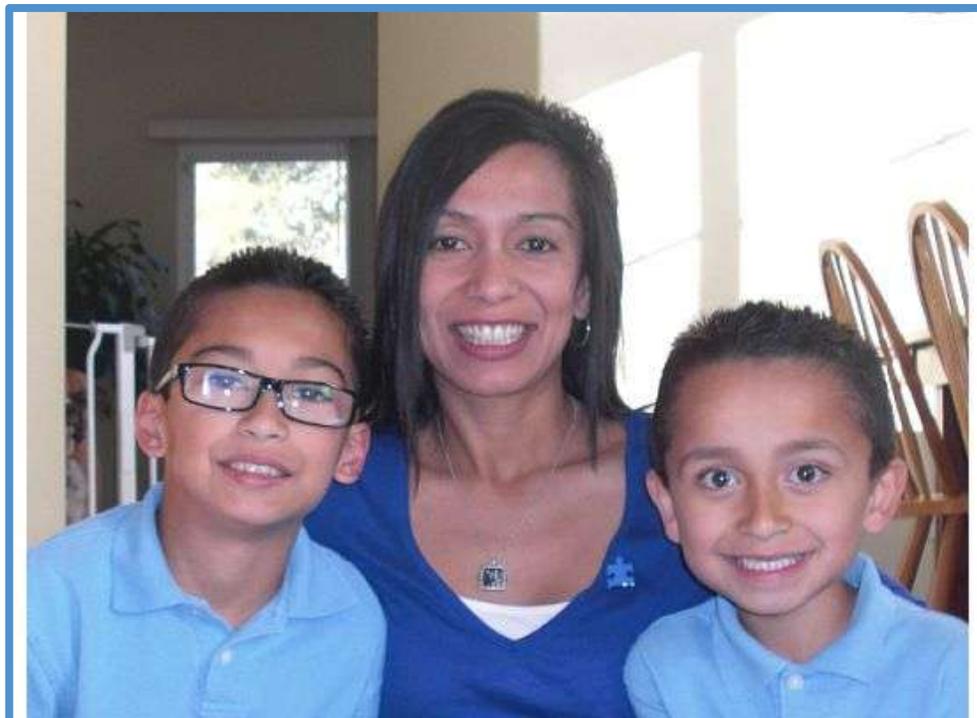




# A Parent's Guide to Autism

*Autism Speaks Family Support Tool Kit*



*Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this email is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.*

## **THIS TOOL KIT IS SPECIALLY DESIGNED FOR PARENTS OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH AUTISM.**

*This Tool Kit will help you:*

- Learn about autism and how it may impact your family.
- Find strategies and resources for raising a child with autism.
- Find support so you don't feel alone or isolated.
- Reduce the negative impact of the diagnosis on your family.
- Promote a positive future for your child and family.

## **THANK YOU TO THE MEMBERS OF THE COMMUNITY WHO REVIEWED THIS TOOL KIT AND SHARED RESOURCES FOR THIS PROJECT:**

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*Other Guides in the Autism Speaks Family Support Tool Kits series:*

A Sibling's Guide to Autism

A Grandparent's Guide to Autism

A Friend's Guide to Autism

*\*For the purposes of this tool kit, the term "autism" will be used to describe children with all types of autism spectrum disorders, including Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)*

# ABOUT AUTISM

## What Is Autism

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders.

People with autism have symptoms or difficulty in three areas:

1. Social interaction
2. Language as used for social communication
3. Repetitive interests or behaviors

## How common is Autism?

Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is not established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 70 boys is diagnosed with autism.

## What causes autism?

The simple answer is we don't know. The vast majority of cases of autism are idiopathic, which means the cause is unknown.

The more complex answer is that just as there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when



combined with exposure to as yet undetermined environmental factors. Timing of exposure during the child's development (before, during, or after birth) may also play a role in the development or final presentation of the disorder.

### **What does autism look like?**

While all children with autism have problems in three main areas, appearance and severity of symptoms is different in each child. No two children with autism are exactly alike.

#### **These are what the core symptoms might look like:**

<b>SOCIAL</b>	<ul style="list-style-type: none"><li>• Less eye contact, use of gestures or facial expression</li><li>• Difficulty understanding the emotions and feelings of others</li><li>• Difficulty playing with same age children</li><li>• Problems making and keeping friends</li><li>• Less sharing of interests with others.</li></ul>
<b>COMMUNICATION</b>	<ul style="list-style-type: none"><li>• Lack of speech</li><li>• Slow to learn speech</li><li>• Unusual speech (repeats things, speech sounds unusual)</li><li>• Difficulty making conversation</li><li>• Less imitation and pretend play</li></ul>
<b>REPETITIVE BEHAVIOR</b>	<ul style="list-style-type: none"><li>• Repeating activities or movements (rocks, spins, flaps hands, flicks fingers)</li><li>• Uncommon, strong, limited interests (often talks about the same topic or plays with same item, knows a great amount of information on topic)</li><li>• Plays with parts of toy rather than the toy as a whole (i.e. spins wheels of toy car)</li></ul>

# RESPONSE TO THE DIAGNOSIS

Learning that your child has been diagnosed with autism is a powerful moment in your life. Suddenly your life may feel very different from what you expected it to be. You worry first about your child and what it will mean for his or her life experiences. You worry about how you and your family will adjust to this in the years ahead. You worry about the day-to-day challenges of caring for your child with autism.

This is an important turning point in your life as well as the lives of your child and other family members. Getting emotional support and factual information to help you cope and promote a positive future for your child and family will be critical during this period.

## Common Reactions to the Diagnosis

*It is important to note each family's reaction to the diagnosis will be different depending on many factors. The list of "Common Reactions" is meant to be an overview of feelings that families may or may not experience.*

When a child is diagnosed with autism, parents and other family members frequently experience a range of uncomfortable emotions that are considered a grief reaction. In her book *On Grief and Grieving*, Dr. Elisabeth Kubler-Ross describes stages or types of grief reactions that make sense of what most people experience. She is careful to point out that we may move randomly between the stages although there tends to be a clear progression toward resolution:



**Shock:** *"I can't remember how I drove home after hearing the diagnosis for the first time." "How can this be happening to my child?"*

Immediately after the diagnosis you may feel stunned. The reality of the diagnosis may be so overwhelming that you may feel confused and unable to accept it.

**Sadness or Grief:** *"I have no energy." "I can't do the things I normally do for my family." "I find myself crying a lot." "I feel overwhelmed by sadness."*

Many parents mourn some of the hopes and dreams they held for their child before they are able to move on. There will probably be times when you feel extremely sad. It is important to remember that there is a difference between sadness and depression. Depression often stands in the way of moving forward. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable.

**Anger:** *"We didn't deserve this." "I am so angry this is happening to those I love." "I wish my neighbor would stay out of my business."*

Anger is a natural part of the grieving process, and you may find that it's directed at those closest to you – your child, your spouse, or a close friend. Anger is a healthy and expected reaction to the feelings of loss and stress that come with your child's diagnosis. Expressing your anger is natural and at times healthy.

**Denial:** *"He will grow out of this." "I can fix it."*

You may go through periods of refusing to believe this is happening to your child. During this time, you may not be able to hear the facts as they relate to your child. Denial is a way of coping. It may be what gets you through a particularly difficult period. It is important to be aware that you may be experiencing denial, so that it doesn't interfere with making good decisions about your child's treatment.

**Loneliness:** *"I have never felt so alone." "I wish I had a friend who would understand my situation." "It is so difficult to reach out to others."*

You may feel isolated and lonely. These feelings come from a variety of sources when you experience a loss. Loneliness may also come from the fact that you simply don't feel you have the time to contact friends or family for company. You may also feel that if you did reach out to others, they wouldn't understand or be supportive.

**Acceptance:** *"I feel we can get through this." "My family will be okay."*

Ultimately, you will likely feel a sense of acceptance. It's helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to advocate for your child.

**It's easy to become overwhelmed with your emotions and concerns about what the future may hold. Painful emotions are natural. If you accept your reactions and acknowledge your feelings, you will be able to move forward and begin advocating for your child. Emotions are powerful. If you deny your feelings or ignore them, they will often surface in unpleasant ways.**

## When to seek professional help

If you have trouble working through your emotions within a reasonable timeframe or you feel unable to function in your usual ways, it may be a good idea to seek professional help. Professional help can prevent serious problems from developing in the near future. It can help to empower us to face challenges more effectively.

If you are experiencing several of the following signs and symptoms over a period of time, you may want to seek professional counseling:

- You have trouble sleeping and don't feel rested when you do sleep.
- You can't control your negative thoughts, no matter how hard you try.
- You have lost your appetite or you can't stop eating.
- Others point out that you seem irritable, short-tempered, or more aggressive than usual.
- You are consuming more alcohol than normal or engaging in other reckless behaviors.
- You have thoughts that life is not worth living.

## What you can do for yourself right now

### Practice self-care.

Even if it is just for 15 minutes a day, take a breather. You need to take care of yourself in order to be able to take care of others.

### Acknowledge what you have accomplished.

It's easy at the end of the day to think about all the things you haven't been able to do that day. But this tends to discourage us from trying later. Instead, think about all that you did accomplish that day. You will be amazed at how long that list is, and you will feel better about getting started the next day.



### Focus on the positive.

Nothing in life is perfect. Every situation has positive and negative aspects to it. Focusing on the positive, such as the progress your child is making or the amazing speech therapist you found, will give you the energy you need to move forward.

### **Continue family rituals.**

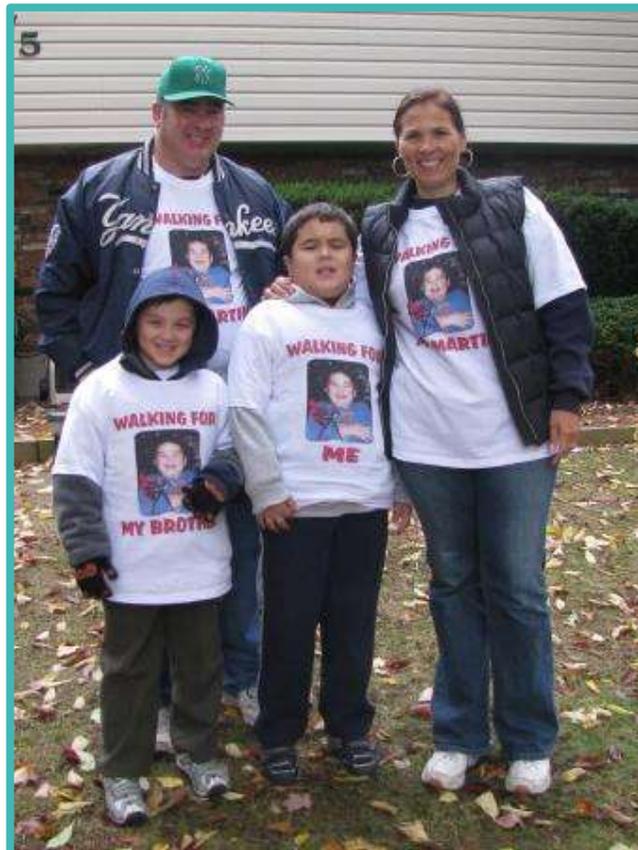
When possible, continue your family routines or rituals. This will be helpful for your entire family. It may be a Friday night trip to the movies, or Sunday lunch in the park. Tradition and rituals give your family an increased sense of stability and create fun times to enjoy together and to remember.

### **Give yourself time to adjust.**

Be patient with yourself. It will take some time to understand your child's disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than the one you had planned. Remember, you will also experience feelings of hope as your child begins to make progress.

### **GET INVOLVED WITH THE AUTISM COMMUNITY!**

Sometimes families of individuals with autism find themselves feeling isolated from others. It is important to connect with families that share similar experiences and seek the support of others. We encourage you to reach out and come together with other families at one of the many Walk Now for Autism Speaks events held around the country. For more info on how to get involved, visit [www.walknowforautismspeaks.org](http://www.walknowforautismspeaks.org)



# YOUR ROLE AS A PARENT

Like any stressful event in your life, learning your child has autism will affect everyone in your family and network of friends. It's probably not a surprise that your role as parent will change and you will go through many positive and negative experiences in your new role. Below are examples of new experiences you may face:

<b>MOTHER</b>	<ul style="list-style-type: none"><li>• May feel burden with everyday responsibility for child with autism.</li><li>• May feel pressure to become an autism expert and learn everything overnight.</li><li>• May worry about family's future.</li><li>• May have difficulty finding balance and time to manage household tasks, other children, daily activities, etc.</li></ul>
<b>FATHER</b>	<ul style="list-style-type: none"><li>• May be less inclined to share feelings.</li><li>• May become stressed about the family's finances and the unknowns of the situation.</li><li>• May worry about child's long term future.</li><li>• May develop other problems such as stress and anxiety that can affect work life.</li></ul>

*It is important to know that most families find a way to work together, grow stronger, and learn ways to reduce the negative impact of the diagnosis, and promote a positive future for their children and families.*

## Your Child's Advocate

When your child is first diagnosed, you will likely find yourself fulfilling many roles: care coordinator, therapist, parent, teacher, etc. One of the most important roles you will have is serving as your child's advocate. Advocating for your child will be a lifelong journey that will require different skills depending on your child's needs.

In her book, *Everyday Advocate: Standing Up for Your Child with Autism*, [Areva Martin](#) describes seven principles that can be applied to serve as an effective advocate for your child:

1. Take Responsibility - *Be a leader*
2. Learn - *Be an expert*
3. Think Critically - *Be discerning*
4. Speak with Authority- *Be proactive*
5. Document - *Be prepared*
6. Collaborate - *Be a team builder*
7. Educate - *Be a voice for your child*

Martin's book offers examples of each principle as it relates to real world activities that parents can do to advocate for their child with autism.



# BUILDING A SUPPORT NETWORK

In today's world there are a variety of family models, and this can be especially true for parents or guardians of children with autism.

Whatever your family structure, you can expect you will need support and help at many times in your journey as a parent of a child with autism. It's important to remember to maintain relationships with your family, friends and community in order for your support network to be there when you need them the most.

## **Keeping your Marriage Strong**

It is important to stay as connected as possible to your spouse and keep the lines of communication open.

**In addition to the normal demands of marriage, parents of a child with autism may also experience:**

- Additional stress from navigating the maze of agencies, funding sources, and paperwork to help your child.
- Loss of income due to one parent not working in order to care for your child and the additional expense of hiring and managing specialized caretakers.
- Different points of view regarding your child's disabilities and decisions about treatments and interventions.
- Loss of friendships or loss of time and energy to maintain outside friendships.
- Worries about the long-term future of your family.
- Changes in your retirement plans, your ability to take vacations or explore enrichment activities, etc.

**What you can do to keep your marriage strong while dealing with the everyday challenges of living with autism:**

- Communicate! The more you can communicate in challenging times, the stronger you will be as a couple. You and your spouse may not react to your child's diagnosis in the same way, but try to explain how you feel and listen carefully as your spouse shares his or her feelings as well.
- Talk openly about problems as they occur.
- Be kind to yourself and your spouse during this difficult time.
- Work together to learn all that you can about autism.
- Help each other focus on the present and what you can do to make things better today.
- Spend time together. Plan some alone time, even if it is just a few hours a week, to relax and have fun together. Try and enjoy the leisure activities you did before your child was diagnosed with autism.
- Share the responsibilities at home when possible. Work together on chores, childcare, homework, and other household tasks.

- Get help if you need it. A marriage counselor can help you and your spouse sort through your feelings and maintain a healthy marriage.
- Sort out what is important and what isn't important to the two of you. Take a close look at the best ways to make a good life for you and your family.

### **Support for Single Parents**

While stress affects all parents, single parents who have a child with autism may experience even more challenges. Single parents often face multiple challenges and are forced to take on several roles. They may be responsible for both the overall emotional and financial needs of their families while also caring for a child with special needs.

- **Come to an agreement that involves both parents.**  
Start with your child's other parent and try to establish “agreements” that support everyone. The best situation is for your child to have frequent contact with the non-custodial parent so that your child will interact with both parents. This also gives the custodial parent a break or some down time.
- **Build a support network of friends and relatives.**  
If you don't have family in your local community, you may want to consider moving closer to family or friends where you and your child will have a support network to fall back on.
- **Take time for yourself.**  
If you can't depend on family or friends, find respite care in your area, so you can recharge and focus on yourself even for a short time each week.

### **Social Networking – Find Support Online!**

Many parents turn to the internet to avoid feeling isolated. Today's social networking sites will make it easy to seek out support from likeminded parents on the web. Social networking sites such as Facebook, Twitter, and autism blogs will allow you to:

- Connect with parents in similar situations, who are facing the same challenges.
- Ask specific question and get immediate feedback.
- Get support from other parents without having to travel or leave home.
- Read communications from trusted health organizations.

**Remember, your child with autism is part of a family and community. Family and friends are more likely to play a part in your support network if they understand your needs and the needs of your child. Do your best to keep family and friends informed and updated on your child's progress.**

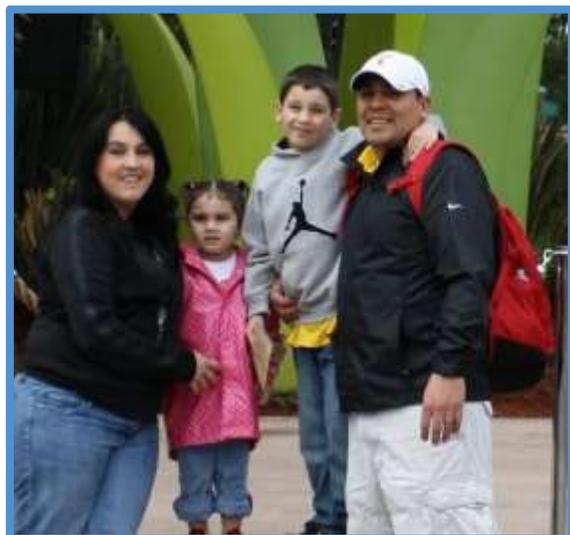
# SUPPORT FOR SIBLINGS

Parents of children with autism can be under tremendous stress. It may seem like there is never enough time to do everything that needs to be done. So much focus and attention is placed on the child with autism, that it is common for parents to have little time or energy left to focus on their other children.

Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings. They often need help understanding the emotional reactions they are experiencing as a result of the many changes occurring in their lives. This support is essential to their future well-being.

## **Some things your other children may be struggling with:**

- Young children may not understand what is wrong with their brother or sister. They may be confused and unable to fully comprehend the implications of diagnosis.
- They may have feelings of jealousy and resentment if they see that their parents are spending less time with them compared to their brother or sister with autism.
- They may feel angry over unequal treatment if their brother or sister is not disciplined in the same way they are or given similar chores to do.
- They may feel embarrassment with friends or in community settings where strangers react negatively because of the unusual and sometimes aggressive behaviors of their sibling.
- They are often frustrated by the fact that they are not able to get their brother or sister to respond or interact with them in “normal” ways.
- Quietly, and sometimes secretly, siblings worry about their brothers and sisters and their parents as everyone in a family is impacted by the disorder in some way.
- Many children are unable to express their feelings so sometimes revert to “acting out” behaviors. For example, they may misbehave by defying their parents or getting into trouble at school.



## Strategies for supporting your other children:

- It is important that your other children understand autism and what is going on with their brother or sister. Talk with them early and often in age appropriate ways. Many books and other resources are available to help them to understand this diagnosis: [www.autismspeaks.org/family-services/resource-library/books#siblings](http://www.autismspeaks.org/family-services/resource-library/books#siblings)
- Help your children learn how to play and form relationships with their sibling with autism. There are a few simple things that you can do that will help with this, including teaching your other children how to get their sibling's attention and give simple instructions. It's also important to praise all your children when they play well together.
- Find sibling support groups that can help them build friendships and relate to other peers who have a sibling with autism. [www.siblingsupport.org](http://www.siblingsupport.org)
- Don't hesitate to consult a professional if you feel your child is internalizing most of their feelings or beginning to act out. The earlier you address this, the better. It is not a failure to ask for this type of help. Rather, it is a sign of strength and evidence of good parenting.



# TAKING CARE OF YOURSELF

Caring for a child with autism can be physically exhausting and emotionally draining. Parenting responsibilities can create extraordinary stress. Trying to balance your time and energy with the needs of your other children, the needs of your marriage and your own personal needs is not easy. It takes time to find a good balance and put it into practice.

## **There are things you can do to help:**

### **Take time for yourself.**

If you don't have a family member or friend to babysit, find respite care in your area so you can recharge and focus on yourself even for a short time each week. Respite time enables you to do errands, relax, or enjoy time with your partner or other family members. Building a relationship with a respite provider gives you a reliable caregiver for your child if there is a family emergency.

### **Make time for your friends.**

Many parents report that long-lasting friendships have given them the strength and comfort during the most difficult times. If you feel isolated, it's time to take action.

### **Explore creative interests outside of autism.**

Try to exercise or explore some creative interests. Take the time to realize that you are important and are more than just the parent of a child with autism.

## **Respite Care**

Respite Care is temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve them and prevent stress and fatigue.

## **When you are ready to Interview respite care providers:**

Keep in mind that the most important step is to observe how the respite worker interacts with your child with autism and your family. If possible, have the worker spend supervised time with your family member. It's true that it can take a few weeks for respite workers and family members to get to know each other, but don't let an uncomfortable situation go on and on thinking it will eventually work itself out.

## **Below is a checklist of what you will want to discuss with a potential respite worker:**

- ✓ **Previous work experience with an individual with autism**  
A respite worker does not necessarily have to have previous experience with autism in order for them to succeed at their job. Because individuals with autism are so unique, some families prefer the worker to have no previous experience, so they can teach the respite worker the

best ways to interact specifically with their child.

✓ **Background Checks**

Examples include DMV records, insurance, criminal history, other certifications such as CPR, first aid certification, etc. Today many agencies require background checks for workers. If you are receiving services through an agency, ask them to share with you the information they require for employment. Agencies differ on what they require for background checks.

✓ **Training Sessions**

Many community agencies offer free workshops on autism. Agencies providing the respite services may also offer training. This will vary depending on the agency. It is reasonable to pay your respite worker a lower rate for attending training sessions than for providing actual respite services.

✓ **Behavioral Concerns**

Behavioral issues such as tantrums, biting, scratching, etc. can be off putting to anyone, so you can expect the worker may have the same reaction. This is an area where the worker will need to be trained by you or a professional. A behavioral plan written by a professional will include an intervention plan. The worker should fully understand their role in managing the specific behaviors of the child with autism.



✓ **Safety Issues**

The issue of safety must be discussed with the worker. Safety issues are highly individualized so it is best to document your concerns. More than anything, the worker needs to demonstrate common sense and good judgment based on your family member's needs.

✓ **Availability and Flexibility**

Let the applicant know exactly what your needs are. It helps if they have some flexibility in their schedule, so you can take a break when you need it the most.

✓ **Work References.**

Work references should be employer references, not personal references. You can ask for personal references as well, but you also want to know about their work habits such as dependability, timeliness, conscientiousness, etc.

To find Respite Care in your area, please look at our online Resource Guide for your state's information: [www.autismspeaks.org/resource-guide](http://www.autismspeaks.org/resource-guide)

# FREQUENTLY ASKED QUESTIONS FROM PARENTS

**Q: My daughter is 2 years old and was recently diagnosed with autism. I have some family members that keep insisting she's just delayed. Can you give me any suggestions for how to respond to them?**

Your situation is very common in families of children diagnosed with special needs, most especially autism. There are so many emotional processes that are occurring for the family as a unit and for each family member individually after getting this diagnosis. Of course there is the initial shock that can send you spiraling into a true grieving process, and each of you in the family will work through this in your own time frame. Part of that process includes a stage of denial as particularly seen from family members who aren't living with your child day-to-day. It's probable that it will take them longer to come to terms with the diagnosis. In addition to everything else you are doing, you must also remain patient for this to happen. Family members who love your child will benefit most from learning about autism so they can adapt their interactions and expectations to more appropriate levels.

There are also professionals and effective support groups in your community who have a lot of experience and expertise in understanding this process. They may be able to provide you and your extended family with assistance.



**Q: My husband refuses to accept the diagnosis, and will not attend appointments with our doctor. What can I do?**

This is not uncommon, where one parent accepts the diagnosis and the other is in denial. Denial happens both to fathers and mothers. As difficult as it may be for you at a time like this, you must be patient and supportive. Your spouse will eventually work through his or her denial. Meanwhile, you might try to recommend a book or share an article about autism but be careful not to pressure. Most people need to do this on their own terms.

**Q: Since my son was diagnosed, I've felt overwhelmed and I can't even bring myself to read anything about autism.**

Being an advocate for your child with autism will most likely be a lifelong activity. Early on when faced with the diagnosis, parents are easily overwhelmed by the news. They feel confused, fearful and angry. Many tire easily as they try to cope. It is helpful to remember that

you are not alone, that others are going through this so there is support available for you. Keep a folder of articles and other information material so that when you are able to read it, you will have it available. Pace yourself and in time you will do what needs to be done and your efforts over time will make a difference.

**Q: My family's involvement in church is important to us. How do I get my church to be more accepting of my son? They almost seem uncomfortable when I try to talk to members about our child and his diagnosis. I expect them to be supporting and caring and really need them in my corner. My child also needs to relate to other families in our congregation.**

■ For many people, including those members of your church, autism is not something they may have experience with or adequate information about, so you must help educate them. A good place to start is with your pastor or minister. See what he or she knows and offer information as needed. Sometimes a leader will incorporate the related issues into a sermon or lesson. He or she can also suggest folks who can be approached as more open to learning about autism. Then, suggest the church invite a professional to do a workshop on special needs children, with emphasis on the challenges associated with autism. Suggest the church develop a plan to accommodate special needs children in their various activities such as the Sunday school classes, the worship service, the choir, etc. At some point, it may be helpful to bring in a behavioral specialist to work with and train the staff. It may mean asking teachers, parents, and other trained professionals in the church to volunteer time helping out in Sunday school, modifying the lessons, etc. Get your community involved and they will thank you later!

Once members of your congregation are given accurate information, they will become more open and supportive. You may have to suggest ways they can become involved with your child and with advocacy organizations. There are so many opportunities for the religious community to get involved and to partner with parents. As advocates, parents have a unique opportunity to lead the charge.

**Q: How do I know everything possible is being done for my child? Sometimes it seems like not enough progress is being made.**

■ Almost daily, every parent with a child with autism asks this question: is there more that can be done to help my child? We work as hard as we can, and very often we feel as though we aren't doing enough. It is also easy for us to project this on to others involved in our child's life. In fact, historically, not enough has been done and in many ways, more should be done in today's world. This is what advocacy is all about. We must continue to push for the best treatments and services available.

Meanwhile, we must recognize that there are some limits that we must accept. Treatments available today have limits. We are learning so much, but we have a long way to go. Government funding clearly has limits, especially in today's economy. Teachers are frequently overworked with too many students. Sometimes it does help to focus on what is being done and to acknowledge our efforts and the efforts of others. At the same time, as suggested above, parents must be their child's biggest advocates.

When you look at what you do each day, you may want to give yourself a compliment for what you have accomplished. Your child is doing the best he or she can given the many challenges he

or she faces daily. Be kind to yourself and remember that your child with autism, like all children, is going to grow and develop at his or her own pace. While we may want to see our children go from one sentence to five paragraphs in a semester, we must accept and celebrate what they do accomplish and gently encourage them forward.

Consulting with outside professionals, such as educational therapists, can also help you set goals and look at progress realistically. On this journey, we have to redefine success and progress. It has to be based on our own child's gifts, and nothing else!

**Q: Is there any financial assistance available to assist in the care and education for our child with autism?**

Financial difficulty is one of the biggest stressors that families with special needs children face. There seems to never be enough funding or financial help available and each family often finds that their own resources are stretched by providing for their child with little hope of reimbursement for all that gets spent.

The primary funding source for your child's services is mandated through a US Federal Law, Individuals with Disabilities Education Act (IDEA). The IDEA governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. Refer to the Your Child's Rights section on the Autism Speaks website [www.AutismSpeaks.org](http://www.AutismSpeaks.org)

In addition, your family's medical insurance may reimburse you for autism services, such as speech therapy or behavioral health treatment, such as Applied Behavior Analysis. Start by speaking with the human resources department where you or your spouse work, and inquire about insurance reimbursement for autism services. Many states now have government agencies monitoring the health insurance industry so this can be a back-up resource to explore benefits as needed.

Continuing to advocate for increased funding by the government and by the insurance industry is important. For more information about autism insurance reform in your state, visit [www.AutismVotes.org](http://www.AutismVotes.org).

**Q: My wife and I worry that over time our other children will develop deep resentments for all the attention and "special treatment" their brother gets and this could negatively impact their lives. Do you have any suggestions for raising our other children so they don't feel resentment?**

Sibling rivalry occurs in all families with more than one child and it can be especially complex when it involves a child with special needs. There is no way to avoid giving some extra attention and treatment to a child with autism. For siblings of children with autism, these feelings may develop early because the children may be together all the time.

Constantly checking in with your other children about how they are doing, what they need, etc. is a good start. Finding time to be with each child individually also helps immensely, when possible. Involving grandparents, aunts, uncles, trusted neighbors, etc., may help as well.

Children at various ages have the capacity to understand the special needs of someone else if you take the time to explain in terms they will understand. Explain behaviors they see in their brother or sister and why you respond differently to deal with these situations. While you don't want them to become surrogate parents, they do need to know some basic explanations. Also, creating a safe space for them to talk about their feelings with you or with others can prevent later development of toxic resentments.

Helping your other children find successful ways to play or interact with their brother or sister is powerful.

Siblings may sometimes feel guilty because they do feel resentment and anger, or even just because they are "normal" while their brother or sister is not. Guilt and resentment are normal growing up issues, made more complex often because of a special needs sibling. But like any feeling, they can be talked about and processed so that your other children move forward in their own emotional development and life journeys.



# A PARENT'S STORY

By Tracy Miranda

I will never forget that day – December 7, 2010. After months of some confusion, lots of questions and speculation, it was now official. My son was diagnosed within the Autism Spectrum.

There were a lot of immediate tears of course and this continued for awhile. There were other reactions. For example, I was reminded of how people talk about a near-death experience. For me, my son's future life passed through my head and there were so many unanswered questions and so much that caused me to worry. Will he be okay? Will he be bullied? Will he get married? Will people think he's stupid?

I had to remind myself that I can't predict the future. I won't know his future until he gets there. I must be present for him and together we will face the future. I allowed myself to cry for a couple of days and that was it. Tears weren't going to change anything. I wasn't crying because of the diagnosis, but rather because as a mother you want to do everything to ensure that life will be great for your child, and I just couldn't guarantee that or fix the future.

My next priority was to learn as much as I could. Boy, what a job that was, quite a bit overwhelming. Like others, I was "aware" of autism, but didn't really understand it.

In his evaluation, the psychologist report had mentioned that he had the potential to be extremely smart, but may be socially awkward. We are huge fans of "The Big Bang Theory" and after reading that my first thought was, "Oh, my gosh we're raising Sheldon!"

It was nice to be able to laugh at the situation, but research was obviously necessary. After doing an internet search for autism, I felt lost. There were so many websites, books, and blogs I didn't know where to start. Who was I supposed to believe when the websites contradict each other? Then I remembered that teachers at my son's school had done the *Autism Speaks Walk* and our family had donated to it. So, that's where I started. I contacted Autism Speaks Family Team for support. I needed to talk to someone who could listen and then relate to my situation. It was only the first week and I already knew I need people and others who knew what I was going through.

As a result of my contact with *Autism Speaks*, I found an amazing community of parents online. Past online experience made me hesitate at first to trust, feeling that I could get misinformation. But, this wasn't the case. I found parents just like me who were there to support each other and stick together. We were able to get accurate and helpful information. When you think that nobody else is going to understand you, someone will. Every time I asked questions, I got answers from people who had been there. If I sent an update on something cool that my son did, I received cheers from people who had lived it. They got me and I got them.

My husband and I were taking the news a little different. He kept a lot of his feelings inside to process them while I wanted to share with everyone and start building my support network immediately. Mind you, some of them weren't sure what to say, but I'm not sure I knew what I needed to hear either. I did get a lot of people telling me that they knew "so and so" who had a child/grandchild/cousin etc who had autism and they were doing great, so I shouldn't worry at all. Um, no offense, but that's just not true. One of the biggest misconceptions about autism affects everyone is the same way. The truth is every child who has it is different and progresses in varied ways.

Right now we have no idea what the future will bring. At that time, I was still trying to process that it was my son; I didn't care who else was dealing with it. I'm not that insensitive now, mind you, but in the beginning all that mattered was him.

I know that the road ahead is still a journey of unanswered questions. However, my son is making great progress. He is very high functioning and doing great in school. I know how lucky I am that he loves affection because many parents of children with autism don't get to experience that. My heart breaks for them.

No matter what lies ahead, my son is the biggest blessing in my life and he makes me laugh every day. When people want to feel sorry for me, I remind them how blessed we are. Things could certainly be a lot worse. Autism is what my son has, not who he is.

We will be just fine.



# RESOURCES

Autism Speaks Family Services Resources are free and available online.

Community Connections:

[www.autismspeaks.org/family-services/community-connections](http://www.autismspeaks.org/family-services/community-connections)

Resource Guide:

[www.autismspeaks.org/community/fsdb/search.php](http://www.autismspeaks.org/community/fsdb/search.php)

Resource Library:

[www.autismspeaks.org/family-services/resource-library](http://www.autismspeaks.org/family-services/resource-library)

Tool Kits:

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

Your child has been diagnosed with autism

[www.autismspeaks.org/what-autism/diagnosis](http://www.autismspeaks.org/what-autism/diagnosis)

Contact the Autism Response Team (ART). ART is specially trained to help families with the day-to-day challenges of living with Autism. Call 888-AUTISM 2 (288-4762) or email

[familyservices@autismspeaks.org](mailto:familyservices@autismspeaks.org)

Autism Speaks hosts [Walk Now for Autism Speaks](#) events in many cities around the country.

These events provide a chance to meet other families in your area, as well as talk to local therapists and other service providers at the walk's Resource Fair. Please click on your state or enter your zip code to find the nearest walk near you.



*Photo by: Dannie Zane Photography*