



# Parent's Guide to Autism





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.

# Table of Contents

Introduction .....	1
Response to the Diagnosis .....	1
Your Role as a Parent .....	3
Ten Things Parents Can Do to Help Their Child with Autism .....	5
Building a Support Network .....	6
Taking Care of Yourself .....	7
How I Let Go of My Expectations and Learned Unconditional Love .....	9
Frequently Asked Questions from Parents .....	10
Resources .....	13

# Introduction

If your child has recently been diagnosed with an autism spectrum disorder, you have come to the right place. **A Parent's Guide to Autism** was developed as part of Autism Speaks' series of *Family Support Tool Kits* to support you and promote a positive future for your child and family during an often challenging time. You are not alone in this journey and this guide is a step toward finding the help you need to travel the road to optimal outcomes for you, your child and your family.

**The Autism Speaks 100 Day Kit for Newly Diagnosed Families** (versions for both children under 5 and school age children) was designed to provide you with the information and tools you need to make the best possible use of the days following the diagnosis. It is a comprehensive tool filled with facts and resources such as information about symptoms, treatment, legal rights and advocacy. The *100 Day Kit* can be found at [AutismSpeaks.org](http://AutismSpeaks.org).

## **A Parent's Guide to Autism will help you:**

- *Learn about how autism 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.*

For additional guidance and support, the **Autism Speaks Autism Response Team** is here to help. The team is specially trained to connect you and your family to resources and information specific to your child's strengths and challenges.

### **Contact the team at**

FamilyServices@AutismSpeaks.org  
(888) 288-4762  
(en Español 888-772-9050)



# 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

Each family's reaction to the diagnosis will be different depending on many factors. When a child is diagnosed with autism, parents and other family members frequently experience a range of uncomfortable emotions. Whether or not you have suspected something for awhile or the diagnosis seems to have been out of the blue, many parents experience shock when they hear the words, "your child has autism."

You may go through periods of denial or 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.

Some 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 sad. 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 is also a natural part of the process and you may find that it's directed at those closest to you. Anger is a healthy and expected reaction to the feelings of stress that come with your child's diagnosis. Expressing your anger is natural and at times healthy.

There are times you might feel isolated and lonely. These feelings come from a variety of sources when you experience a diagnosis or other significant life change. 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.

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.

*Ultimately, you will likely feel a sense of acceptance. Your life may not look like what you had planned and you may have to alter your expectations, but your goal remains the same: to help your child live a happy and fulfilling life. Once you accept the diagnosis, you will be ready to advocate for your child and start working toward a brighter future.*

## Common Areas of Concern

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 feelings you may encounter:

- *May feel burden with everyday responsibility of caring child with autism.*
- *May feel pressure to become an autism expert and learn everything overnight.*
- *May worry about child and family's future.*
- *May have difficulty finding balance and time to manage household tasks, other children, daily activities, etc.*
- *May be less inclined to share feelings.*
- *May become stressed about the family's finances and the unknowns of the situation.*
- *May develop other problems such as stress and anxiety that can affect work life.*



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.

## When to Seek Professional Help

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.*

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 future. It can help to empower us to face challenges more effectively.

# Your Role as a Parent

## 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.

## Supporting Your Other Children

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 their sibling's unusual and sometimes aggressive behaviors.*

*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, some of which are listed on the Books page of the Autism Speaks Resource Library.*

*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.*

Don't hesitate to consult a professional if you feel your child is internalizing most of his or her 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.

## Ten Things a Parent Can Do to Help Their Child with Autism

*This is a post by Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP).*

*Kim is also the author of a blog about her two children with autism, at [AutismMommyTherapist.Wordpress.com](http://AutismMommyTherapist.Wordpress.com). Her book "Raising Autism" is available on Amazon.*



---

Thirteen years ago this fall our beautiful son, Justin, was diagnosed with PDD at seventeen months of age. He would later go on to receive an "official" autism diagnosis, and would remain on the more severe end of the spectrum. I will never forget the day he was diagnosed – it was both comforting to put a name to something I'd suspected he'd had for a long time, and overwhelming because I just didn't know what to do next. I remember leaving the developmental pediatrician's office wishing someone had given me a checklist of things to accomplish which would help both him and our family in those early days post diagnosis.

Here are some things I did (and some things I wish I'd done) – I hope they are helpful to you and your family. Number ten is the most important!

---

- 1) No matter how exhausted you are, get your child out in the community. It was a struggle with us with Justin (I have the tiny little bitemarks on my body to prove it) but getting him out so he could have a repertoire of leisure activities was crucial to his happiness and to our family's. It set him up for a lifetime of being able to try different things, which will set him in good stead when I'm no longer here to take him places. Yes, I'm always planning.
- 2) If you haven't already done so, join a parent group and/or your school district's special education PTA. You will make invaluable connections at both. Try to find parents of kids with your kid's level of autism as you're making friends. These people will be a wealth of information for you and a lifeline.
- 3) If you can afford it, hire an advocate to check out your child's school program. A fresh set of eyes may see areas that need to improve, or may reassure you that they are doing all they can for your son or daughter. It's always good to know one in case you need an advocate at an IEP meeting. If you've already met, you won't be scrambling to find one.
- 4) If possible, volunteer at school functions or offer to be a class mom. This is a great way to get to know your child's teacher and your school's administrators better. You may also make friends with other parents too.
- 5) No matter how difficult your child can be, take any offer of babysitting you can and get out. You need a night off from autism once in a while. Even if it's for a few hours, a break will help.
- 6) Now that your child's program is set, tackle the big issues one at a time- perhaps it's sleeping, or eating, or potty training. If your child is in a private school there may be a BCBA on staff who can help you. If not and you can afford it, consider hiring a BCBA from an agency. Pick an issue and prioritize.
- 7) Educate your friends and family as to what's going on in your household. Perhaps you've been too tired up to this point to talk to people not in the "tribe" about what raising an autistic child is really like. It's time to tell them and ask for the support you need, even if it's just an ear to listen. My husband and I kept too much to ourselves, and if I could go back in time I'd be more open with everyone in our lives.
- 8) Make those doctor appointments for yourself that you've been putting off. Just do it.
- 9) Get involved in an autism walk in your community. It is so powerful to meet so many families like (and unlike) yours. It will give you strength.
- 10) I can't stress this one enough – take care of yourself, not just your kid. Autism is a marathon, not a sprint. You owe it to yourself and your child to be whole, healthy, and happy. Do whatever it takes to get there.



# 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 challenges 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.*



### Tips 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 are often 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.** *If possible, 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.*

*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, as well as anything they might be able to do to help.*

## 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.**

## 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.

## 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. Take time to yourself so you can run errands, relax or enjoy time with your partner or other family members.

### **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.

### **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.

### **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 *Autism Speaks Walks* held around the country. For more info on how to get involved, visit [AutismSpeaksWalk.org](https://www.autismspeaks.org/walk).

### **Respite Care**

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. Building a relationship with a respite provider gives you a reliable caregiver for your child if there is a family emergency. Respite care allows you to take a break in order to relieve you 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. Below is a checklist of what you will want to discuss with a potential respite worker:

- *Previous work experience with an individual with autism*
- *Background checks*
- *Training sessions*
- *Behavioral concerns*
- *Safety issues*
- *Availability and flexibility*
- *Work references*

To find respite care in your area, please look at our online *Resource Guide* for your state's information: [AutismSpeaks.org/Resource-Guide](https://www.autismspeaks.org/resource-guide).

## How I Let Go of My Expectations and Learned Unconditional Love

*This is a post from blogger Chrissy Kelly who has two sons on the autism spectrum.  
Read more from Chrissy's blog, [Life with Greyson + Parker](#), at [LifewithGreyson.com](#).*



With one final, excruciating push he flew into the world. All the pressure was released and for the first time in so long I am able to take in a deep inhale. In that same very instant a brick house of expectation was also born.

He was perfect. Ten fingers and toes and I sighed, and fell in love with every single blessed detail. Soaked him up and felt it - the sweetest, purest love. I didn't know it existed quite so lucidly. My expectations already had his life all planned out for him.

He will smile and sit and crawl and one day even walk. He will say Momma, and love ice cream. He will dress up for Halloween. He will love his birthday. He will say the funniest things. I will read him books at night and scare the monsters away from under his bed. He will ask for extra pancakes and wrap me around his currently teeny tiny finger.

He will go to school. He will be smart. I will help him with science projects and pretend to be annoyed but actually love it. He will play sports, and be a humble winner and the very best loser. He will be fast. He will be brave. He will be kind. He will go to college and get married and have babies.

I had great expectations. And then right before his third birthday, I heard the words, "Your son fits the diagnostic criteria for autism". In an instant, my boy's life vanished right before me.

I didn't realize at the time, but it was really just the death of expectation. You see, I confused the two; my real boy and the son I expected him to be. And mourning expectation is so very hard. Letting go of years worth of day dreams doesn't happen in a day or a week. And like many before me, I deeply grieved the loss of that expectation. Some of what I expected for me. Some of what I expected for him. I ached for each and every single one of those experiences I might not ever have.

*But the more I shed the pain of expectation, the better I got to know my boy.*

The real one I got, not the made-up one I expected. He doesn't deserve to be expected to be anyone other than who he is, and who he is - is amazing. It took time and strength and a determination to willingly let my expectations go, without throwing hope out at the same time. To wake up every day still, and decide to let go again and again. And the truth is that my real boy is alive and better than any of my wildest expectations- in ways completely different than I could have even imagined.

And as far as his future - anything is still possible. I just don't need certain things to happen in certain order to be happy and to measure the worth of my parenting experience.

The truth is, for most of us, reality is nothing like we expected. It is only in the letting go of our expectations that we are able to realize that our reality may not be so bad at all. When you are living an unexpected life it is easy to focus what you don't have. But there is also incredible beauty, perspective, love and experiences that come with the unexpected. It's so important that we notice those gifts too.

Sometimes I have moments when I still focus on the death of the expected. But now I remind myself how awful it would feel if someone constantly expected me to be different - and to be someone I'm not.

*I've learned the very definition of unconditional love is choosing to love someone exactly for who they are.*

A love not based on expectations, but on reality. I've finally knocked down that brick house of expectations. Turns out it was hiding the most incredible view.

# Frequently Asked Questions from Parents

**Q: My daughter is 2 years old and was recently diagnosed with autism. I have some family members who 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?**

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, yet 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 have to 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 United States federal law, the Individuals with Disabilities Education Act (IDEA). IDEA governs how states and public agencies provide early intervention, special education and related services to children with disabilities.

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 the Autism Speaks website.

**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.

# Resources

## **Autism Speaks Autism Response Team**

*The **Autism Response Team (ART)** is specially trained to connect people with autism, their families and caregivers to information, tools, and resources. A team member can help you find resources to meet your family's specific needs.*

888-288-4762 (en Español 888-772-9050)

[FamilyServices@AutismSpeaks.org](mailto:FamilyServices@AutismSpeaks.org)

## **Autism Speaks 100 Day Kit for Newly Diagnosed Families**

*The **100 Day Kit** was created to help families make the best possible use of the 100 days following an autism diagnosis. Important topics include understanding symptoms, accessing services, finding the right treatments and knowing your child's rights.*

[AutismSpeaks.org/Family-Services/Tool-Kits/100-Day-Kit](https://AutismSpeaks.org/Family-Services/Tool-Kits/100-Day-Kit)

Versions for both young children (under 5) and school age children (5-13)

## **Autism Speaks Tool Kits**

*Autism Speaks has developed nearly 50 tool kits for parents and caregivers of children and adults with autism on topics ranging from toilet training and challenging behaviors to housing and employment for adults. All tool kits are available free of charge.*

[AutismSpeaks.org/Family-Services/Tool-Kits](https://AutismSpeaks.org/Family-Services/Tool-Kits)

## **Find a Local Resource: Autism Speaks Resource Guide**

*The **Resource Guide** contains tens of thousands of local resources including pediatricians, behavioral therapists, after school programs and more.*

[AutismSpeaks.org/Resource-Guide](https://AutismSpeaks.org/Resource-Guide)

## **Autism Speaks Walk**

*The **Autism Speaks Walk** is a great way to connect with families and services in your area. Autism Speaks Walk is the world's largest autism fundraising event dedicated to improving the lives of people with autism. Powered by the love of parents, grandparents, siblings, friends, relatives, and supporters, the funds raised help ensure people of all abilities have access to the tools needed to lead "their best lives".*

[AutismSpeaksWalk.org](https://AutismSpeaksWalk.org)



**Have more questions or need assistance?  
Please contact the Autism Response Team for  
information, resources and tools.**

**TOLL FREE: 888-AUTISM2 (288-4762)**

**EN ESPAÑOL: 888-772-9050**

**Email: [FAMILYSERVICES@AUTISMSPEAKS.ORG](mailto:FAMILYSERVICES@AUTISMSPEAKS.ORG)**

**[AUTISMSPEAKS.ORG/ART](https://AUTISMSPEAKS.ORG/ART)**



Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

**To learn more about Autism Speaks, please visit [AutismSpeaks.org](https://AutismSpeaks.org).**