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For and About Siblings

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Autism Society of America: Sibling Issues

Raising a child with autism places some extraordinary demands on parents as individuals and on the family as a whole. Prime among these demands is the lack of enough hours in the day to do all one wishes. The time involved in meeting the needs of a family member with autism may leave parents with little time for their other children.

Many parents indicate that even as they do all they can for their child with autism, they are always struggling with how best to respond to the needs of the family as a whole. They say that although their own life as an individual may be put "on hold" and a couple may share an understanding of the need to make sacrifices on behalf of their child with autism, few parents are willing to make that same demand of other children in the family. As a result, there is a continual tension between the needs of the child with autism and the other children.

This section offers suggestions to parents about ways to help the other children in the family cope gracefully and effectively with the experience of having a brother or sister with autism. Research indicates that the majority of brothers and sisters of children with autism cope well with their experiences. That does not mean, however, that they do not encounter special challenges in learning how to deal with a sibling who has autism or a related disorder.

There are special demands on siblings, and learning how to manage these demands will make their childhood easier and will teach them skills that will make them more effective and resilient adults. The most important teachers of these coping skills are a child's mother and father. The gifts you give to your youngsters in childhood will serve them immediately, and in all the years ahead.

Sources of Stress for Siblings

There are also potential sources of stress for siblings. Not all siblings will experience these issues, but here are some to be aware of:

- Embarrassment around peers; jealousy regarding amount of time parents spend with their brother/sister
- Frustration over not being able to engage or get a response from their brother/sister
- Being the target of aggressive behaviors
- Trying to make up for the deficits of their brother/sister
- Concern regarding their parents stress and grief
- Concern over their role in future caregiving

Many of the suggestions provided here are things that parents can do within the family to help a child understand what autism is all about, to improve the interactions among the children in the family, and to ensure that brothers and sisters grow up feeling they have benefited from the love and attention we all need.

Explaining Autism to Children

Common sense tells us and research supports the idea that children need to understand what autism is all about. The rule of thumb: Do it early and do it often! It is important that your children know about autism and that the information you give them is appropriate for their developmental age. From early childhood, they need explanations that help them

understand the behaviors that are of concern to them. For the preschool, child this may be as simple as "Rick doesn't know how to talk," while for the adolescent, it may involve a conversation about the possible genetics of autism.

The key is to remember to adjust your information to your child's age and understanding. For example, very young children are mostly concerned about unusual behaviors that may frighten or puzzle them. An older child will have concerns of a more interpersonal nature, such as how to explain autism to his or her friends. For the adolescent, these concerns may shift to the long-range needs of their sibling with autism and the role they will play in future care. Every age has its needs, and your task is to listen carefully to your child's immediate concerns.

Another key to success is to remember that children need to be told about autism again and again as they grow up. Young children may use the words they hear us use, but not understand the full meaning of those words until they are much older. Don't be misled by a young child's vocabulary of words like "autism" or "discrete trial." That does not mean the terms have real meaning for him or her. Just as you would not expect an early conversation about the obvious physical differences between boys and girls to constitute a sufficient sex education for children 5 or 10 years later, similarly, you must explain again and again, in increasingly mature terms, what autism is all about.

Helping Your Children Form a Relationship

Because of the nature of autism, it is usually difficult for a young child to form a satisfying relationship with a brother or sister who has the disorder. For example, your child's attempts to play with his/her brother are probably rebuffed by his ignoring her, fall flat because of his lack of play skills, or end abruptly because his tantrums are frightening. How many of us would keep trying to form a friendship with someone who turned her back when we spoke to her or, even worse, seemed angry when we approached? It is not surprising that young children may become discouraged by the reactions they encounter and seek their playmates elsewhere.

The good news is that young children can be taught simple skills that will enable them to engage their brother or sister in playful interactions. Research has shown that siblings can learn basic teaching strategies to engage their brother or sister with autism. These skills include things like making sure they have their brother's attention, giving simple instructions, and praising good play. One research study showed that videotapes made before and after the children learned these skills showed in a very touching manner that, after training, they played together more and seemed much happier than they had been prior to training.

Special Times

Along with ensuring that the child with autism is a fully integrated member of the family; it is important to remember that other children in a family need their times to be special. Families are often urged to find some regular, separate time for the children in their family who do not have autism. It may be one evening a week, a Saturday morning, or even a few minutes at bedtime each night. If your child with autism has a home-based program or exhibits serious management problems, you will have neither the stamina nor the energy to give your other child exactly the same amount of attention. It is not necessary that everything in childhood be exactly the same. What is important is the opportunity to feel

special to your parents and to feel that there is an overall atmosphere of equity in your home.

Not Everything as a Family

There are activities that should be shared by the entire family and times that should not. Along with having regularly scheduled special times for each child, it is also important to remember that there will be some events when one child in the family deserves to be the focus of everyone's attention. Children have told us that it is sometimes frustrating to have to do everything with their brother or sister with autism. In fact, there may be times when it may not be fair to insist that he or she be included. For example, if your child with autism cannot sit still for a school play, then it may be better if he or she stayed home when your other child performs.

Adult Siblings

Being the brother or sister of a person with autism does not end with childhood. These are lifetime relationships that mature and grow over the years. The concerns of an adult sibling will be different from those of children. For the young adult, questions may focus on his/her own plans to have children and concern about whether there is a genetic component in the autism of their sibling. In some cases, young adults may also feel a keen sense of responsibility for their brother or sister with autism that makes it difficult for them to leave home and begin an independent life.

It is important that parents discuss with their adult children the expectations they have in caring for the person with autism, as well as reassuring them about the legitimacy of their assuming their own role as adults.

The questions of the role of the adult child become most acute as parents age and begin to anticipate the point when they will no longer have the stamina to continue to care for their child with autism. If the person with autism is not already living outside of the home, this may be a time when placement in a group home or supervised apartment becomes important. In those families where such care is necessary, adult children and parents must together address the question of who will assume guardianship for the person with autism when the parents die.

It is not easy for any of us to talk about our own death, and both you and your child may shy away from the conversation. Nonetheless, your adult children need to understand the financial plans you have made, the care arrangements in place, and your own expectations for them. Having these difficult conversations will ultimately be a gift to your adult children who will know that they can honor your wishes.

Sibling Groups and Other Resources

A problem frequently reported to clinicians by siblings is a sense of isolation. An ideal means of combating this isolation is to help the sibling connect with other siblings of children with autism. Peer support groups for siblings of children with autism and related disorders are becoming more available.

[The Sibling Support Project of The Arc of the United States](#), based in Seattle, Washington, is one example. They offer a range of information on siblings of children with disabilities, including: reading lists for children and adults, information on local sibling group meetings, information on facilitating sibling discussion groups, or online resources.

The New Jersey Center for Outreach and Services for the Autism Community (COSAC) matches siblings with pen pals around the country as well as internationally. Online resources are also available. For example, a chat room for siblings of children with disabilities, called "SibChat," meets periodically. A final resource to consider for siblings, particularly for those who are experiencing difficulty in adapting to the disability, would be individual counseling.

Most Siblings Cope Very Well

While growing up as the sibling of someone with autism can certainly be trying, most siblings cope very well. It is important to remember that while having a sibling with autism or any other disability is a challenge to a child, it is not an insurmountable obstacle. Most children handle the challenge effectively, and many of them respond with love, grace and humor far beyond their years.

Note: The previous section was provided by Sandra Harris, Ph.D., professor and dean at the Graduate School of Applied and Professional Psychology and Executive Director of the Douglass Developmental Disabilities Center at Rutgers University.

Last updated: 25 January 2008



Siblings Perspectives: Some Guidelines for Parents

Contributed by [Marci Wheeler M.S.W.](#)

There is little doubt that those of us raised with siblings have been influenced by that relationship. Living with a brother or sister with an autism spectrum disorder adds more significant and unique experiences to that relationship. Throughout numerous accounts of parents and siblings of children with disabilities it becomes very clear; when a child in the family has a disability, it affects the whole family. Also clear is that families and each member can be both strengthened and stressed from this situation. It is the degree of these conflicting effects that seem to vary from family to family and person to person. There are some factors that have been found to help strengthen families and minimize the stressors. This brief article is meant to arm you with important information and practical suggestions for helping and supporting siblings.

Though limited research has been done, a child's response to growing up with a brother or sister with a disability is influenced by many factors such as age, temperament, personality, birth order, gender, parental attitudes and modeling, and informal and formal supports and resources available. Certainly parents have little control over many of these factors. However, parents do have charge of their attitudes and the examples they set. Research by Debra Lobato found that siblings describing their own experiences consistently mentioned their parents' reactions, acceptance and adjustment as the most significant influence on their experience of having a brother or sister with a disability (Lobato, 1990).

It is also important to note from Lobato's research that a mother's mental and physical health is probably the most important factor in predicting sibling adjustment regardless of the presence of disability in the family (Lobato, 1990). Positive outcomes that siblings frequently mention are learning patience, tolerance, and compassion and opportunities to handle difficult situations. These opportunities also taught them confidence for handling other difficult challenges. Research by Susan McHale and colleagues found that siblings without disabilities viewed their relationship with their brother or sister with autism as positive when: 1) they had an understanding of the siblings

disability; 2) they had well developed coping abilities; and 3) they experienced positive responses from parents and peers toward the sibling with autism (McHale et al., 1986).

There are negative experiences of having a sibling with an autism spectrum disorder that should be acknowledged and addressed. Anxiety, anger, jealousy, embarrassment, loss, and loneliness are all emotions that children will likely experience. Because of the nature of autism spectrum disorders there are barriers to the sibling bond that can cause additional stress as a result; communication and play can be difficult between siblings when one has an autism spectrum disorder. Often the sibling without the disability is asked to assume or may on their own feel obligated to assume the role of caretaker. It is best to be proactive in addressing these issues. Siblings are members of the family that need information, reassurance and coping strategies just as parents do.

Each family is unique. There are various family structures such as single parents, multi-generational households, and households with other significant stressors including more than one member with a disability. Each family has its own beliefs, values, and needs. Regardless of family circumstances, the suggestions for parents discussed here should be viewed as supportive strategies that can be considered to assist siblings in coping with having a brother or sister with an autism spectrum disorder.

Twelve Important Needs of Siblings and Tips to Address These Needs

1. **Siblings need communication that is open, honest, developmentally appropriate, and ongoing.** Parents may need to deal with their own thoughts and feelings before they can effectively share information with siblings. Children may show their stress through their withdrawal or through inappropriate behaviors. Parents should be alert to the need to initiate communication with their son/daughter. Siblings may be reluctant to ask questions due to not knowing what to ask or out of fear of hurting the parent. While doing research on siblings, Sandra Harris found that developmentally appropriate information can buffer the negative effects of a potentially stressful event (Harris, 1994).
2. **Siblings need developmentally appropriate and ongoing information about their siblings' autism spectrum disorder.** Anxiety is most frequently the result of lack of information. Without information about a siblings' disability, younger children may worry about catching the disability and/or if they caused it. The young child will only be able to understand specific traits that they can see like the fact that the sibling does not talk or likes to line up their toys. School aged children need to know if the autism will get worse, and what will happen to their brother or sister. Adolescents are anxious about the future

responsibility and impact of the disability on their future family.

3. **Siblings need parental attention that is consistent, individualized, and celebrates their uniqueness.** Many families make a major effort to praise and reward the child with the disability for each step of progress. This same effort should be considered for the siblings even if an accomplishment is somewhat “expected.” Self esteem is tied to this positive recognition by parents. Remember to celebrate everyone’s achievements as special.
4. **Siblings need time with a parent that is specifically for them. Schedule special time with the sibling on a regular basis.** Time with the sibling can be done in various ways such as a 10 minute activity before bed each night or a longer period of ½ hour to an hour 3-4 times a week. The important thing is to have some specific times with a parent that siblings can count on having just for them.
5. **Siblings need to learn skills of interaction with their brother or sister with an autism spectrum disorder.** Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings necessary play skills to interact successfully with their brother or sister with an autism spectrum disorder. It is important to go slow and generously praise the sibling for his or her efforts. Toys and activities should be chosen that are age appropriate, hold both children’s interest and require interaction. The sibling needs to be taught to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2003).
6. **Siblings need to be able to have some choice about how involved they are with their brother or sister with an autism spectrum disorder.** Be reasonable in your expectations of siblings. Most siblings are given responsibility for their brother or sister with a disability at one time or another. Show siblings you respect their need for private time and space away from the child with the disability. Make every effort to use respite services, community recreational programs, and other available supports so that you are not overly dependent on the sibling.
7. **Siblings need to feel that they and their belongings are safe from their brother or sister with autism.** Some children with an autism spectrum disorder can be destructive and hard to redirect. They can also be quick to push, bite, or engage in other challenging behaviors with the sibling as a target. Siblings must be taught how to respond in these situations. Generally this would include asking a parent for help in handling the situation. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their siblings’ aggressive behaviors. Thomas Powell and Peggy Gallagher offer ideas on teaching basic behavior skills to siblings (Powell & Gallagher, 1993).
8. **Siblings need to feel that their brother or sister is being treated as “normal” as possible.** Explain differential treatment and expectations that apply to the child with a disability. As they mature, siblings can

better understand and accept the modifications and allowances made for the brother or sister with a disability. For various reasons, parents sometimes do not expect their child with an autism spectrum disorder to have chores and other responsibilities around the house. Attempts should be made to make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with the autism spectrum disorder.

9. **Siblings need time to work through their feelings with patience, understanding, and guidance from their parent(s) and or a professional, if appropriate.** Listen and acknowledge you hear what is being said. Validate the sibling's feelings both positive and negative as normal and acceptable. Repeat back what you have heard the sibling say and check for accuracy. Sharing your positive and negative emotions appropriately is also important. Remember parents are important models of behavior. Help siblings learn ways to cope with and manage their emotions.
10. **Siblings need opportunities to experience a "normal" family life and activities.** If needed, draw on resources in the community both informal and formal. Some families are uncomfortable in asking for help. For the sake of everyone in the family, it is important to find and use resources available such as respite care services and other community programs for persons with disabilities and their families. Most families would be overwhelmed without some breaks from the ongoing demands of caring for children with a disability. Siblings and parents need opportunities for activities where the focus of energy is not on the child with special needs.
11. **Siblings need opportunities to feel that they are not alone and that others understand and share some of the same experiences.** Parents should recognize the need for siblings to know that there are others who are growing up in similar family situations with a brother or sister with a disability. Opportunities to meet other siblings and/or read about other siblings are very valuable for most of these children. Some children might benefit from attending a sibling support group or a sibling event where they can talk about feelings and feel accepted by others who share a common understanding while also having opportunities for fun.
12. **Siblings need to learn strategies for dealing with questions and comments from peers and others in the community.** Parents should help prepare siblings for possible reactions from others toward their brother or sister with a disability. Make sure the sibling has facts about autism spectrum disorders. Discuss solutions to possible situations. They may even benefit from carrying their own information card for friends which they can hand out as needed.

Siblings have a unique bond with each other which is usually life long. Having a sibling with a disability impacts this bond and will impact each sibling

differently. The information presented here highlights some of the limited research and the most significant factors influencing a positive experience for siblings of a child with a disability. As a parent of a child with an autism spectrum disorder you can directly influence and support positive relationships for siblings. Just as you have learned to be proactive for the sake of yourself and your child(ren) with an autism spectrum disorder, siblings need you to be proactive in helping them, too.

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What Siblings Would Like Parents and Service Providers to Know

Source: The Sibling Support Project (www.siblingsupport.org)

In the United States, there are over six million people who have special health, developmental, and mental health concerns. Most of these people have typically-developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than **anyone**. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True "family-centered" care and services will arrive when siblings are actively included in agencies' functional definition of "family".

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. The Right to One's Own Life.

Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their own lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically-developing siblings may assume without a frank and open discussion. "Nothing about us without us" -- a phrase popular with self-advocates who have disabilities -- applies to siblings as well. Self-determination, after all, is for everyone -- including brothers and sisters.

2. Acknowledging Siblings' Concerns.

Like parents, brothers and sisters will experience a wide array of often ambivalent emotions regarding the impact of their siblings' special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings' life-long and ever-changing

concerns.

3. Expectations for Typically-Developing Siblings.

Families need to set high expectations for all their children. However, some typically-developing brothers and sisters react to their siblings' disability by setting unrealistically high expectations for themselves -- and some feel that they must somehow compensate for their siblings' special needs. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

4. Expect Typical Behavior from Typically-Developing Siblings.

Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters -- even when one has special needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically-developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. Expectations for the Family Member with Special Needs.

When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically-developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically-developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules -- one for them, and another for their sibs who have special needs.

6. The Right to a Safe Environment.

Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. Opportunities to Meet Peers.

For most parents, the thought of "going it alone", raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and SibKits, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters -- like parents -- like to know that they are not alone with their unique joys and concerns.

8. Opportunities to Obtain Information.

Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling's disability, and its treatment and implications. Parents *and* service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. Sibs' Concerns about the Future.

Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitude toward the extent of their involvement as adults may change over time. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

10. Including Both Sons and Daughters.

Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when the parents no longer can. Serious exploration of sharing responsibilities among siblings -- including brothers -- should be considered.

11. Communication.

While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips

on communicating with children.

12. One-on-One Time with Parents.

Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. Celebrate Every Child's Achievements and Milestones.

Over the years, we've met siblings whose parents did not attend their high school graduation -- even when their children were valedictorians -- because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. Parents' Perspective is More Important than the Actual Disability.

Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

15. Include Siblings in the Definition of "Family".

Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs -- the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered" -- instead of "parent-centered" -- services.

16. Actively Reach Out to Brothers and Sisters.

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

17. Learn More About Life as a Sibling.

Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop,

hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

18. Create Local Programs Specifically for Brothers and Sisters.

If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families.

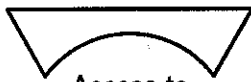
Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

20. Fund Services for Brothers and Sisters.

No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models". As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone -- longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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Respite Care
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National Resource Center for Respite and Crisis Care Services

A Division of the National Respite Network

Chapel Hill Training-Outreach Project

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Siblings of Children with Special Health and Developmental Needs Programs, Services and Considerations

Background

Since 1986, when Congress passed the *Temporary Child Care for Children with Disabilities and Crisis Nurseries Act* (as amended), respite care programs for children with special health and developmental needs have expanded to almost every state. Increasingly, agencies that administer these programs are broadening their attention to include all family members, and to offer many family support services in addition to respite care.

While the parents of the child with special health and developmental needs have been the first to benefit from this heightened awareness, agencies are now beginning to understand that brothers and sisters of children with special needs have concerns that in many ways parallel their parents' experience. But compared with their parents, these brothers and sisters enjoy far fewer programs, services and considerations—even though the sibling relationship is frequently the longest lasting relationship in the family.

In the last several years, however, this has been changing. Research has documented the concerns of siblings of children with special health and developmental needs as programs designed specifically for these siblings have been developed. The following information provides an overview of some of the special concerns of brothers and sisters, one model approach to address these concerns, and a number of considerations for respite care agencies.

Understanding the Concerns of Siblings

Through research and clinical literature, the concerns of brothers and sisters have been well-documented. The concerns include feelings of *loss and isolation* when a parent's time and attention is consumed by a sibling's disability or illness. Siblings may feel "left out of the loop" when parents and service providers, wanting to protect them from possible stress, do not share information about a sibling's condition. They may feel isolated with their concerns if they do not have opportunities to talk with peers who are experiencing similar concerns.

Although they frequently have a life-long *need for information* about the disability or illness and its implications, siblings have far fewer opportunities for obtaining information than their parents do. Written information about disabilities or chronic illnesses is not often developed for young readers. Should brothers or sisters accompany their parents to a clinic visit or an IEP (Individualized Education Program) or an IFSP (Individualized Family Services Plan) meeting, their questions, thoughts or opinions are rarely solicited.

Although both brothers and sisters help care for children with developmental disabilities, studies show that older sisters especially have *increased caregiving demands*. Research suggests that these sisters participate less in their own activities outside the home and have more conflict with the child who has the disability.

Other concerns siblings may have include *over identification* (fearing that they also have the siblings' condition); a perceived *pressure to achieve* in academics, or sports; feelings of *guilt* about having caused the illness or disability or of being spared the condition; feelings of *resentment* when the child with special needs becomes the focus of the family's attention or is permitted to engage in behavior unacceptable for other family members; and *concerns about their and their sibling's future*.

Increasingly, the opportunities many siblings experience by growing up with a brother or sister with special needs are also being acknowledged. These include *insight* on the human condition; *maturity* from successfully coping with a siblings' special needs; *pride* in their siblings' abilities; *loyalty* toward their siblings and families; and *appreciation* for their own good health and families.

Creating Programs Specifically for Brothers and Sisters

Like their parents, brothers and sisters appreciate opportunities to meet others who have had similar experiences, discussing their common joys and concerns and learning more about issues and services that affect their families. Understanding this, agencies are more frequently creating programs designed specifically for siblings by providing some of the following opportunities:

To meet other siblings in a relaxed, recreational setting. The chance to meet peers in a casual atmosphere has several benefits. First, it can help reduce a sibling's sense of isolation. Participants quickly learn that there are others who share the special joys and challenges that they experience. Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Third, the recreational setting helps make the experience rewarding to attend. If a brother or sister regards any service aimed at siblings as yet another time demand associated with the child with special needs, he or she may find it hard to be receptive to the information presented. Sibling events should offer activities that are personally satisfying for the participant, so that he or she is likely to attend in the future.

To discuss the joys and concerns common to brothers and sisters of children with special needs.

Siblings need opportunities, such as sibling support groups, to network. Through these discussions, siblings may realize they have many common concerns and experiences. These support systems can help decrease feelings of isolation and provide an opportunity for ongoing support. Serve refreshments and incorporate fun activities along with more serious discussions.

To learn how others handle situations commonly experienced by siblings of children with special needs. Brothers and sisters of children with special health and developmental needs routinely face problems that are not experienced by other children. Defending a brother or sister from name-calling, responding to questions from friends and strangers, and coping with a lack of attention or exceedingly high expectations from parents are only a few of the problems siblings may experience. Special events for siblings can offer a sibling a broad array of solutions from which to choose.

To learn more about the implications of their brothers' and sisters' special needs. Brothers and sisters need information to answer their own questions as well as the questions of friends, classmates and strangers. Siblings want to know how the disability or illness may affect their brother or sister's life, schooling and future.

To give parents and service providers opportunities to learn more about the common concerns of the siblings. Because parents and service providers often are unaware of the range of sibling issues, activities can be conducted to try to help them better understand "life as a sib." For example, a panel of young adult and adult siblings might relate what they appreciated in their parents' treatment of the children in their families and also what they wish their parents had done differently.

A National Model Format

One model that has been used successfully throughout the U.S. offers brothers and sisters of children with special health and developmental needs peer support and education through workshops as brief as two hours and as long as a weekend. Typical workshops in this model are approximately four hours long, usually from 10 A.M. until 2 P.M. on Saturdays. Generally they are held monthly or bimonthly. During these workshops, information

and discussion activities are mixed with lively recreational activities. These might include "New Games" designed to be unique, slightly off-beat, and appealing to a wide range of abilities; cooking; and special guests, who may teach participants mime or juggling. A workshop schedule might look something like this:

Trickle-in activity: Group Juggling

Warm up activity: Human Bingo

Discussion #1: Strengths and Weaknesses

Game: Stand Up!

Game: Sightless Sculpture

Lunch: Supernachos

Game: Push-pin Soccer

Discussion #2: Dear Aunt Blabby

Game: Triangle Tag

Guest: Physical Therapist

Closing activity: Sound Off

Sibling support programs in this model were designed originally for children eight to thirteen years old, but they can be adapted easily for younger or older children. Originally begun for siblings of children with developmental disabilities, these workshops have expanded to include brothers and sisters of children with other special needs, such as cancer, hearing impairments, epilepsy, emotional disturbances and HIV+ status, and for children who have lost a family member.

Including Brothers and Sisters: a Checklist for Agencies

Here are a few considerations to facilitate the inclusion of siblings in planning and implementing family support services.

Are siblings included in the definition of "family?"

Many educational and health care agencies have begun to embrace an expansive definition of families (e.g., IFSPs, family-centered care). However, providers may still need to be reminded that there is more to a family than the child with special needs and his or her parents. Organizations that use the word "parent" when "family" or "family member" is more appropriate send a message to brothers and sisters, grandparents and other family members that the organization is not for them.

With siblings and primary-caregiver grandparents assuming increasingly active roles in the lives of people with disabilities and health impairments, we cannot afford to exclude anyone.

Does the agency reach out to brothers and sisters? Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sister also have informed opinions and perspectives and can make significant contributions to the child's team.

Does the agency educate staff about issues facing young and adult brothers and sisters? A sibling panel is a valuable way for staff members to learn more about life as a brother or sister of a person with a disability or chronic illness. Guidelines for panel discussions can be prepared in advance to help facilitate a meaningful discussion. Other methods to help educate agency staff include videotapes, books, and newsletters.

Does the agency have a program specifically for brothers and sisters?

Programs for siblings—preschoolers, school-age children, teens, and adults—are growing in number across the United States. Determine the needs of families served in your local community and develop sibling support programs to meet identified needs.

Does the agency have brothers and sisters on the advisory board and policies reflecting the importance of including siblings? Reserving board seats for siblings will give the board a unique and important perspective and indicate the agency's concern for siblings. Developing policy based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

Summary

Acknowledging the contributions of the siblings of children with disabilities or chronic illnesses is an important step toward recognizing the valuable role they play in families. In addition to recogni-

tion, siblings need information, support, and the opportunity to *be children* and to form relationships with other children who have similar experiences. Many crisis nurseries and respite care programs serve all family members and may benefit from understanding sibling issues.

Resources

Curricula for starting sibling programs:

Meyer, D. J., Vadasy, P. F., and Fewell, R. R. (1986). *Sibshops: A Handbook for Implementing Workshops for Brothers and Sisters of Children with Special Needs*. Seattle: University of Washington Press.

Lobato, D. J. (1990). *Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities*. Baltimore: Paul H. Brookes Publishing Co.

Fish, T. *The Next Step* (videotape on sibling issues). Publications Office, Nissonger Center UAP, 434 McCampbell Hall, Ohio State University, 1581 Dodd Drive, Columbus, OH 43210.

Books on sibling issues:

For parents and service providers: Powell, T.H., and Gallagher, P.A. (1993). *Brothers & Sisters: A Special Part of Exceptional Families*. Baltimore: Paul H. Brookes Publishing Co.

For school age brothers and sisters: Meyer, D.J., Vadasy, P.F., and Fewell, R.R. (1985). *Living with a Brother or Sister with Special Needs: A Book for Sibs*. Seattle: University of Washington Press.

Newsletters:

NASP (National Association of Sibling Programs) *Newsletter*. Published by the Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371.

The Sibling Information Network Newsletter. Published by the A.J. Papanikou Center, University of Connecticut, 1776 Ellington Road, South Windsor, CT 06074.

Organizations:

The Sibling Support Project. The goal of the Sibling Support Project is to increase peer support and education programs for brothers and sisters of children with special health and developmental

needs, providing training, demonstration Sibshops and technical assistance to agencies and organizations wishing to add a program for siblings to their existing services. For more information, contact: The Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371. (206) 368-4911.

About the Author: Donald Meyer is the Director of the Sibling Support Project, and, for the past fifteen years, has been involved with programs for traditionally underserved family members of children with special needs.

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GUIDELINES FOR ANSWERING CHILDREN'S QUESTIONS

Children ask some questions to receive information. Other questions may be directed at alleviating uncomfortable feelings. Almost every question has some feeling attached to it. Sensitivity to the child's need for information and reassurance will enable the adult to respond in ways that will keep the channels of communication open. All people like to feel understood. Addressing both content and feeling will accomplish this important task.

"Listening with the third ear" has been described as the skill of comprehending the hidden thoughts and feelings through intuition and attending to the small clues or signals the child gives out. The facial expressions, the body language, the tone of voice, the speech, the time and place of questions may all give the adult a clue to the meaning behind the question.

Because adults are not always aware of the child's perception or reactions, there may frequently be misunderstandings or miscommunication in terms of what the child is asking. By being sensitive and showing respect for the child's concern, the adult permits the child to ask again, with the knowledge that his/her questions are heard and addressed. A climate of openness is the goal of the adult-child interaction that will eventually provide the child with the information or assurance needed.

The adult may elicit some unexpressed questions or feelings by saying, "Some children wonder if they might also lose their legs when they get to a certain age." Such a "trial balloon" will merely go by, if it doesn't fit. If such a question does tap the child's concerns, the adult can then discuss it further. If that "balloon" doesn't fly, send up others.

Labeling or identifying children's reactions acknowledges feelings they may have and gives them "permission" to have those feelings. It may also encourage them to talk about their feelings. It may also encourage them to talk about their feelings.

Though each adult will answer questions with his/her own style, the following guidelines may help enhance adult-child communication around the child's questions and responses:

- Be brief and factual. Children absorb information in small doses.
- Give your undivided attention, if possible, so you can observe the child's response.
- Show your interest in the question or comment by your animation.
- Use simple concrete words or metaphors the child understands, i.e. "Hearing for Pam is like listening to someone whisper."

- Remember that the attitude you convey during your discussion is as important as the content you give.
- Be respectful of the child's questions or comments. Laughing, shaming, or interrupting may discourage more questions.
- Avoid arguments or dogmatic statements. Simply state what you know or think.
- Be empathetic. Try to understand and identify with the child's concerns.
- Be congruent. Be sure your content and attitude are consistent. Laughing at a child's clever, though rude, remark as you reprimand him/her does give a mixed message.
- Reflect on the underlying thoughts and feelings as well as the content of the child's questions.
- Give accurate information. If you do not know the answer to a question, it's okay to say, "I don't know." You can try to find the answer and share it at a later date.
- No one answer to any question is going to satisfy a child's curiosity. Sometimes you may need to pay close attention to statements a child may make at the end of a question to find out what their real concern is.
- Focus on child's strengths as well as their disability. For example, "Sammy hasn't learned to walk yet, but he knows all his letters and can count to 20."
- Be positive! Remember, the attitude you have about the child in question will be conveyed to the child asking the question—whether you mean to do so or not.

Adapted from: New Friends

Brotherly love and interaction defy the stereotype of autism

People sometimes generalize about children with specific disabilities. For example, one of the stereotypes of children with autism is that they cannot form loving relationships. The personal story of PACER staff member Stacey Dinner-Levin offers another view.

By Stacey Dinner-Levin

Our son, Geordy, was 2½ years old when he was diagnosed with autism. His brother Ryan was six weeks old at the time of the diagnosis. Among the losses for which my husband, Michael, and I grieved was the loss of the big brother/little brother relationship we expected our boys would have.

What unfolded for our family, however, exceeded everything we could have hoped or imagined for two brothers, typical or not.

It is difficult to say when Geordy's and Ryan's camaraderie began. All we know is that they began to interact with each other in ways that no one could have predicted or contrived. For example, one evening my husband and I happened upon the boys performing a scene from *The Wizard of Oz*. We were awestruck as they acted out each part, waiting for each other's cue, as well as exchanging roles and laughing in delight.

This type of play has expanded into other film repertoires. We have since been entertained by scenes from *Oliver*, in which Geordy walks Ryan around the house singing "Boy for Sale." Their "acting" led to other play, companionship, and mischief between them. An example is the time I followed the noise at bath time and found a



Geordy and Ryan Levin are "best friends." Just ask them.

wet, pajama-clad Geordy singing "I'm Singing in the Rain" on a flooded bathroom floor as Ryan threw buckets of water from the tub on him.

Sometimes Ryan, now age 4, is the "big" brother." He models play and other behavior for Geordy. Sometimes he teaches him—and, on occasion, scolds him. Before the diagnosis, we had thought this would be Geordy's role. Despite some role reversal, Ryan looks up to his older brother. Geordy can read to him, operate the VCR, and use the computer in ways that Ryan cannot.

We expect that in the future, Ryan will face complex issues and emotions as the sibling of a child with a disability. Geordy's and Ryan's relationship with each other, however, is not so much a concern to us as is the attitude of people

from outside the family who seem to lack an appreciation for the uniquely special relationship that the presence of a disability can provide. If Ryan has a tantrum, I have been asked if he is imitating Geordy or if he is expressing anger because of Geordy. Most often I'm asked when I'm going to tell Ryan about Geordy. The simple answer is, "When he asks." To Ryan, Geordy is just his big brother. He's never known anything else, and he does not seem to care.

Recently Ryan said, "Me and Geordy are best friends." He turned to Geordy, "Aren't we Geordy?" Geordy responded, "Yeah." Then they embraced, and kissed, and laughed. What mother could ask for anything more?

The Levins did receive "more." Their third son, Spencer, was born last spring.

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CHILDREN'S PAGE

OH BROTHER!

by Katie Hershberger

My 10-year-old brother, Jeff, has autism. Many people with autism also have mental retardation, but Jeff does not. Jeff has always been good with numbers. He learned to multiply in first grade. He can also spell well. Sometimes some of the kids in his class might ask him how to spell a word.



Jeff likes fans because they spin around. He enjoys just sitting in front of a fan and watching it spin. He always remembers all the fans that he sees. If he visits someone's house, he will memorize the location of all the fans. The next time he goes to that house he might ask, "Where's the fan with the three blades and the broken knob?"

Jeff has to have a routine. If we change just one little thing he gets mad; that makes me mad. If we are going somewhere, he has to know where we're going and what time we are supposed to leave. If we are even one minute late, he'll say, "We were supposed to leave at 4:00! Now it's 4:01!" But he doesn't really understand time. To him, time is just numbers.

One time, I was drawing and Jeff tried to draw the same thing. I got mad at him and told him not to copy me. Then my parents told me that that's how he learns—by imitation and repetition. For example, if he rents a video and there's one part he likes, he will just keep rewinding it and watching it over and over. I get tired of hearing it all the time.

When my brother began attending public school, he became popular with his classmates. I think the kids were interested in him because first of all, he's a lot bigger than they are—some people say that he looks like a football player—and because they'd never seen anyone with autism. They would talk to him and ask him questions. That soon became too much for him. He can't take too much stimulation at once.

Once we were in a restaurant and a family with a baby came in. Jeff said, "Oh no! Here comes a stupid baby!" Jeff said that because he literally can't stand the sound of babies crying. If he hears one, he will plug his ears and make a humming sound so he can't hear it.

Jeff does not socialize well. If someone he knows comes up to talk to him, Jeff might say, "Go away." It doesn't mean that he doesn't like them—just that he doesn't want to talk.

Living with a brother who has autism has had its ups and downs, but all in all, I'd say it has been a good experience.

Katie Hershberger lives in Goshen, Indiana. She wrote this essay about her brother when she was 12 years old. She is now 15 and will be a sophomore at Goshen High School where she plays the clarinet in the marching band. She also takes piano lessons and enjoys art, writing and playing Nintendo games with her brother, Jeff.

Jeff is 13 years old and will enter seventh grade at Goshen Middle School. He has been successfully mainstreamed since second grade. He has a playing card collection, an electric fan collection and many stuffed animals. His big dream is to turn 16 years old and drive a Ford Mustang.



The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to:

Children's Page
Exceptional Parent
209 Harvard Street,
Suite 303
Brookline,
MA 02146-5005

QUESTIONS FOR SIBLINGS

Focus On The Issue

- ◆ Do you ever wonder, “What About Me?”

- ◆ Have you ever felt that your sibling’s disability was your fault?

- ◆ What do you do to include your disabled sibling in your activities?

- ◆ Have you ever gotten angry or frustrated with your brother or sister who is disabled? Is it okay to feel this way?

- ◆ Do you ever feel your disabled brother or sister is doing things just for attention or to get people to do things for him or her? How does that make you feel?

- ◆ Do you feel you are getting enough time by yourself? If not, how can you change that?

- ◆ What worries you most about your disabled sibling or the rest of the family? Who can you talk to about this?

- ◆ Do you think you get your fair share of attention? Do you get more or less than your friends?

BROTHERS & SISTERS—THIRTY STRATEGIES FOR PARENTS

1. Be open and honest.
2. Value each child individually.
3. Limit care giving responsibilities.
4. Use respite care and other support services.
5. Be fair.
6. Accept the disability.
7. Put together a library of children's books on disabilities.
8. Schedule special time with the sibling.
9. Let siblings settle their own differences.
10. Welcome other children and friends into your home.
11. Praise siblings.
12. Recognize that you are the most important, powerful teacher of your children.
13. Recognize the uniqueness of your family.
14. Listen to siblings.
15. Involve the siblings.
16. Require the child with a disability to be as independent as possible.
17. Recognize each child's unique qualities and family contribution.
18. Help establish special sibling programs.
19. Recognize stress times for siblings and plan to minimize negative effects.
20. Use professionals to help siblings.
21. Teach siblings to interact.
22. Provide understandable answers and repeat them as often as requested.
23. Don't expect siblings to be saints.
24. Provide understandable answers and repeat them as often as requested.
25. Ask.
26. Let them know that they come first sometimes.
27. Let siblings teach you what it is like.
28. Give siblings a set of strategies.
29. Talk about the future with them.
30. Don't forget to laugh!

SIX IDEAS TO PREVENT QUARRELLING

Can quarrelling be prevented? I really don't know. In our culture some "rivalry" is certainly the norm and has been cultivated to support our current competitive mode of business. However, personal experience and observation suggest that the frequency and severity of quarrels can be reduced.

The following is a list of six things to do to prevent or reduce quarrelling:

- 1. GIVE EACH CHILD SOME SPECIAL TIME EACH DAY.**
Give regular, undivided parental attention focusing on what the child wants to do.
- 2. TEACH CHILDREN TO ASK FOR ATTENTION CONSTRUCTIVELY.**
Children will get attention when they need it. Adults can influence how.
- 3. RECOGNIZE CHILDREN AS INDIVIDUALS.**
Look for ways each child is special. Avoid judgmental comparisons between children.
- 4. TEACH CHILDREN HOW TO NEGOTIATE WITH OTHERS.**
Encourage children to look at alternative, consequences, and how their behavior affects others.
- 5. STRUCTURE THE ENVIRONMENT TO REDUCE CONFLICT.**
Provide space and activities so children can play together.
- 6. VISUALIZE CHILDREN AS COMPETENT AND CARING.**
Children often act as we think they will. Spend time thinking of them as successful.



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A Sibling On The Spectrum

3 years old

My typical daughter is building blocks. Painstakingly, she stacks them neatly making a tall tower. In walks her autistic brother and in one fell swoop, knocks them down. He thinks it's hilarious. My daughter looks at her hard work now scattered about the floor. Then she looks at her brother's laughing face and she starts to cry.

5 years old

My daughter wants a friend. She approaches her autistic brother and in a gesture of kindness, she offers him one of her toy animals. He accepts it gladly. She reaches for one of his action figures but with no intention of reciprocating the kind gesture, he roughly pushes her away. With hurt feelings, my daughter turns around with her head hung low.

7 years old

My daughter wants to play monopoly. She invites her brother to join her but he keeps taking the pieces off the board and lines them up instead. In frustration, she throws everything back in the box and stalks off.

11 years old

My daughter is excited. We're going on vacation and she wants to plan. She tries to discuss her ideas with her brother but he keeps talking about a blue whale. "You're just stupid" she screams at him as she runs from the room. He stares after her, not knowing why he made her so mad.

15 years old

My daughters friends come over. They watch TV, eat pizza and have a good time. As they're saying good-bye, her brother walks in, notices the pizza and begins to flap his arms. Everyone laughs at him and somebody comments "You're a freak family". In dismay she screams at her brother "You're an embarrassment and I never want to be seen with you again".

16 years old

My daughter is playing in a soccer match. With less than a minute to go, she is feeling over confident. Knowing she should pass the ball to her team player, she goes for the goal instead. She misses. The buzzer rings. The game is lost. Her team is mad. Everybody Boo's at her. As she looks up into the jeering crowd, she suddenly spots her biggest fan. Her brother. Not caring what anyone else thinks, he is cheering wildly. He knows she did her best and he is proud. Her heart fills with love and tears spring to her eyes.

17 years old

Walking out of school, my daughter is approached by the guy she has a huge crush on. To her delight, he asks her out and she accepts readily. "I was only joking" he says and everyone begins to laugh. Knowing she was set up, my daughter is crushed. Even her friends are not willing to risk ridicule and they lower their eyes, avoiding my daughters gaze. Suddenly her brother walks out the school. He doesn't know what happened but he knows his sister is distressed. Not caring about public opinion or swayed by popularity, he walks up to his sister, gives her a huge grin, interlocks his arm in hers and leads her away. With deep gratitude and tears in her eyes, she clutches on to him as they walk away.



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20 years old

My daughter fails her college test. Everywhere she turns, she faces disappointed stares. There is pity in everyone's eyes. In walks her brother. He understands she failed her test but it doesn't define her as a person. "Can you take it again?" he asks. "Yes" she replies. "OK", he says innocently. Then he smiles broadly at his sister and asks if she wants to watch a DVD. She is filled with love for him and the two walk off together.

24 years old

My daughter is at her job. Her boss offers her complimentary tickets to a famous tennis match. My daughter is filled with excitement and thanks him profusely. "Who are you going to take?" he asks. "My best friend of course", she says dialing the phone. "Hello" says her brother as he picks up on the other side.

To all those with autism, thank you for your unconditional love and for accepting us as we are. May we take a leaf out of your book and learn to do the same for you.

- By Jene Aviram

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Her Autistic Brothers - Karen Olsson - New York Times

February 18, 2007

Her Autistic Brothers

By KAREN OLSSON

Tarah Perry wishes her brothers would remember to put on deodorant. Other 16-year-olds, after all, don't need to be reminded of that by their 14-year-old sister. Other families don't keep a stick of Degree in the glove compartment to enforce deodorant compliance on the way to school in the morning. Granted, Justin and Jason are different from other brothers - they are autistic twins - and Tarah's family is therefore different from other families, and generally speaking she is perfectly O.K. with that. It's all she has ever known.

But lately she has been fighting more with her brothers. They irritate her, she says. They stink. She tells them as much, and they squabble about it, as any siblings might - only when you're 14 and your brothers are disabled and you don't know whether they'll ever make it on their own or whether you'll be responsible for taking care of them, then even the little things take on greater weight. Because what Tarah also wishes is that her brothers will one day manage to hold jobs and find friends and live the kind of life that regular deodorant-wearing people live, or some semblance of it. And in the meantime, it would be nice if they didn't smell up the car.

If you were to meet Tarah apart from her family, there's plenty you might learn about her before the subject of her brothers ever came up. She is in the ninth grade and likes to clown around: one day this fall, for instance, when her biology teacher seemed to be in a bad mood, she drew a large smiley face on a sheet of notebook paper and held it up over her own face to try to coax a smile out of the teacher. (It worked.) Her own face is heart-shaped, sprayed with faint freckles and often demurely animated - lips slightly pursed, eyes knowing - by a look of private amusement on the verge of being made public. There is no mention of her brothers on her MySpace page, and she is more likely to talk about the marching band or her best friend, Alex, who sits near her in band, or the music she likes or gossip from school. Or trees. For some reason she can't stand pine trees. The central Texas town of Bastrop, about 30 miles southeast of Austin, is overhung by tall loblolly pines, on account of which Tarah occasionally petitions her parents to move the family someplace else, like Ireland, where they could live in a castle and have free health insurance - although, she concedes, she wouldn't really want to move away from her friends.

Yet she has no doubt that growing up in her brothers' shadows has shaped her own character. "I think I'm a much nicer person than I would have been if they weren't autistic," she says. "I would have been pretty mean and snobby. Still, I'm kind of mean sometimes, but I don't think I'm snobby."

All her life, she has been not just their younger sister but their de facto older sister, sometime translator and mom's right hand. (Her biology teacher is not the first stressed-out woman Tarah has tried to cheer up.) When they were young, Jason and Justin spoke only about 50 words, and

those in odd, high-pitched voices. But according to Tarah's mother, Jennifer: "It was like she knew what they wanted when I didn't, and she would help me figure it out. Tarah was mother hen to these boys. I probably shouldn't have put her in that position, but oh, my God, she helped me so much."

The boys are now easier to understand and cope with, but their unpredictability keeps the family on edge. "We'll be going along just fine, and then boom, something will happen," Jennifer Perry says. One day last winter, she took the kids to the hospital to see a friend who had just had a baby. Jason, who is unnerved by strange environments, said that he didn't want to go inside, and so Jennifer let him wait in the car while she went in with the other kids. Once the visit was over, they piled back into her big black Suburban - Justin on the rear bench, Tarah and Jason in the middle and their younger sister, Melissa, 11, in front. They were headed for the parking-lot exit when Tarah said, "Mom, when we get home, the boys better take a shower, because they smell really bad." Jason slammed his hand on the seat. "Mom, I asked you not to let Tarah say that anymore!" he said. Then he turned to Tarah and pulled back his fist and shouted, "I'm going to hit you so hard!" Jennifer stopped the car, ordered Jason out and told him he wouldn't be allowed to continue living with the family if he resorted to violence. He apologized and climbed back in. Though he hadn't hit her, the incident frightened Tarah. Several months had passed when she told me about it, and although Jason hadn't threatened her in the interim, she was still "kind of scared to go around him," she said. "I don't want to say anything bad because I think he's going to attack me, but then I think: How could he hurt me? He's my brother."

For most of the last century, the prevailing view in America was that raising a child with a disability at home was detrimental to siblings. "I've been in the field long enough to know a time that families were told that for the sake of their brothers and sisters, kids with disabilities should be institutionalized," says Zolinda Stoneman, author of numerous sibling studies and director of the Institute on Human Development and Disability at the University of Georgia. In many cases, "that was just very misguided advice." It wasn't until the 1980s that many people actually began to analyze sibling relationships, and relationships between disabled and typically developing siblings in particular. With the drive toward deinstitutionalization, more kids with disabilities stayed home, and researchers started investigating what influence that really had on brothers and sisters. At first, they sought to test for the expected negative impacts, interviewing parents and their typically developing children to measure those children's levels of depression and behavior problems. For the most part, those studies failed to uncover the sorts of difficulties that had been hypothesized. Researchers concluded that although growing up with a developmentally disabled sibling may be challenging, it doesn't cause any sort of pathology. Subsequent research suggested that when one child has a disability, siblings may in fact benefit. After all, they receive what amounts to an intensive training in tolerance and empathy. In various studies, parents in such families have characterized their typically developing kids as more caring and mature than average, while college-age siblings have described growing up with someone with a disability in favorable terms. Children with a disabled sister or brother have reported more positive interactions and less conflict with their sibling than kids whose siblings aren't disabled, though "less conflict" cuts both ways, since sibling fights aren't necessarily bad. In conversation, researchers will refer to "supersiblings" - children who are especially sensitive and responsible as a result of growing up with someone with a disability. But such children haven't been studied extensively, and it now seems too simplistic to categorize the experience of having a sibling with

a disability as strictly positive or negative. The supersibling notion may have provided a useful corrective to earlier views, says Tamar Heller, head of the department on disability and human development at the University of Illinois-Chicago, but researchers have moved on to address more practical questions: Are support groups useful? How can families best plan for the future? "We're just starting to have some research that's really looking at what are the variables that make things better for families," Heller says.

Because of the particular challenges of autism, siblings of children with the disorder tend to have a harder time than siblings of children with other sorts of special needs: they enjoy fewer positive exchanges with their brothers or sisters and show more behavior problems themselves. Fewer positive interactions might simply follow from the fact that the disorders on the autism spectrum are characterized by social deficits - from difficulty with eye contact and absence of reciprocity on the milder end to total lack of speech in severe cases. But it has also been shown that typically developing children have trouble forming a concept of autism, which may itself have an impact on the way they relate to their siblings.

The very mysteriousness of autism, says Beth Glasberg, a behavior analyst and consultant at the Douglass Developmental Disabilities Center at Rutgers University, might be inherently stressful for siblings. In the late 1990s, as a graduate student at Rutgers, she interviewed 63 siblings ranging in age from 5 to 17 to learn how they conceived of autism and to evaluate those conceptions, not for correctness but for their level of sophistication. In her analysis, Glasberg relied on classic categories established by the child psychologist Jean Piaget, who described children's intellectual development as progressing from a stage at which concepts are based on direct experience through an intermediate stage of linking direct experiences with logical thinking and finally, at around the age of 12, to a stage at which they use abstract reasoning and make generalized predictions. When it came to grasping the implications of autism for their siblings and for themselves, the study subjects reasoned in a way appropriate to their age groups: a teenage sibling could predict various ways in which her brother would never enjoy a normal life, for instance. But when it came to understanding autism itself, many of the older kids reasoned in the sort of concrete terms corresponding to the earliest stage of development: a 13-year-old girl described autism as "a disability that makes problems with language" just as a 6-year-old said that autism meant needing help learning to talk. In both cases, the children characterized the disorder by referring to their siblings' symptoms rather than to a more general definition. Perhaps that is just because autism is such a difficult diagnosis to grasp, Glasberg says - after all, it is poorly understood even by adults - but whatever the reason, children who lack a clear concept of their sibling's disorder could well experience anxiety as a result. As part of her research, Glasberg examined how well adjusted her interview subjects were relative to the norms for children who do not have a sibling with a disability. Her results matched those of earlier studies: on average, there was no difference in how well they were doing. Among the siblings of the children with autism, there were a higher number of scores in the critical range for behavioral or emotional problems, balanced out by a higher number of kids with fewer problems than normal. "That actually mirrors my clinical experience with kids," Glasberg says. "The majority are sort of bopping around in the middle, but you do see these kids that are having a lot of adjustment problems, and then you do see the ones that have become like superchildren, who talk about how they really feel like they want to not cause any problems for their parents because

their parents are already upset about their brother or sister. They kind of want to make up for it and be like the perfect kid."

Presumably trying to be the "perfect kid" has its own set of liabilities. What researchers have yet to determine are the factors that cause some siblings to struggle more and some to over compensate. Of course, the complexity of family life makes it difficult to isolate the causes of a child's behavior. When that child is a sibling of someone with autism, the analysis becomes all the more complicated because the disorder is known to have some genetic component. Also unanswered is the question of what happens to each group - the siblings with problems, the average ones and the so-called superkids - as the children mature.

Tarah is one of those kids in the middle, neither maladjusted nor striving to be a perfect child. She stands a little over five feet and has no desire to grow any taller, though she would like to put a couple of hot-pink streaks in her hair and, as soon as she turns 16, to get a nose stud and multiple ear piercings and a tattoo of a smiley face on her index finger. She doesn't class herself among the popular kids or the anime geeks or the poseur preps or the losers, while in the division of ninth-grade girls into those who wear makeup and those who do not, she falls into the second group, unless you count her bitten-off black nail polish. She attends seminary class at her Mormon church every morning before school, plays French horn in the band and spends much of her free time at home on the computer, trading messages on MySpace or writing funny stories.

In September, I accompanied Tarah, her mother and her brothers to an autism conference in Dallas, where Justin and Jason had been invited to take part in a presentation. Tarah had agreed to come along to cheer on her brothers and to help her mom - reluctantly, because she hadn't wanted to miss school and the first band performance. Jennifer works as a special-education aide and obtained permission from the school district to attend the conference; her husband, Brian, an auto mechanic, stayed home with Melissa. Time was when such a trip would have been unthinkable. Jennifer had just turned 22 when she gave birth to Jason and Justin, after a difficult pregnancy, and from the start she knew something wasn't right. "They wouldn't let me hold them," she recalls. "They would be fine as long as they were in their carrier, as long as I stayed to an exact routine, but if I would try to pick them up, they would cry, and the eye contact wasn't there. It was like they didn't want me to be their mother." The strain on her young marriage was intense: Brian was making \$8 an hour; she couldn't find day care that would take the boys; and when a year after their birth she told Brian she was pregnant again, he burst into tears. In family home videos from those years, Tarah appears first as a Maggie Simpson character, the placid witness, watching from her walker as Brian tosses the boys in the air or lying on the carpet as Jennifer and a visiting specialist help the boys play with simple toys. A few years later, Tarah would dress Jason and Justin in her ballerina outfits; one video taken when the boys were 4 or 5 shows Jason teetering down a hallway in a party dress and pink plastic heels.

Other moments, not captured on tape, were more difficult. Into their early school years, Jason and Justin threw daily tantrums. Sometimes they would bang their heads against the wall. They tore down pictures and broke windows. They injured themselves often enough that the Perry's made sure to rotate emergency rooms, to avoid coming under suspicion of child abuse. They slept only a few hours each night. In the car, they demanded that their mother make only right turns - left turns or driving in reverse would provoke screaming fits. "We were complete

prisoners," Jennifer says. "We couldn't go anywhere." She remembers one time, after the boys tore up the house yet again, that she just sat down on the living room floor and sobbed, with Tarah by her side. Jason and Justin matured, not like normal boys, but they stopped having tantrums and started talking more. By the standards of their youth, the twins are positively sedate these days. Pale and rangy, with wide-set blue eyes and stiff-shouldered, loping gaits, they sometimes seem like anxious 5-year-olds trapped in elongated bodies. They speak in insistent monotones and have trouble making eye contact or exercising simple motor skills: last summer, Jason shut the car door by himself, and Tarah rewarded him with praise and a high-five. This fall, she taught him how to clean the toilet. Because of their motor-skills deficits, it falls upon Tarah to show her older brothers how to do chores, though she suspects that sometimes they just want her to demonstrate so that they don't have to do it themselves.

The drive to Dallas had its share of mundane sibling quarrels. A long foam pool noodle had somehow found its way into the back of the car, with the suitcases, and was obstructing the rear window. When Tarah told Jason to move it, he ignored her. "Boys!" Jennifer said. "Could you please listen to Tarah?" "Mama, he just doesn't answer me - all the time," Tarah said. "He doesn't like you," Justin said. "He tells me you're mean and always screaming at him." "And telling him he's an idiot," Jennifer added. "I don't call him an idiot," Tarah protested. "I call him a weenie." A few hours later, her role shifted. It was evening when we arrived at the Adam's Mark Hotel in downtown Dallas, and all of us waited in a busy lobby while Jennifer and Justin parked the car. By the time they found us, Jason had retreated to a corner near a window, where he was half-hidden by a cardboard sign, and had wrapped himself in a faded plaid comforter that he'd brought from home. Unnerved by the strange and crowded surroundings, he wouldn't budge, then was coaxed out of his hiding place. Reluctantly, he followed us to the reception desk, averting his eyes and still cloaked in the blanket. When Jennifer joined the line, he retreated to a pillar, sat down and began to rock back and forth. She signaled to Tarah, and at once Tarah crouched in front of him and spoke to him in a low, soothing voice until he got up and joined his mother.

Tarah's earliest memories are dreams she had when she was very young, all of which concern her brothers. In one, she and Justin and Jason were out in the backyard, where their grandfather was showing them how to use a telescope, "but there were holes in the yard with monsters in the holes, and my brothers fell into them, and one of them got a broken leg." In another dream, "they got chemicals in their eyes and went blind." In a third, a thug beat them up.

She has long known that her brothers are vulnerable. When she was in middle school, sometimes kids didn't realize that Justin and Jason were her brothers and would make fun of them right in front of her. They would spit in her brothers' food or threaten them or call them worthless, and she had to stick up for them a lot. Then one night in the spring of 2005, Tarah and Jennifer and Melissa were all cuddling in Jennifer's bed together when Justin walked into the room, upset. "My mom took him into the bathroom and started talking to him," Tarah says. Not long after that, a complaint was filed against a boy who had recently started inviting the twins over to his house. (The boy's father denies that his son did anything to Justin.) Soon other kids were approaching Tarah to tell her they were sorry for what had happened; the news had somehow made it around the middle school, much to Justin's dismay. For a while, the boy was still around: "I'd see him and I'd almost start crying," Tarah says. "One day I saw that he was talking to them,

and I got really, really worried, like 'Oh, my God, what should I do?' So I pushed them away, and then I was just yelling at him. I started screaming, 'If you even come near my brothers I'll kill you!' He said, 'I didn't do anything Tarah, I don't know what you're talking about.' I told him to go away, to not come near them, and that's when my mom pulled up." The Perry's and the boy's father say the case will be tried - because it's a juvenile case, none of this is in the public record, and the Bastrop County District Attorney's office would not comment. Whatever is proved in court, the episode has stayed with Tarah: she says she still thinks about it often and fears that something similar could happen in the future. It's a fear so different in magnitude from her concerns about whether they do their chores or take showers, and yet it's lumped in together with all the other worries.

On a drizzly December afternoon in Scarsdale, N.Y., 20 kids ages 5 to 15 trickled into a spare all-purpose room at the Jewish Community Center of Mid-Westchester, took seats around a long table and helped themselves to goldfish crackers as they waited for a group meeting to begin. Different as it may be to grow up in suburban New York as opposed to a semi rural town in Texas, the members of the Wednesday-afternoon support group for siblings of kids with disabilities - or "Sibshop," as many such groups are called - have plenty in common with Tarah. Almost all have a brother or sister with autism. That so many kids attend the Scarsdale group comes as a result of the active recruiting efforts of its leader, Charley Moskowitz, a social worker and fervent Sibshop advocate who also runs a Sunday program for children with disabilities. "Every time someone calls me for my Sunday program, I say, 'Do you have another child?'" she told me. "And they will say to me, 'Yes, but they're not the affected one.' I say, 'Now you have to listen to my spiel.' My spiel is, There's no such thing as an unaffected child in a family that has a child that has special needs. I say to them, 'Do you go to a support group?' And they say, 'Of course.' Well you know what? Your other child needs a support group, too."

Shortly after 4:30, the goldfish crackers were whisked away, and Moskowitz, a vigorous, tawny-haired woman in her early 60s wearing a Sibshop T-shirt, asked whether anyone was troubled by anything that had happened since the last meeting. "My brother's been having a big problem," began a pensive 6-year-old girl named Ruthie, her brown hair falling around her small face, her voice soft and melancholy. "He's been having a hard time with beeping noises. When he goes to school, there's a little beep, but you can hardly hear it, but he can hear it, but he still comes in the door and then he runs out of the other door and right into the classroom, and he's scared." She continued in this vein, until Moskowitz interrupted: "Let me ask you a question, O.K.? Why are you so sad about this?" "Because I don't want my brother to be like this, and it makes me feel sad that he has to be afraid of that." "Can anybody help her?" Moskowitz asked. Thomas, a chatty 10-year-old with a buzz cut, raised his hand. "Well, a lot of times what autistic kids do, is like - my brother will go through a phase. This could just be, like, one month he might be afraid of beeps, and then next month he'll love beeps." Thomas, it was later revealed, attended the group for almost a year before he admitted that he had a brother with autism. A kid named Nick chimed in. "The reason your brother might be doing that is because autistic kids, they have almost better senses. I know it sounds weird, but, like, my brother, he can hear things that are really low. It's nothing really bad; it's just something that happens." "Ruthie, you know what? There are some things that we can't change," Moskowitz said. "One of the things that we can't change is the way your brother reacts to things. What is she doing, Nick?" "She's trying to change what her brother feels." "What else is she doing that you did for a very, very, very, very long time?" "Oh, you

blame yourself." "What else?" "You care way too much." "How about the R-word?" "Responsibility. You're having too much responsibility for your brother. I've learned from that by the way. I only help when I need to help." "Did we pound something into him? Finally? Let's give him a hand." A sense of obligation weighs on even the younger children, Moskowitz says, and often it's the brightest of the children, thinkers like Ruthie, who seem to struggle the most. "These are the kids who are going to be taking care of their siblings when their parents die," she says. "These are the kids that are going to have all the responsibility, and if they don't get help now, who's going to help them? They have to work through this before they graduate from high school so that they can have the courage to go off to college and have a life and still be connected to their sibling when it comes time to make a decision about what they have to do."

Often Tarah imagines what life would be like were Jason and Justin not autistic. "I think me and my brothers would actually be kind of close," she says. She would be able to talk about her problems with them; they would protect her and help her with schoolwork. Her dad would let them drive her places and do more things. They would care about their clothes and the way they smell. "They'd be cool people, people that everybody knows. They'd be known as the cool kids instead of the autistic kids." The gulf between kids with special needs and their siblings widens during adolescence, as the typical siblings begin to tie up the phone lines, venture off with friends and begin dating. A more severely disabled sibling might not notice or care, but Justin and Jason Perry seem keenly aware of the difference. Justin, more than his brother, wants to make friends, but the people he befriends most readily are elementary-school kids he meets in the video-game department at Wal-Mart. (He has also occasionally expressed a desire for a girlfriend and used to claim he had one named Crossfire.)

"The boys get upset because Tarah and Melissa get to have friends over and go places, and they don't," Jennifer said. "They get along awesome with kids like 8 and under, but it's inappropriate to most people. Justin will want me to invite them over. So finally I asked, 'Why do you like them?' And he said, 'Because they don't make fun of us, and they're nice to us.'

"Back when the boys were more volatile and the Perry's rarely went out in public, Justin and Jason "used to be my best friends," Tarah says. Starting a couple of years ago, though, "I started getting a life. I started being able to do things. It was really cool, and I got carried away with it and just stopped talking to them as much. I used to be the cool sister. Now, Melissa is the cool sister."

One evening I asked Jason and Justin what they thought of Tarah. I was at the Perry's' house in Bastrop, and Tarah had left, with nails freshly painted black and temporary pink dye in her hair, for a church dance. "She used to be nice," Justin said. "Now all she does is call us names. She's mean." I asked what names. "Stupid, idiot, rat, loser," Justin said. "Pig," Jason added. "She calls us that. And a slob." "She's starting to be old and be a stupid teenager," Justin said, "and that's what Melissa's going to do later."

Yet while she may call them names and run off to church dances, Tarah also wonders whether she might one day become her brothers' caretaker. The Perry's haven't made concrete plans for Justin and Jason, and since the boys are still maturing, it remains to be seen just how independent they'll become. "If they end up living with me, I'm going to make them get a job and have some

responsibility," Tarah says. "That way, they wouldn't be just sitting around the house playing video games all the time. Then I'd take what they earn, and some would go to keeping house and some to buy them more video games." They could maybe work at GameStop, their favorite store, she says.

In Dallas, the panel went off smoothly enough. Justin, Jason and three other boys from their class showed power-point presentations they assembled with their teacher's help, the twins sitting silently as they advanced the slides. The real highlight of the trip, though, came the day before, during an excursion to the Dallas Children's Museum. In one area, there were large, free-standing trays of bubble liquid, with metal wands more than a foot in diameter resting in them. The group drew bubble after bubble from the trays, in long shimmering tubes and bobbing globes. "Megabubble!" intoned the largest and most cheerful of the boys, over and over. This went on for a while. At one point, Tarah stood next to Jason and told him to bend his head forward over one of the trays.

"Is it going to hurt?" he asked.

"No," she said. She drew the wand out of the tray and over his head, so that a bubble surrounded his face.

"Ohhh," he said, peering out through the window of glycerine and cracking a cautious smile. "Tarah made me get inside the bubble!" he exclaimed.

But by the time he'd spoken, it had already popped.

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Julie Wolf, PhD

Recommendations for Families to Meet the Needs of Non-Affected Siblings

- Right to own life
 - Siblings should never be *expected* to care for their affected sib
- Manage Expectations
 - Monitor for the possibility that the non-affected sib is setting high expectations for him- or herself, to compensate for sib
 - Expect household responsibilities from all children, so no perception of unfairness
 - Benefits the affected sib, too!
 - Expect typical sibling rivalry - don't deny the non-affected child the right to be a typical sibling (i.e. avoid "You should know better" language)
 - Encourage non-affected sib to help out, but not to be another parent
 - Non-affected sib should not be a disciplinarian
- Right to safe environment
 - Have a plan so sib knows what to do if safety threatened by aggression from sibling
 - Seek professional consultation if unable to keep all kids safe
- Allow non-affected sib one-on-one time with parents
- Allow non-affected sib private time to themselves
- Acknowledge achievements & allow sib to shine (i.e. don't miss out on concerts, sporting events, and other achievements because you need to care for your affected sib – find a way of being there)
- Provide opportunities for social support (Parents often would never dream of "going it alone," and yet we often expect this from siblings)
- Acknowledge and respect child's experience; recognize developmental phases (e.g. if teenage child does not want affected sib to hang out with him and his friends, acknowledge this, and compromise by expecting one-on-one time with sib instead)
- Encourage independence
 - Non-affected sibs may not want to separate from parents if they feel parents are under stress or need their support
 - Explore reasons for not wanting to leave home & reassure that it's okay
- Seek counseling / therapy if there are significant adjustment issues
- Promote communication among family members

Talking to Sibs about ASD

- Mention autism from time to time
- Initiate the conversation
- Hear your child out
- Be prepared for negative emotions
- Stay neutral, don't judge
- Praise child for sharing his/her feelings
- Make child feel comfortable (so they continue to share feelings in future)
- Don't share too much at once (stick with just answering the question)
- Repeat information over time (will be absorbed differently as child ages)
- Share your own feelings – children sense them!
 - Otherwise, children may attribute your distress to something he/she did
 - But, maintain appropriateness – don't burden child with the full intensity of your feelings
- Keep it at your child's developmental level
 - For young children
 - Keep it simple
 - E.g. "She's crying because she's afraid of loud noises."
 - Correct mistaken info
 - E.g. "You can't catch autism."
 - Create a book explaining autism (with your child's help)
 - For Adolescents
 - Can understand on adult level
 - Allow access to as much info as child wishes
 - Allow child to express emotions
 - Emotional acceptance may not be at same level as cognitive understanding
 - Respond to questions about the future and their role toward sib
 - For Adults
 - Discuss caretaking decisions
 - Acquaint with advocacy
 - Should sib decide to take over caregiving role, provide thorough information about caretaking needs
 - financial arrangements, living arrangements, legal guardianship, government benefits and other sources of aid, etc.

Autism Information for Kids

Resources:

Websites, Books, Videos, & Movies

WEBSITES

Autism Information for Kids!

<http://www.angelfire.com/pa5/as/talkingtokids.html>

Information Written for Kids

From the Autism Society of Delaware.

http://www.delautism.org/kids_only.htm

Kid's Quest

<http://www.cdc.gov/ncbddd/kids/kautismpage.htm>

"I've heard on the news about kids having something called "autism spectrum disorder (ASD)." What is it and what do I need to know about it?"

Autism Information Written for Kids

<http://www.autism-ascc.org/kids.htm>

Includes topics such as "What are people with autism like?" and "Things you might discuss with your child if they know someone with Autism".

Kids and Kaboodle

<http://www.kidsandkaboodle.com/features/autism.htm>

Autism questions and answers.

About Autism

<http://www.gnasd.com/autism.htm>

Information for kids who know a friend with Autism.

Kids Health: Autism

http://www.kidshealth.org/kid/health_problems/brain/autism.html

A short story and information for kids!

Oliver

<http://www.thepeacefamily.force9.co.uk/guide.html>

A personal website about a boy, Oliver, who has autism. Good information provided to promote autism awareness! Useful, printable information.

Fitting In

http://www.hoagiesgifted.org/fitting_in.htm

"Fitting In and Speaking Out: Me and Asperger's Syndrome" Written by a 5th grade student with Asperger's Syndrome to promote awareness to his peers.



Sibling-related books and movies

(* indicates author or filmmaker is a member of the SibNet, the Sibling Support Project's adult sibling listserv community)

Books for adults on sibling issues and on creating services for brothers and sisters:

- *Sibshops: Workshops for Siblings of Children with Special Needs* by Donald J. Meyer* and Patricia F. Vadasy (1994, new edition in preparation)
- *Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities* by Debra J. Lobato (1990, out of print)
- *Brothers & Sisters-A Special Part of Exceptional Families* by Thomas H. Powell and Peggy Gallagher (1993, currently out of print, new edition in preparation)
- *Siblings of Children with Autism: A Guide for Families* by Sandra L. Harris (2003)

Fiction for young sibs:

- *We'll Paint the Octopus Red* by Stephanie Stuve-Bodeen, Pam Devito (Illustrator) (1998)
- *Are You Alone on Purpose?* by Nancy Werlin (1994)
- *Tru Confessions* by Janet Tashjian (1997)
- *Way to Go, Alex!* by Robin Pulver, Elizabeth Wolf (Illustrator) (1999)

- *My Brother, Matthew* by Mary Thompson (Illustrator) (1992)
- *Our Brother Has Down's Syndrome* by Shelley Cairo, et al (1988)
- *The Summer of the Swans* by Betsy Byars (1996)
- *Princess Pooh* by Kathleen M. Muldoon, et al (1989)
- *Welcome Home, Jellybean* by Marlene Fanta Shyer (1988)

Non-fiction for young sibs:

- *Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs* by Donald J. Meyer* (Editor), Cary Pillo (Illustrator) (Paperback - September 1997)
- *Living With a Brother or Sister with Special Needs: A Book for Sibs* by Donald Meyer* and Patricia Vadasy (Paperback - November 1996)

Nonfiction and memoirs by adult siblings:

- *Riding the Bus with My Sister: A True Life Journey* by Rachel Simon* (2002)
- *Siblings: Brothers and Sisters of Children with Special Needs* by Kate Strohm* (2002) Wakefield Press (Australia)
- *The Ride Together: A Brother and Sister's Memoir of Autism in the Family* by Judy Karasik* and Paul Karasik (2002)
- *Special Siblings: Growing Up With Someone with a Disability* by Mary McHugh (1999)
- *My Sister's Keeper* by Margaret Moorman
- Without Apology, a documentary film by Susan Hamovitch*

Fiction about adult sibling issues:

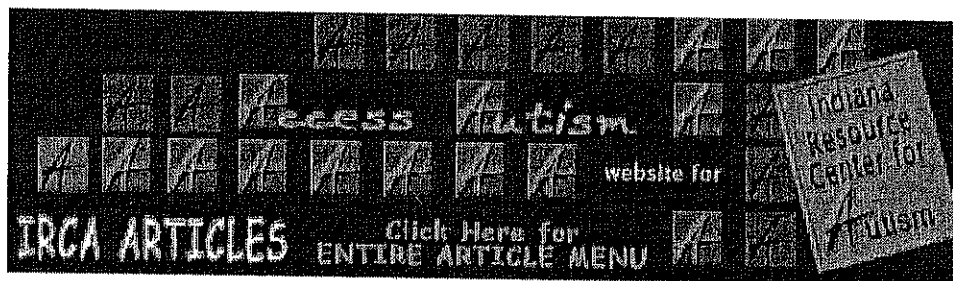
- *I Know This Much Is True* by Wally Lamb

Feature films featuring sibling issues:

- *Tru Confessions* (Disney Channel movie)
- *What's Eating Gilbert Grape* (rated PG 13 for adult situations)
- *Benny and Joon* (rated PG)
- *Dominick and Eugene* (rated PG-13 for violence, adult situations, adult language)

If you would like to nominate a sibling-related book or movie, please write us with the title, publisher, and year of publication and a sentence or two why it should be included. Please [contact us](#).

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Selected Resources for Understanding and Supporting Siblings

Contributed by Marci Wheeler, M.S.W.

The following articles, books, and other resources provide a sampling of materials which describe and support the experiences of siblings of children on the autism spectrum. Selected items may be available at your local library. Many may be borrowed by Indiana residents from the Library of the Indiana Institute on Disability and Community, 2853 East Tenth Street, Bloomington, IN 47408-2696, 1-800-437-7924 (toll free in Indiana; voice/TT); 1-812- 855-9396 (Bloomington, voice/TT).

Celiberti, D. R., & Harris, S. L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy*, 24(4), 573-599.

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23(1), 147-163.

Harris, S. ((2003). *Siblings of children with autism: A guide for families*. Bethesda, MD: Woodbine House.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: Care, Health and Development*, 14, 395-408.

Klein, S. D., & Schleifer, M. J. (Eds.). (1993). *It isn't fair! Siblings of children with disabilities*. Wesport, CT: Bergin & Garvey Press.

McHugh, M. (2002). *Special siblings: Growing up with someone with a disability* (revised). Baltimore, MD: Paul H. Brookes Publishing Company.

Meyer, D., & Vadasy, P. (1994). *Sibshops: Workshops for siblings of children with special needs*. Baltimore, MD: Paul H.

Brookes Publishing Company. A new edition is in preparation.

Meyer, D., & Vadasy, P. (1996). *Living with a brother or sister with special needs: A book for sibs* (2nd ed.). Seattle, WA: University of Washington Press.

Powell, T., & Gallagher, P. (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing Company. Currently out of print; a new edition is in preparation.

Siegel, B., & Silverstein, S. C. (1994). *What about me? Growing up with a developmentally disabled sibling*. New York, NY: Plenum Publishing Corporation.

Stoneman, L., & Berman P. (1993). *The effects of mental retardation, disability and illness on sibling relationships*. Baltimore, MD: Paul H. Brookes Publishing Company.

Books Specific to Autism Spectrum Disorders for Siblings and Peers

Amenta, C. (1992). *Russell is extra special: A book about autism for children*. New York, NY: Magination Press.

Band, E.B. & Hecht, E. (2001). *Autism through a sister's eyes: A young girls view of her brother's autism*. Arlington, TX: Future Horizons, Inc.

Bleach, F. (2001). *Everybody is different: A book for young people who have brothers or sisters with autism*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Cullen, D. T. (1999). *Trevor Trevor*. Higganum, CT: Starfish Specialty Press.

Dalrymple, N. (1979). *Learning together*. Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

Edwards, B., & Armitage, D. (1999). *My brother Sammy*. Brookfield, CT: Millbrook Press.

Gagnon, E., & Myles, B. S. (1999). *This is Asperger syndrome*. Shawnee Mission, KS: Autism Asperger Publishing Company.

Gartenberg, Z. (1998). *Mori's story: A book about a boy with autism*. Minneapolis, MN: Lerner Publications Company.

- Hoopman, K. (2001). *Blue bottle mystery: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Hoopman, K. (2001). *Of mice and aliens: An Asperger adventure*. Philadelphia, PA: Jessica Kingsley Publishers.
- Katz, I., & Ritvo, E. (1993). *Joey and Sam*. Northridge, CA: Real Life Storybooks.
- Karasik, P. & Karasik, J. (2003). *The ride together: a brother and sister's memoir of autism in the family*. New York, NY: Washington Square Press.
- Landalf, H. (1998). *The secret night world of cats*. Lyme, NH: Smith and Kraus.
- Lears, L. (1998). *Ian's walk: A story about autism*. Morton Grove, IL: Albert Whitman and Company.
- Martin, A. (1990). *The babysitters club: Kristy and the secret of Susan*. New York, NY: Scholastic Inc.
- Martin, A. (1984). *Inside out*. New York, NY: Scholastic Inc.
- Messner, A. W. (1995). *Captain Tommy*. Stratham, NH: Potential Unlimited Publishing.
- Peralta, S. (2002). *All about my brother: An eight-year-old sister's introduction to her brother who has autism*. Shawnee, KS: Autism Asperger Publishing Company.
- Rosenberg, M.S. (2000). *Everything you need to know when a brother or sister is autistic*. New York, NY: Rosen Publishing Group, Inc.
- Rosenberg, M.S. (2001). *Coping when a brother or sister is autistic*. New York, NY: Rosen Publishing Group, Inc.
- Simmons, K. (1997). *Little rainman: Autism through the eyes of a child*. Arlington, TX: Future Horizons, Inc.
- Sprecher, J. (1997). *Jeffery and the despondent dragon*. Muskego, WI: Special Kids Company.
- Sullivan, C. (2001). *I love my brother: a preschooler's view of living with a brother who has autism*. Stratham, NH: PHAT ART 4.
- Thompson, M. (1992). *My brother, Matthew*. Bethesda, MD: Woodbine House.
- Thompson, M. (1996). *Andy and his yellow frisbee*. Bethesda, MD: Woodbine House.

Watson, E. (1996). *Talking to angels*. San Diego, CA: Harcourt and Brace Company.

Selected Resources for Siblings

Family Resource Associates, Inc.

35 Haddon Avenue
Shrewsbury, NJ 07701
Phone: (732) 747-5310
Quarterly newsletters: For Siblings Only (ages 4-9) and Sibling Forum (ages 10 & up).
www.familyresourceassociates.org

The Sibling Support Project

Donald Meyer, Director
The Arc of the United States
6512 23rd Avenue NW, Suite 213
Seattle, WA 98117
Phone: (206) 297-6368
www.thearc.org/siblingsupport/

Videos:

Just Call Him Matthew. (1992). VHS format; 26 minutes. Produced by Mountain Productions, New Mexico; (505) 291-9284. Young brothers and sisters of children with autism speak openly about their feelings and experiences.

Brothers and Sisters on Siblings with Developmental Disabilities. (1989). VHS format; 20 minutes. Produced by YARC Sibling Support, Waisman Center, Madison, Wisconsin. Older siblings discuss their experiences, joys, and disappointments concerning their brothers and sisters with disabilities.

Brothers and Sisters-Siblings. (1995). VHS format; 21 minutes. Society of British Columbia. Narrated by a teenage sister. Visits with a variety of siblings and their families who discuss the challenges and rewards of having a brother or sister with autism.

Sense of Belonging: Including Students with Autism in their School Community. (1997). VHS format; 19:34 minutes.

Distributed by Indiana Resource Center for Autism. Illustrates the value of inclusion and importance it plays for the future of all students.

Being Friends (1991). VHS format; 8:08 minutes. Produced by the Indiana Resource Center for Autism and WTIU. For use with young children and peers.

Straight Talk About Autism: Adolescent Issues (1999). VHS format; 38 minutes. An Attainment Production, P.O. Box 930160 Verona, WI 53593-0160. Phone: (800) 327-4269; Fax: (800) 942-3865. Adolescents with autism and their parents discuss openly their feelings and insights about social experiences that are both rewarding and challenging.

Booklets:

Brothers and Sisters Talk with PACER. (1987). Produced by Parent Advocacy Coalition for Education Rights (PACER), Minneapolis, MN; (612) 827-2966. Booklet with accounts based on interviews conducted with siblings of children and young adults with disabilities.

In Our Own Words: Stories by Brothers and Sisters of Children with Autism and P.D.D. (1997). Edited by Patricia Leonard-Toomey. Published by Community Autism Resources, Adsum, Inc.; (508) 677-9239.

Views from Our Shoes. (1997). By Donald Meyer. Published by Woodbine House, Bethesda, MD; (800) 843-7323.

Web Sites:

www.siblingsofautism.com This is the web site of a teen-aged sibling from New Jersey. Ashley is three years younger than her brother. She offers information, links, chats, resources and pen pal opportunities.

