attempt to take on parental responsibilities and become over-protective of sister or brother leading to conflicts with peers
  - Continues to demonstrate own needs through behavior (e.g., demonstrating non-compliance, being overly well-behaved)

### **Adolescence/Young Adulthood**

- Autism is understood in terms of "physiology"; the sibling has developed an abstract concept of "illness" or disorder and views this in terms of a malfunctioning body part or system
  - The sibling can reason logically about past and future events and uses knowledge rather than perception to reason
  - The sibling can evaluate the impact of their brother or sister's disorder on situations that have
- May worry that brother or sister's disorder is hereditary
  - Wants to conform to peer group; may be embarrassed by brother or sister
  - Feels conflicted between desire for independence and for maintaining their special relationship
  - May resent the degree of responsibility taken on or imposed on them; may feel anger toward parents, professionals, sister or brother and self
  - Begins to worry about theirs and their brother or sister's future, even to the point of "what if ...", and questions their possible role in their sister or brother's future

- not yet occurred
- Understands and desires more detailed information and explanations regarding their brother or sister's specific disorder
  - Has concern regarding how others will treat and accept their brother or sister (e.g., social groups, dating, marriage)
  - May sacrifice own lives, dreams and goals to fulfill family responsibilities
  - May grieve the loss or absence of independence and the development of relationships (e.g., typical sibling relationships, friendships)

#### 4. Talking to Mom and Dad

- **When to "Tell"**

In your eagerness to inform your child, don't make the mistake of giving too much information at one time. You have an entire childhood to help your child understand what he or she needs to know to feel confident of his/her factual information, to become accepting of themselves and their brother or sister, and to handle the curiosity and ignorance (whether intentional or accidental) that he or she is likely to encounter on the journey through childhood.

However, open the door by mentioning the topic of autism from time to time and act on the following opportunities when they arise.

- Transitional periods (e.g., when brother or sister enters a treatment program or new school)
- When a brother or sister's report card or program report is sent home
- Following an incident that has possibly upset the sibling
- When the sibling first comes into contact with other children the same age as their brother or sister
- During developmental and social transitions experienced by the sibling (e.g., reaching puberty, entering Junior High School, developing a new peer group)
- When issues arise resulting in the sibling wanting specific information (e.g., brother or sister begins medication)
- Watch for and respect signals indicating that the sibling has the information they need at that time (e.g., changing the subject, asking if you are "done")

## 5. Strategies for Developing Positive Relationships

- **Ways to Divide Your Time**
  - **Do Things As A Family And Separately**
    - Sibling without autism has a school concert and you know the sibling with autism will be a disruption. Do not bring the sibling with autism. Sibling without autism needs a chance shine.
    - Go camping as a family
  - **Give Each Child Separate Time With Mom And Dad**
    - Dad takes his daughter to the hardware store to pick up a tool
    - Both parents take turns putting a different child to bed each night
  - **Private Time**
    - Time alone is also important for the sibling without autism. They should have time where they take part in their own interest, daydream and to be a kid.
- **Sharing the Load and Special Moments**
  - **Divide up Household Workload**
    - Give each member of the household chores and this includes the child with autism. Remember that chores should be divided up according to developmental ages.
  - **Use Resources to Give Yourself a Break**
    - Close friends and extended family members
    - Other families who have children with autism
    - Formal support networks (e.g., respite, counseling)
  - **Let Everyone Know They Are Special**
    - Take time to tell each other what they've done well, praise them, give hugs and kisses. This should include all members of the family including yourself, so let family members know when you need a hug.

- **Laugh Together**
  - Autism is a serious disorder and can be very trying on a family. The family will come to a place where they gain some perspective and when that happens it is important to regain a sense of humor and laugh about those embarrassing moments that autism bring. Remember laughter relieves tension and it allows you all to have fun together.

## 6. Activities to Encourage Communication

- **Feelings Box**  
Find a box with a lid and cut a hole in the top. Leave a pad and pencil near by. On the pad siblings and parents can write unspoken anger, sadness, confusion or happy moments they would like to share about their sibling or child with autism. Make time when the notes can be shared and discussed.
- **Scrap Booking**  
With help a child can create a book by cutting pictures out of a magazine and dictating a text, which summarizes their feelings about their sibling.
- **Puppet Plays**  
Using puppets, dolls or other toys children can learn about autism or deal with their emotions around their sibling with autism through role-play. For example a child who is upset by their sibling who throws tantrums may find it helpful to act out the scenario and see how the situation is resolved by the parent puppet.
- **Journaling**  
An older child can use a journal to express all their feeling (e.g., positive, negative, angry and confused). The journal allows the sibling to engage in self-reflection and gain strength and wisdom. (You can provide your child with a book but never insist that he or she write in it!)
- **Favourite Things**  
Take time to share your favourite things about your child with autism with siblings and have them share with you as well.
- **Together Time**  
Brainstorm activities together that the sibling can enjoy with their brother or sister who has autism (e.g., shopping, snack, bowling).

## 7. Super Parent - Exit Stage Left

No one knows all the answers and it is not essential that your child view you as "all knowing". Siblings need a realistic perspective in which they see Mom and Dad as people who are able to cope with problems in spite of difficulties they may face. This provides the sibling with a role model to refer to as they develop, rather than a superhero they could never live up to!

Barrett, K. (1993); Brill, M. T. (2001); Cunningham, Alexis (2001);  
Harris, Sandra (1994); Glasberg, Beth A. (2000); LaPorte, Jennie (2002);  
Meyer, Donald (1994); Powell, Thomas H. & Ahrenhold Ogle, Peggy (1985);  
Powers, Michael D. (1989); Siegel, Bryna (1996)

### Local Respite Services (Calgary, Alberta)

Bayshore	229-3929
Calgary Family Service Bureau Care	269-9888
Calgary Home Support	232-8770
Children's Cottage	233-2655
Comcare	228-3877
Developmental Disability Resource Center	240-3111
Just 4 U	590-2122
Rehoboth	250-7333
Supported Lifestyles	207-5115 ext 280

Families are encouraged to contact these agencies directly to determine if these services are appropriate to meet their needs.