

## Sibling Resource Packet

### **Parent Information Brochure**

A collection of helpful tips to parents on how to support all of their children, including siblings of the child with ASD.

### **Sibling Resources List**

A list of various resources found online for siblings of children with Autism. The resources range from informational websites and interactive sibling packets to sibling support groups.

### **A Short Story for Younger Siblings (age 5-8 yrs.)**

This story, told from the perspective of 6-year-old Maya, presents key concepts and aspects of life with Autism in a way that allows young children to easily understand and relate.

### **Interactive Comic for Tweens/Teens (10-14 yrs.)**

This comic touches upon the social aspect of living with a sibling with Autism, providing siblings with a space to express their thoughts, feelings and questions.

### **Young Adult Resource (15-18 yrs.)**

This short packet includes information, suggestions and tips for older siblings addressing various questions or concerns they may have. Along with this the packet includes links to stories from other siblings and additional resources.

## 10. Opportunities to Experience Typical Family Life

Siblings and parents could both benefit from opportunities for activities where the focus of energy is not on one particular family member. Find and use community resources that invite participation from the whole family, while utilizing opportunities to take time for yourself!

## 11. Opportunities to Feel Understood

Siblings may benefit from knowing that others are growing up in similar families.

Opportunities to meet other siblings or read about them could help them to feel less isolated. Sibling support groups also offer a chance to share common understanding while having fun. One sibling support style are Sibshops, which combine games, discussion activities, and projects to promote new friendships and support siblings.

<http://www.siblingsupport.org/sibshops/>

[find-a-sibshop](#)

## 12. Learn Strategies for Responding to Peer Questions and Comments

It can be helpful to prepare siblings for possible reactions from others, and equip them with facts about autism. Discuss solutions for possible situations so the child feels prepared. Some examples of questions from peers may be, why doesn't your brother talk? Why does your sister repeat herself? Knowing some examples up front may help determine how to best respond to them.

Siblings without disabilities viewed their relationship with their sibling as positive when

- They had an understanding of the sibling's disability
- They had well-developed coping abilities
- They experienced positive responses from parents and peers toward the sibling with autism.

Normal emotional responses can include

- Anxiety
- Anger
- Jealousy
- Embarrassment
- Loss
- Loneliness



Wheeler, M. (2006) Sibling Perspectives: Guidelines for parents. Indiana Resource Center for Autism <http://www.autism-society.org/living-with-autism/family-issues/sibling-perspectives.pdf>

Harris, S.L. & Glasberg, B.A. (2033). Siblings of Children with autism: A guide for families. (2nd ed.) Bethesda, MD:Woodbine House.

¡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,MD: Paul Brookes Publishing Co.

## Sibling Support



## A Parent's Guide

Research shows 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.

# 12 Key Needs for Sibling Support

## 1. Communication

Before talking with your other children regarding your child's diagnosis, it will probably be helpful to begin to process and start to understand autism. Once you have a general understanding, you will probably be ready to share the information with your children, keeping in mind what they will be able to understand at their varying ages. Without concrete information, siblings may withdraw or display inappropriate behavior due to stress or fear of hurting the parent with questions. Creating open lines of communication can make the entire experience less stressful.

## 2. Developmentally Appropriate and Ongoing Info

Without information, siblings may develop only a partial or simply an inaccurate understanding of autism. They may wonder if they can "catch" it, or whether they did something to cause it. Younger children may only understand specific traits, such as, their sibling not using words to communicate, or not making eye contact.

## 3. Consistent, Individual Attention

Many families praise and reward the child with autism for every step of progress. The same effort should be considered for the siblings. Celebrating everyone's unique achievements will build positive self-esteem!

## 4. Special Time

While the sibling with autism will naturally receive a great deal of parental attention in school meetings, or working with therapists and doctors, it's important the child without autism feels important as well. With busy schedules, it can be especially hard for every family to create time for each child. If possible, schedule a special one on one time with each child. This can be a ten minute activity before bed each night, or a longer period several times a week.



When the activity is scheduled, each child can look forward to it all week!

## 5. Interaction Skills

Siblings can learn certain skills to interact with their brother or sister with autism. Siblings can be encouraged to be patient and use appropriate praise. You can model best way for your family to give instructions, prompts, and praise.

## 6. Choices

Be reasonable with your expectations of siblings. Some siblings are given responsibilities in the care of their brother or sister with autism, but that still means they need you to respect their private time and choice in how involved they are.



## 7. Safety

Siblings may need to feel that they and their belongings are safe from their brother or sister. Whenever possible, try to allow for a safe space and teach them how to respond if their sibling is prone to biting, pushing, or engaging in other challenging behaviors

## 8. Fairness

Young children may have a difficult time understanding why their brother or sister with autism gets treated differently than they do. As they mature, siblings will better understand these adjustments. Whenever possible, try to make responsibilities of all of your children as equal as possible.

## 9. Time to Work Through Feelings

Listen to, acknowledge, and validate both positive and negative feelings as normal. This is also a great time to appropriately share your own positive and negative emotions. Modeling these emotions can make a child feel better about experiencing them.





# The Autism Program

AT BOSTON MEDICAL CENTER

## Links to Resources for Siblings of Children with Autism

### Tips for Parents

Information from the Autism Society on how to explain Autism to children, as well as on how to help them form meaningful relationships with their siblings

<http://www.autism-society.org/living-with-autism/family-issues/siblings>

Information from the Massachusetts Sibling Support Network that shares perspectives, stories, tips and techniques for families.

<http://www.masiblingsupport.org>

### Informational Packet

Put together by Autism Speaks, this interactive informational packet for siblings of children with autism is designed for children ages 6-12 years old. The packet is a great opportunity for parents and children to read and interact with the guide together. The guide gives opportunities for the child to write and talk about their feelings and emotions.

[www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#siblings](http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#siblings)

### Sibling Support Groups

The website provides support to siblings of people with various health and special needs, including Autism. Gives access to support groups, online pen pals, workshops, etc.

[www.siblingsupport.org](http://www.siblingsupport.org)

### Books

The link provides various book suggestions for siblings of children with special needs.

<http://astore.amazon.com/thesibsuppro-20>

Written by children between the ages of 4 and 18, *Views from Our Shoes: Growing up with a Brother or Sister with Special Needs* has stories written by siblings for siblings. Complete with a glossary of definitions it provides information as well as personal tales about life with children with special needs.

<http://astore.amazon.com/thesibsuppro-20/detail/0933149980/186-5043888-1723433>

*The Sibling Slam Book: What It's Really like to Have a Brother or Sister with Special Needs* provides truthful insight into the perspectives of teens with siblings with special needs.



# The Autism Program

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Hi! My name is Maya, I am 6 years old.

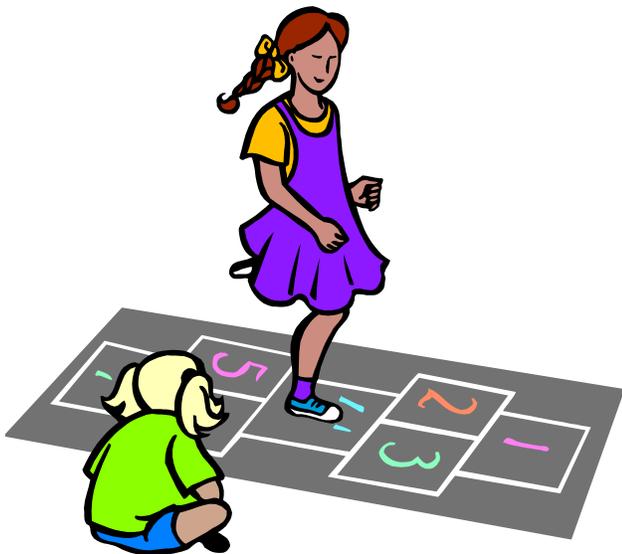
I have a brother named Ted. Mom says that Ted has something called autism, and Ted plays different from me, because his brain works a little differently than my brain.



Mom says that Ted thinks and acts a little bit different from most other people. He might not know how to play with toys the same way I play, and he might not be able to play pretend with me.



Sometimes, my friends and I go outside to play. Ted might not always want to join us. Even though we like to run, jump, and play pretend, Ted likes to play with his trains most of all. We are very patient when he does decide to play with us, and we tell him how happy we are when he does!



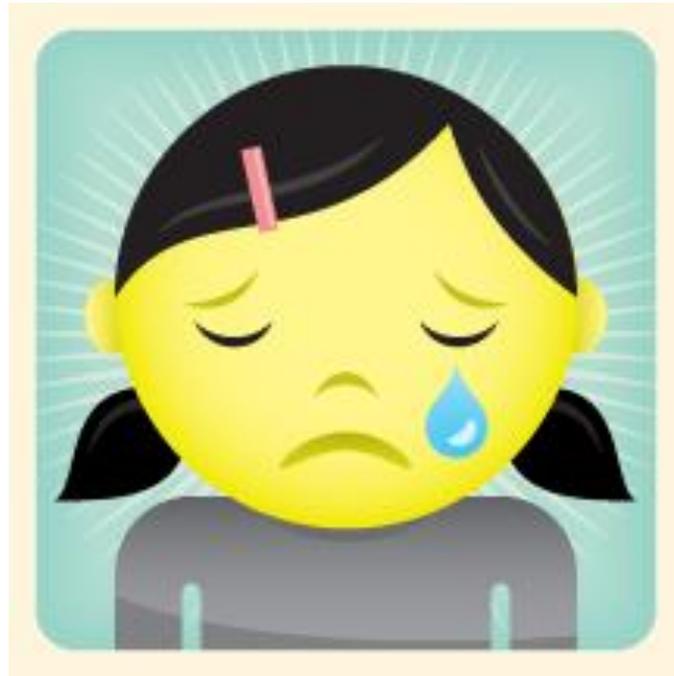
Mom is going to try very hard to make sure I get special time with her, just like Ted does. We are both very special to Mom and Dad. Ted needs a little extra attention sometimes, and sometimes I do too. It's okay to tell Mom or Dad if I am sad and want some extra time with them.



When Ted and I each get special time with Mom and Dad, it makes us so happy to do things all together as a family!



Now I understand Ted so much better! Even though I do understand him, sometimes brothers just do things that upset their sisters.



Ted may not understand right away when he does things that upset me. Because his brain works differently, he has a little trouble understanding others' feelings. Ted loves me, and he doesn't mean to hurt my feelings.



If Ted does upset me, I might have feelings that I should talk about with Mom or Dad. Whenever I get upset I should tell Mom or Dad and they will listen to me very carefully. It's nice to have lots of grown ups that also want to listen to me. I can ask Mom and Dad, my teacher, or my doctor, any time I have questions about Ted.



I have learned that Ted is different, just like everyone is different in their own way! He is special, just like me. When we talk about our feelings, I feel much better, and I can go back to being a good helping sister to Ted!



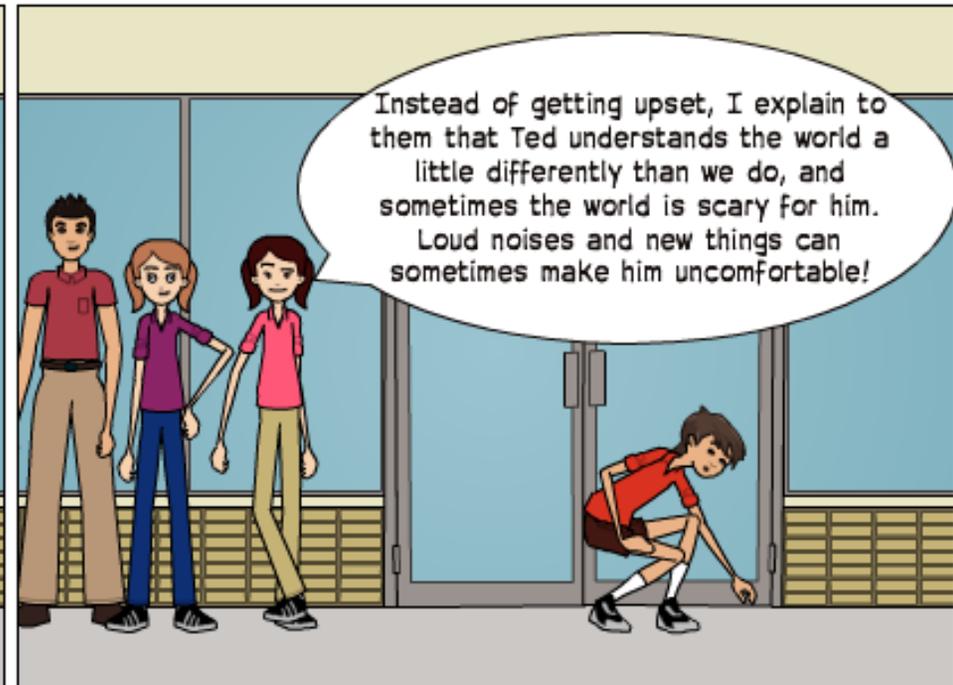
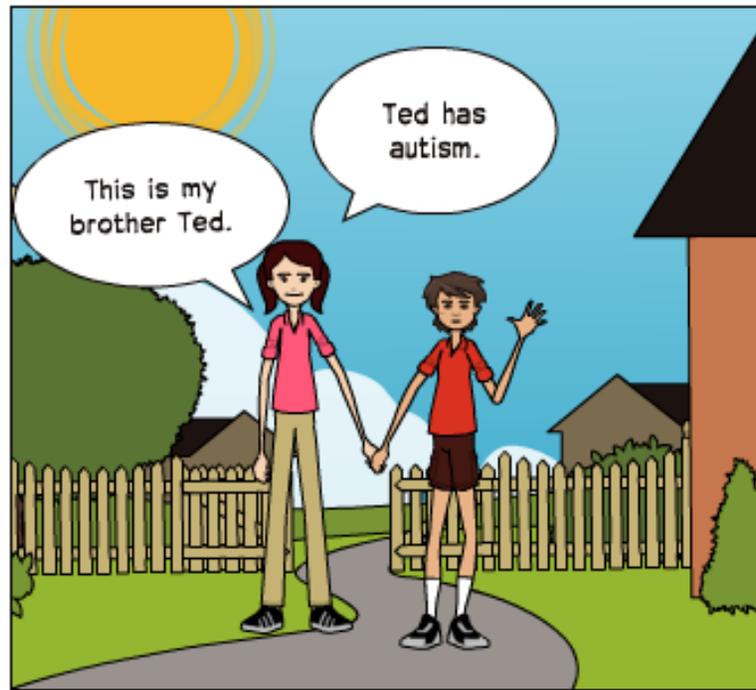


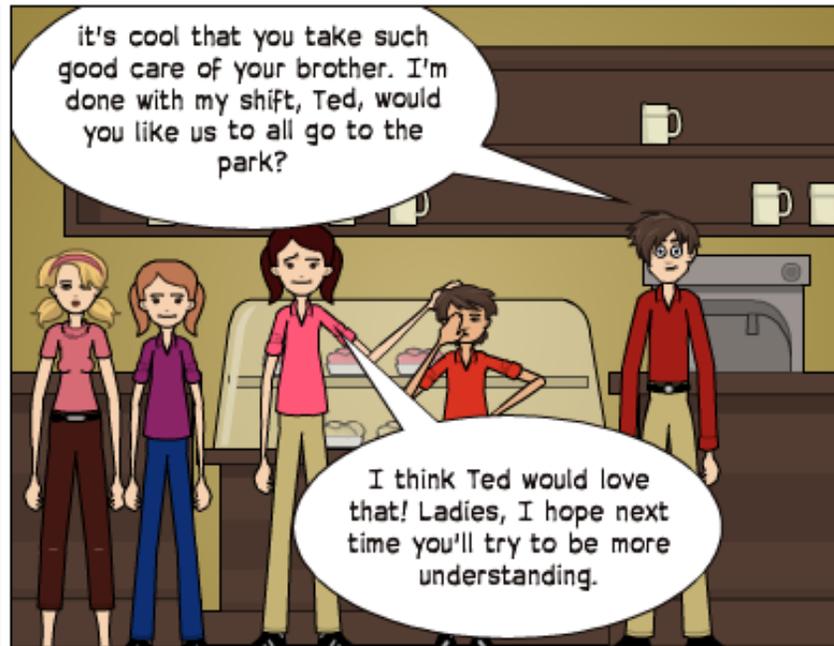
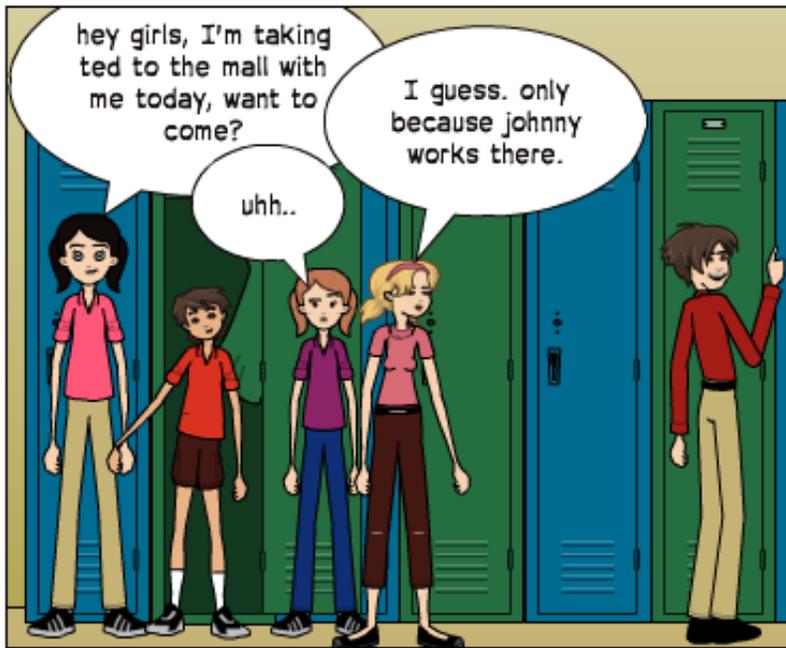
Ted is a little different from me. But, our relationship isn't different from most siblings! We hang out, we play video games together, and sometimes we fight.

Some days, it's easy for me to explain to people what autism is. When people understand the things Ted does, they get to know how cool he is!

But, like everyone, some days I need some space. When I need that time, I just tell my mom or dad and I know I can come to my room and chill out. If I feel upset by something Ted does, I talk to my mom or dad about it. Nobody's perfect, and Ted and I both make mistakes and upset each other sometimes, like any siblings!









## Tips for teens who have a sibling with ASD

Always remember that you are not alone. There are many other teen siblings out there who may share your similar experiences, and also have questions, concerns and thoughts just like you.

Read below to see what some of them are thinking.

**Worries:** Do people mistreat you because of your brother or sister? Are you having difficulties at school or with friends?

### Suggestions:

Having a sibling with autism can be difficult. You often may have to explain your brother or sister's behavior. You may feel responsible for them, and you may not connect with your peers as well because you lead such different lives. However, this is no reason for anyone to be bullied, and if you are having serious difficulties at school you should talk to your parents or to your administration to stop it. It is also important to remember that hostility stems from ignorance. By informing people about autism you provide more information and understanding to them. You have the power to spread autism awareness just by talking to people. Thanks to you, more people could know and accept autism for what it really is.

### Question: What about the future?

As they reach adulthood, many siblings begin to wonder about the future. What kind of life will you be able to have? What about your brother or sister? Who is going to take care of them? What will my role be in caring for my sibling?

**Answer:** The answers to these questions will be different for each family as each situation is unique. This is why you should talk to your parents and/or care providers about such questions. Although these may not necessarily be topics you want to think about or discuss (and even if it feels awkward), it is important to talk them over with your family. Everyone needs and deserves to be on the same page so you can all plan accordingly for the future.

Some useful things to do are:

- Make a plan with your parents about your siblings' future care
- Clearly establish what your role in your siblings' life is and what you would like it to be
- If desired, participate in meetings and appointments. Try to gather information from your parents, doctor and other care providers. Ask questions and seek advice.

### Problem: Not communicating well with your parents?

It's kind of a universal fact—families are busy and they can get on our nerves. You have school, friends, hobbies; your parents' time is taken up by work and taking care of your sibling. As a result you may not get one-on-one time with them. Communicating with parents can be hard in any situation, but when you add on all these other factors, it can be very easy to run into communication obstacles.

### Solution:

It is completely ok to ask your parents to set aside time specifically for you. Try finding a common interest or activity that you and your parents could take part in. Set aside a time every week to do that activity. You'll get a chance to become closer with your parents and you can learn something new along the way. For example, Ben, who has two brothers with autism, took up gardening to spend time with his mom. Not only has their relationship improved, but he is now a junior judge at gardening competitions! Who knows, maybe you could uncover a new passion too!

## **Want to know what other siblings are saying? Check out some of these blogs and websites by other sibling teens and young adults!**

Carrie, with a twin brother who has autism, worries about projecting onto her brother:

<http://www.autismspeaks.org/blog/2013/09/24/am-i-just-projecting-sister-wonders-how-her-nonverbal-twin-feels>

A teen writes about his closer relationship with his autistic brother:

<http://www.experienceproject.com/stories/Have-A-Sibling-With-Autism/3437982/>

Bridget writes about her sister's recent diagnosis of autism and how she has come to accept it:

<http://www.autism.org.uk/living-with-autism/real-life-stories/real-life-stories-from-siblings/a-bond-that-nobody-can-break.aspx>

Peggy describes the difficulties she has had in connection to her brother and how she has managed to overcome it:

<http://www.autism.org.uk/living-with-autism/real-life-stories/real-life-stories-from-siblings/making-a-new-start.aspx>

### **Some useful resources:**

**Want to talk to someone else in a similar situation as you?**

**Check out this sibling support group with workshops, online groups, pen pals, useful information and more!**

[www.siblingsupport.org](http://www.siblingsupport.org)

**Sibling support includes resources such as sibshops, online support groups for siblings, information on autism and book suggestions;**

