

Brothers, sisters, and autism: a parent's guide to supporting siblings

Having a child with autism and children without comes with unique challenges. You're not only faced with doing what's best for your child with autism, but also with paying attention to the needs of their brothers or sisters. No matter what you call them (neurotypical, typically developing, normal, etc.), these siblings are often dealing with the same struggles and feelings that you do as parents. They, too, feel a sense of loss, confusion, and frustration – all at a time before they've developed comparable coping skills. These future advocates, potential caretakers, and friends will establish the longest lasting relationship with your child on the spectrum, and therefore need guidance and support from the start. You're likely to find that supporting your children without autism will prove to be a long-term investment in your child with autism. The topics addressed in this resource outline ways you can help your kids without autism adjust, understand, and enjoy being a sibling.

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1. Explaining autism

Why it's important

An autism diagnosis can be a tricky thing to discuss, not only for the child diagnosed, but for their siblings as well. Kids are the masters of asking "why," and they may ask questions about autism (or specific aspects of their sibling's behavior) before you have all the answers. It's important to be ready to talk to your children about what autism means, even if you think they already understand. You may be surprised at how little your children actually know. Siblings may pick up a few pieces of information here and there, but they likely have more questions than they do answers.

When should I start?

There is no "perfect time" to explain autism to your other children. However, starting early and revising these definitions often will ensure that they have a good understanding of what autism means for their sibling. It's a good idea to talk to kids about their sibling with autism before they enter school or start having friends over. This will help prepare them for the seemingly inevitable question: "What's up with your brother/sister?"

Kids will generally need more mature explanations of their sibling's autism as they get older. Younger children are likely to do better with ability-based definitions, accompanied by concrete examples. For instance, try "Your brother just learns a little differently than you and me, so he needs extra help," or "Your sister's autism means she can't talk and has trouble playing like you do, but she still loves you very much." In contrast, incorporating the term "autism" into your explanation may help an older child understand the disorder more fully. It is important to periodically check your children's understanding of autism, especially as it pertains to their own sibling. An accurate and age-appropriate understanding of their sibling's condition can help children feel more comfortable when explaining it to others, interacting with their sibling, and understanding what their brother or sister is going through.

"Your sibling's autism..."

When explaining autism to your other children, remember to be specific to their sibling's particular experience. Siblings who don't have autism want to know what is going on in their brother or sister's world, so offer any insight that you can. Try explaining behaviors in terms of the motivation and purpose behind them. For example, if your child with autism "stims" in a certain way (like rocking back and forth, hand flapping, or repeating noises), explain that they do this to calm down or feel safe; it's just like asking for a hug or playing on the swings to wind down. Many siblings wish they had known more about how autism affected the way their brother or sister felt, saw things, learned, and interacted. While you can't know the inner workings of anyone else's mind, it's still a good idea to share whatever perspective you can offer.

Siblings might understand their brother or sister's "unusual" autism behaviors better by comparing them to their own feelings and actions. For example, if your children without autism get excited, they might express themselves by telling you just how excited they are. On the other hand, your child with autism might flap their hands to express the same feelings because their brain works differently. Keep these explanations age-appropriate and relevant to your children's daily interactions, like behaviors expressed during play or mealtime.

The way your children react towards their brother or sister with autism's "unusual" behaviors will be reflected by their peers and friends. Similarly, your response is also likely to influence the way your other children see their sibling. If your children notice how accepting and compassionate you are in spite of difficult circumstances, both towards your child with autism and other members of the special needs community, they will be more likely to follow suit.

1. Explaining autism

What siblings wish they knew about their brother or sister with autism when growing up:

- "Autism is not contagious."
- "It's not his choice whether he responds or not. Also, when he repeats things, he does it for comprehension."
- "The way he acted was not my fault. I thought I was doing things to cause his behavior."
- "Some of the things my brother does, he doesn't do on purpose"
- "My brother is not the only one who had autism."

Try these resources for more tips on starting a conversation about autism:

Autism Society of America's Guide for Parents

Source: *Autism Society of America (ASA)*

What it offers: A well-rounded look at specific issues that siblings deal with, including emotional issues, learning about autism, and tips for leading a healthy family life

Link: <http://bit.ly/OARSibs1>

Parent Tips: Explaining Autism Using Everyday Examples

Source: *Pathfinders for Autism*, article by Shelly McLaughlin

What it offers: A reference sheet and framework for explaining some of the behaviors associated with autism; it may be especially useful for parents with children who might not understand why their sibling does "weird" things

Link: <http://bit.ly/OARSibs2>

Autism Speaks: Siblings Guide to Autism

Source: *Autism Speaks*

What it offers: A guide on how to explain Autism Spectrum Disorder to younger children that contains helpful questions and tips for children first learning about autism

Link: <http://bit.ly/OARSibs3>, and then scroll to where it says "A Sibling's Guide to Autism"

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2. Family life

“It’s not FAIR!”

Children in all kinds of families have a unique ability to sense discrepancies in fairness. From chore distributions to bedtimes, chances are your children will be acutely aware of who gets more or less of something. When a child has autism, the perceived unfairness at home can seem monumental to their siblings. To them, special teachers, special toys, and fewer chores are unfair “luxuries” afforded to their brother or sister with autism.

It’s important to address these frustrations as they come up; your children without autism will often need to be reassured that they are just as important and as loved as their sibling with autism. It may also help to explain that what appears to be “playtime” can actually be a lot of hard work for your child with autism, and probably isn’t as fun as it looks. Try explaining therapy appointments, giving each of your children one-on-one time, and ensuring that everyone does some share of chores (no matter how trivial). You may want to remind your child without autism that while their sibling has therapists who come to the house and “play,” everyone in the family gets to participate in their fair share of special activities.

Sharing your attention

A big struggle for your children without autism can be the feeling that their brother or sister with autism is getting more of your attention. There is likely some truth to this, considering that children with autism often have busy schedules full of appointments, therapy sessions, and at-home support. Kids don’t always recognize this as their brother or sister with autism engaging in hard work. Instead, it can appear as if their sibling just gets more of their parents’ love and time.

Remember that little signs of affection can go a long way. Taking a second to say something as simple as, “I’m so proud of you” can be very meaningful. One-on-one time with you can be a huge boost, but it may also sometimes be difficult to schedule. If time is short, strive for consistent bits of time each day. Many parents master the art of stealthily manufacturing personal time with their other children, such as bringing them along to run errands or buy groceries. Car time is also great for check-ins and giving one child your undivided attention. Kids will eventually come to understand that their sibling with autism may require more of your attention, but that does not mean they get more of your love.

Parents share concerns about family life:

- “Sometimes we don’t do certain activities together as a family - like taking a boat ride – because of her anxiety, so the family has to separate into two groups. That can be hard on us as parents.”
- “We certainly spend a disproportionate amount of time taking care of his brother, which takes time away from him. He has to be more self-reliant, he has to tolerate his brother’s outbursts and the lack of understanding about boundaries.”
- “[The] amount of time my son needs takes parental attention away from her. She’s had to grow up faster”

2. Family life

For more on fairness and attention:

Giving Siblings Attention

Source: *Sibs*, a UK-based organization dedicated to helping the siblings of individuals with special needs of all kinds, including autism

What it offers: Tips and ideas for parents about giving their children without autism love and attention despite the hectic schedule that a sibling with autism brings

Link: <http://bit.ly/OARSibs4>

Trying to be Fair

Source: *Raising Children Network*, a parenting website based in Australia

What it offers: Advice on finding fairness and balance with both children with autism and children without

Link: <http://bit.ly/OARSibs5>

Recognizing differences

Siblings of children with autism are as diverse as their brothers and sisters! Each of your children without autism will experience having a sibling on the spectrum in a different way. This experience is influenced by a variety of factors, such as gender and whether they're an older or younger sibling. You may find your daughter steps into the nurturing role with ease, while your son wants very little to do with his brother or sister with autism – or vice versa. There is also a tendency for younger children to model their behavior on their older sibling, regardless of whether or not they have autism. It can therefore be very difficult for children if they find themselves getting reprimanded for copying their sibling's behavior, while their sibling is seemingly allowed to do as he or she pleases.

It's important for parents to observe and listen to how each child reacts towards their brother or sister with autism. Keep your expectations flexible, and try not to assume that one child's reaction will be the same as another's. While one child may be more outwardly caring towards their sibling with autism, it may not be as easy for your other children to feel that kind of compassion. Ensure that you acknowledge and validate each child's feelings; doing so will help them work through some of the more challenging aspects of having a sibling on the spectrum.

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3. Out in public

Embarrassment

It's natural for siblings to unintentionally embarrass one another, but when the embarrassment stems from autism, brothers or sisters may feel conflicted. Your children without autism may not only feel embarrassed, but also guilty for feeling embarrassed. They may resent when their brother or sister acts out in public. Stimming, meltdowns, and things that may look "odd" to strangers can all be hard for siblings to deal with.

All families have their quirks, even if some are more visible than others. Let your children know that it's okay to feel embarrassed. If they feel comfortable explaining autism or their sibling's behaviors to strangers, equip them with enough information and confidence to do so. Some siblings may even need guidance on being helpful (rather than defensive) when talking about autism. Explain to your children that they don't have to say anything if they don't want to, and that some things don't require an explanation. Some people will be rude or stare, and it's okay to ignore them. There will always be people who don't understand, but there are things your children can control, like their attitude and how they respond.

Siblings talk about embarrassment:

- "It often makes me feel awkward or nervous because I feel like I have to compensate for my brother's lack of social skills. It can also be frustrating because I always have to go along with him and make sure he's doing alright."
- "He yells a lot, so when my friends hear, it's embarrassing. But mostly, besides the odd looks, people are understanding."
- "She has many outbursts and people stare a lot, but I either tell them to mind their own business or ignore them because it's rude to stare no matter what the situation."

For more tips on family time, going out, and embarrassment, check out:

I get embarrassed about my sibling on the spectrum. Help!

Source: *The Den*, a site for individuals on the spectrum (and their friends and family) that provides guidance on social, work, and life issues for people with autism

What it offers: Advice for siblings on how to deal with embarrassment, as well as some tips for making outings go as smoothly as possible

Link: <http://bit.ly/OARSibs7>

Embarrassment (supporting siblings with feelings)

Source: *Sibs*, an organization dedicated to helping the siblings of individuals with special needs of all kinds, including autism

What it offers: Advice for parents on helping their children deal with embarrassment. Offers tips on how to overcome the feeling of embarrassment, finding sources of embarrassment, and preventative measures

Link: <http://bit.ly/OARSibs8>

3. Out in public

Special events, holidays, and going out

Having a child with autism means that special occasions and outings can be challenging. There may be sensory issues with surroundings, struggles in social situations, and difficulties when deviating from a routine. Your children without autism might feel like they can't enjoy these times because of their sibling's behavior or the constant threat of a meltdown. They also may be upset that only a fraction of the family can be at an occasion because their sibling with autism has something else going on. When one of your children has a recital, a game, or a show, it can be hard to explain that one or both parents can't attend, let alone their sibling with autism.

These types of occasions are special for your children without autism and it's important to find ways they can enjoy them. If holidays tend to get cut short, maybe they can still enjoy their favorite parts (e.g. playing with their cousins early, getting to unwrap a gift first, or bringing home a piece of cake from the party). When one of your children is performing or competing, consider looking into a babysitter or respite care so one or both parents can attend the event. There may be times when that's not a possibility; in those instances, kindly ask another parent to digitally record everything so you can watch it together with your child later on.

For more on events, holidays, and parties:

Holiday tips for children with autism, siblings

Source: Eileen Garvin, writing for *Psychology Today*

What it offers: The writer grew up with a sister who has autism; she reflects on her experience, as well as what parents can do to ensure that their children with and without autism have a good holiday

Link: <http://bit.ly/OARSibs9>

Special Times & Not Everything as a Family

Source: *Autism Society of America*

What it offers: The "Special Times" and "Not Everything as a Family" sections outline some ideas for dealing with special occasions and going to outings that may be stressful for a child with autism

Link: <http://bit.ly/OARSibs1>

3. Out in public

Friends and peers

There will come a time when your children without autism have a collision of worlds: when their outside life, like school and friends, meets their home life. Bringing friends into life with autism can be a challenge, especially the first time someone comes over for a playdate. Some children handle this transition with ease, while some actively avoid it, even hiding the fact that they have a sibling with autism from others. Sometimes a kid will be afraid of being embarrassed by their sibling with autism and will avoid having friends over altogether. If your children go to the same school, peers and friends may ask one of your children without autism, "what's up with your brother/sister?"

Parents should address how to deal with peers who ask questions, or are even rude about a sibling's behaviors. School can be a stressful time for any of your children if they feel judged for having a sibling who does "weird" things or requires special attention. Prep them for these kinds of conversations and help them come up with simple, efficient explanations for their peers. They shouldn't have to feel defensive about their sibling, but being able to have a quick, thoughtful dialogue with a friend or classmate could make it easier for them when people ask questions.

For playdates at home, it might be a good idea to establish boundaries, like having your child with autism play in another room when a sibling's friend is over. This may be easier said than done, so encourage your children to be open with their friends about what to expect. More likely than not, your children will end up with kind, non-judgmental friends, who appreciate them and their brother or sister with autism.

As with any sibling relationship, age can make a big difference. The teenage years add a new level of complexity, because peer relationships and social acceptance become increasingly important. As your child with autism enters the later teen years and young adulthood, they might start to look mature, but their emotional or intellectual maturity may lag behind. This can be another source of embarrassment for your children without autism. These are difficult issues that require love, acceptance and patience on everyone's part. Encourage your children to respect their sibling with autism's difficulties and differences.

Parents said...

- "My daughters do not want their brother's autism to be the first thing they tell someone... but they have always judged their friends, and especially boyfriends, by how they reacted to their brother."
- "At the age of four, she defended him to her peers. A couple of boys in her class made fun of him for his movements and an outburst he was having over a toy he couldn't take. She walked right up to them and said, 'He's just a little boy!' No truer words have ever been spoken. She 'gets it' more than many adults do."

For more info, check out:

Growing up Together: Teens with Autism

Source: *Autism Society of America*

What it offers: A guide for teens with a classmate or a friend who has autism; this could be a useful tool in explaining, or getting ideas to explain, autism to teenagers that addresses both how to be a friend and ways to communicate

Link: <http://bit.ly/OARSibs10>

What's up with Nick?

Source: *Organization for Autism Research*

What it offers: A guide for younger children (originally written for a classroom setting) that explains autism in simple terms; it also gives suggestions to younger children about playing with and talking to kids with autism

Link: <http://bit.ly/OARSibs11>

4. Challenges and feelings

Negative feelings

Autism comes with a host of feelings that can be difficult to process. Your children may deal with anger, resentment, guilt, loss, and many others. They may not know how to cope, or may not want to talk to you about it for fear of being a burden or sounding negative about their sibling with autism. It is important to assure your children that it's okay to have these feelings. Listen to what they have to say, acknowledge that their feelings are legitimate, and give suggestions on how to work through things. Even if it's something as harsh sounding as, "I hate my brother!" or "I wish I didn't have a sister," you as a parent should be open to these very real feelings and guide your children through them.

It's important to keep an open line of communication between you and your children without autism. You may want to open up opportunities for conversation by revealing your own struggles and feelings in ways your children can understand and appreciate. Siblings of children with autism often feel more comfortable expressing themselves if they know you're going through similar emotions. Also, remind your children that siblings of all kinds have moments when they fight or don't get along. Encourage them to accept the difficulties that come with being a sibling of someone with autism, but also remind them to appreciate their sibling's quirks. Everyone is different, and there's something to appreciate in every person. Your children will learn that better than most.

Siblings on tough feelings:

- "She can say incredibly hurtful things... I used to get very upset and yell back at her, which would only make things worse. Now I just walk away and try to avoid her until we have both cooled off."
- "I wish I had known that it's okay to feel angry or annoyed, and not want to spend a lot of time with him. I spent a lot of time feeling guilty when I should have just accepted my feelings."
- "Sometimes my sister plays on my iPad and deletes games on it. I just usually let it go and say to myself that it isn't the most important thing in the world."

Thinking about the future

As children become older and start to think about their future, they may ask questions about where their sibling with autism fits. When the time is right, make sure to involve them in the planning process. Keeping an open line of communication that involves your children without autism will ensure that everyone feels comfortable with any plans that are set in place. If circumstances lead to you being unable to care for your child with autism prematurely, the earlier discussions will help your children without autism deal with such a situation.

If your child with autism will need care in the future, it's important that you listen to your other children's thoughts concerning the matter. Many parents will find that their children develop a sense of responsibility towards their sibling from a young age; however, some siblings might not have given the matter much consideration.

As a parent, the best thing you can do for your children without autism is to validate their feelings and be supportive of the decisions they make regarding their part in their brother or sister with autism's future. Perhaps one of your children will feel obligated to take responsibility for their sibling. They're also likely to experience guilt if they don't feel confident in their ability or desire to do so. Whatever the decisions your children make, your guidance and reassurance will allow them to feel more comfortable about whatever the future holds for themselves and their sibling.

For more information on making future plans with your children without autism, go to:

Making a Future Care Plan/Planning for an Emergency

Source: *Sibs*, an organization dedicated to helping the siblings of individuals with special needs of all kinds, including autism

What it offers: These pages were produced as guidance for adult siblings; however, parents may also find the information given relevant and useful

Link: <http://bit.ly/OARSibs14>
<http://bit.ly/OARSibs15>

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4. Challenges and feelings

Aggressive behaviors

As children, we are told the basics about violence: hitting other people is bad and any kind of violence is unacceptable. However, the lines can be blurred when a sibling with autism is aggressive. Violent tendencies aren't always a symptom of autism, but they usually serve as a source of stress, tension and fear within families. Siblings may ask why their brother or sister gets away with being aggressive, and your children may feel angry, confused, or even afraid if they see their sibling with autism hitting a family member – or experience getting hit themselves. Some children may resent their sibling's violent outbursts or feel protective of parents who bear the brunt of aggression.

Explaining a sibling's violent behavior is a sensitive subject that should be approached delicately. Children with autism can act out violently because they are experiencing pain, sensory overload, or frustration. It may be worth explaining to your child without autism that while they are able to let someone know when they are hurt or bothered, it's not as simple for their sibling to express themselves. Though it may be tempting to say something like, "your sibling can't help their behavior," keep in mind this may make your other children feel like they're not supported, or that their safety isn't a priority. You can soothe fears and concerns through a combination of explanations, comfort, and plans for prevention. No matter what, it is important that the issue of violence is addressed.

No family members should feel unsafe in their own home. If you or any of your children (including the one with autism) end up seriously hurt after a meltdown or other violent episode, there are services out there that can provide additional support. Consider looking into specialists who can offer advice about reducing violent behavior.

For more on how to help your children without autism deal with their sibling's aggressive behaviors, go to:

Siblings Getting Hurt

Source: *Sibs*, an organization dedicated to helping the siblings of individuals with special needs of all kinds, including autism

What it offers: Guidance for parents on what to do when one of child experiences aggression from their sibling with a disability

Link: <http://bit.ly/OARSibs12>

Challenging Behaviors Toolkit

Source: *Autism Speaks*

What it offers: A guide to dealing with challenging behaviors related to autism; this not only applies to violence, but other issues that families might struggle with

Link: <http://bit.ly/OARSibs13>

5. Relationships between siblings

Growing up together

Every sibling relationship is special, but sometimes autism can make it harder for brothers and sisters to bond. While some children have no trouble developing a close relationship, others can find it difficult to overcome autism's major sibling-related barriers: communication, displaying affection, and finding common interests. Your children may feel rejected or distant from their sibling with autism, or even guilty for not having the same closeness they see between siblings from other families. Some children may have genuine feelings of love for their sibling with autism, and yet at the same time experience a sense of loss when thinking about the brother or sister they "could have had".

Fostering a good relationship can be as easy as finding ways younger siblings can play together, or helping older siblings find shared interests they can connect with. This, like all relationships, will take love, patience, and time. Siblings may have very different interests – one child might be a budding geologist, while the other loves to run around outside. Search for overlaps: maybe they can go for a walk and look for cool rocks together. Parents can't force their kids to have a better relationship, but it can be helpful to facilitate opportunities to play together and find common interests.

Siblings say they get along best when:

- "We talk about a subject he is really into. I try to get into the same stuff he does so we have something to talk about."
- "We play video games together or talk about his favorite things. He loves playing games and talking about them, too!"
- "I tickle him and jump on the trampoline with him."

For ideas on how to promote positive sibling interactions and relationships, check out:

Ways to play together

Source: *We Rock the Spectrum LLC (created by My Brother Rocks the Spectrum Foundation)*

What it offers: A place for kids on and off the spectrum to play in a safe environment and have fun together; this is one example of an environment for sibling interaction, but look in your community for others (e.g. autism-friendly movie showings and inclusive sports leagues) or consider organizing playdates with other autism families.

Link: <http://bit.ly/OARSibs16>

Peer Play Predicament

Source: *Organization for Autism Research (OAR)* – blog post from September 24, 2013

What it offers: This blog post talks about the special challenges of kids with autism and playdates, whether they're with other children with autism, or their peers without autism; the post offers some good insight on how to help kids with autism and kids without autism play together, which can be a huge help to siblings

Link: <http://bit.ly/peerplay>

How can I get my brother or sister to respond to me?

Source: *Organization for Autism Research (OAR)* – newsletter from September 2004

What it offers: Within a full article spanning multiple sibling topics, the section "How can I get my brother or sister to respond to me?" gives kids guidance on how to play and connect with their sibling with autism in a way that they can both benefit from

Link: <http://bit.ly/OARSibs17>

5. Relationships between siblings

Time apart

Being a sibling of someone with autism can sometimes feel like a full-time job, so it's important for children to have time and space to be their own person. Siblings occasionally need to take a break from one another and recharge. Beyond getting involved in a club or their own activities, siblings of children with autism might find it helpful to connect with others who are going through the same things. This gives children time and space to vent, as well as get advice on how to deal some of the issues they're experiencing. If your children feel like they can have time to relax and be themselves, they're more likely to enjoy spending time with their sibling... and get more out of it!

There are support groups for siblings of children with disabilities in many communities; it's worth seeing if there is one near you. You may be surprised at how close the nearest group can be. There are also online forums, websites, and social media pages for siblings to safely express themselves and talk with others going through similar things. Here are some examples:

If you find that there aren't any suitable support groups available for your children without autism to attend, think about getting together with other families in your local special needs community to facilitate a less formal but still meaningful support session. From organizing a playdate for younger siblings to arranging for contact details to be exchanged amongst teenagers, providing opportunities for your children without autism to validate their feelings is likely to have a positive effect on their relationship with their brother or sister with autism.

Sibshops

Source: *SiblingSupport*, created by Don Meyer

What it offers: Sibshops provide support and community for siblings, as well as a chance to let off steam and be a kid; siblings often make strong friendships with one another, can talk over problems with leaders and peers, and enjoy the special time just for them

Time commitment: Typically once a month for 2-3 hours, depending on the specific program

Pricing: Varies depending on location and facilitating person/group; runs from free to \$40 or more per session (memberships or grouping packages are often available)

Find one near you: <http://bit.ly/OARSibs18>

Sibs

Source: *Sibs*, an organization dedicated to helping the siblings of individuals with special needs of all kinds, including autism

What it offers: There is a "doing your own thing" section that outlines a few tips to help younger siblings to take healthy breaks from their sibling

Link: *YoungSibs*: <http://bit.ly/OARSibs19>

AdultSibs: <http://bit.ly/OARSibs20>

SibTeen Facebook Group

Source: *SiblingSupport*, created by Don Meyer, a Facebook group geared specifically for teens with siblings with disabilities

What it offers: An outlet just for teens to talk about their problems, seek advice, and celebrate their role as a sibling of someone with a disability; members of the page can contact each other, make general posts, and form friendships with others in similar situations

Link: <http://bit.ly/OARSibs21>

6. Finding balance

Families impacted by autism know that the ride isn't always easy or predictable. You may experience challenges and make plenty of sacrifices, but there will also be laughs and warm memories. Parents are completely tuned into these ups and downs, and siblings will be, too. With your guidance and support, they will learn how to laugh, teach, learn, and grow alongside their brother or sister with autism. They'll also learn how to be there for you (and each other) during times that aren't so joyful. Siblings often develop the skills and attitude to not only great advocates for their brothers and sisters, but the entire special needs community.

What parents say about their children without autism:

- "She is absolutely amazing. I have never seen a more compassionate child her age. She treats her peers so wonderfully and has reached out to many kids with behavioral and developmental challenges on her own. For her brother, she is his greatest teacher and his biggest fan. When he learns something new, no one is more proud and excited than her."
- "He is a very patient person and very accepting of others with disabilities or problems. He is always the one in his peer group reaching out to help or encourage someone else."
- "She has become a great advocate for other kids who have special needs. She shows kindness and respect for other students in her class with autism. She has learned to be flexible and patient."



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(866) 366-9710

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