

Step Two: Information on Family Life

This section contains information about how a child with a PDD can affect the whole family. There are articles for parents, siblings, and the extended family. There is also information about reacting to the diagnosis, and how to move forward after the diagnosis.



WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

*Finding Out Your Child Has a Disability...
It's Not the End of the World*

Finding out that a child has been born with a disability, or that a previously healthy child has suffered an injury or disease that causes a disability can be the most traumatic moment in a parent's life. Shock is usually the first thing people experience. It can temporarily paralyze you, preventing you from taking action, or even making rational decisions. In this difficult first period it is always wise to take the counsel of professionals and family members with experience or others whom you trust, while always maintaining the right to make the final decision yourselves.

After coming to grips with the shock of their situation, many parents come to feel that their expectations have been dashed, that they are failures as parents or that their family has been destroyed. Uncertainty, blame or jealousy may arise. Parents may worry about hundreds of questions that have few immediate answers which can lead to an unbalanced and overly bleak view of the opportunities, potential, and joy that can be found in raising a child with a disability.

These emotions however are normal; part of a "mourning" process that many parents of children with disabilities go through. If you have these feelings, remember that you are not the only ones who feel this way, and that you will get over them. You can adjust more quickly by obtaining accurate information, sharing your feelings openly with others, seeking professional counseling, and, most importantly, having open discussions with all members of your immediate family. With time, love, and support, any negative emotions you feel can be replaced by positive ones leading to productive actions that will benefit your child.

It is not the end of the world, and many families have become stronger, more loving, and more closely knit because of a disability in the family. The disability gave them the opportunity to work together to help out their loved one, and the entire family shares in the gains that are made by the child. Many of the negatives that parents imagine that go along with having a child who has a disability simply do not occur. While you will have to make some sacrifices, you will still have time for your friends, family, and hobbies. After awhile, many of the activities you once viewed as sacrifices will come to be seen as part of every life, rather than an exceptional burden.

Developing a positive attitude is very important, and although children with disabilities will inevitably become aware of their limitations, they should always be encouraged to take on new challenges. This is sometimes difficult as children with physical limitations may be reluctant to participate in physical activities out of fear of failure. Despite these fears, both the child's and the parent's perspective should be "have fun, and do your best."

Some parents of children with disabilities are unable to have their special child live at home with them, but the vast majority is able to successfully manage within the home. If you are finding you cannot cope, there are alternatives available that will allow you to maintain a loving relationship with your child while maximizing appropriate care.

The most important factor in a family's success is the motivation to succeed. If a child realizes that his parents always encourage success and will not be satisfied with anything less than his best effort, he will be motivated to succeed. Never settling for failure becomes part of his character, and his self-esteem will be enhanced and maintained.

There is a wide range of disabilities that affect children but the constant emphasis on always trying your best, reinforced in an atmosphere of warmth and support, will help any child with a disability triumph over the challenge that he will face. Instilling this confidence will help him have faith in himself and work on his own behalf throughout the course of his or her entire life.

Coping with the Stress of Autism: When to Find Professional Help

Why Do Parents Need Help in Coping with the Stress of Autism?:

Of course, not all parents with autistic children are under stress. But most are. Robert Naseef, Ph.D., a psychologist who works exclusively with families with special needs, explains why parents with autistic children may need extra help: "When you have a child with special needs, you learn to live with a lot of stress and you throw yourself into your everyday job as a parent; if you work outside the home, you work even harder - and you don't think much about taking care of yourself."

Guilt, Anger, and Frustration May Add to Troubles:

Many parents with autistic children worry that they could or should have done something to prevent their child's problems. They also agonize over whether they could do more now. They feel angry at their circumstances, which set them apart from other parents, and frustrated that they can't enjoy family life and share in the ordinary activities as easily. All these issues can make day-to-day coping even harder.

What Is "Normal" Stress?:

"Some stress is to be expected," says Naseef. As long as you're sleeping and eating well, enjoying much of your day-to-day life, and finding support where you need it, your stress is probably not too overwhelming.

How Do You Know When Your Stress Level Is Too High?:

Ask yourself these questions: Are you having a hard time eating, sleeping, or getting up in the morning? Are these symptoms impeding your functioning? Are you finding it hard to get through the day's activities? "If you're not the person you normally are, that's a reason to get help, or at least consider that possibility," Naseef says.

Why Is Managing Stress Important?:

If you're exhausted and overwhelmed on a regular basis, you're more susceptible to physical and mental disorders. You may need time and help to recharge your batteries and find coping mechanisms. And it's important to take action now for the future. After all, when you're the parent of a child with autism, even high-functioning autism, you're in it for the long term. "Figuring out coping skills and how to have a decent life in the process is pretty crucial," says Naseef. "If you have no happiness or contentment, how can you expect your child to feel happy or content?"

How Can a Professional Help Relieve Stress?:

An experienced professional can help give you concrete ideas for finding time and space for yourself. He or she can also work with you to develop specific coping strategies. Changes in attitude can make a big difference, and there are many ways to work on your own feelings. It may also be helpful to have an

appropriate time and place to let out pent up anger and frustration that's so often a part of coping with a child with special needs.

What's the Best Way to Find Help?:

It's important to find a psychologist, psychiatrist, or social worker who has specific experience working with parents of children with special needs. To find such a person, get in touch with local autism support groups and ask for advice. Check out online databases like AutismLink. Ask your family doctor for suggestions, too. Some states offer a service called "mobile therapy." This program brings therapists into your home to work with you and your whole family.

Is It Really Possible to Raise an Autistic Child and Still Live a Happy Life?:

Absolutely. Many people go through a difficult time when their child is first diagnosed with autism. But after a year or two, most do learn to cope, enjoy their child's achievements and their own lives, and have fun.

Ten Things Every Child with Autism Wishes You Knew

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute -- the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look "normal" but his behavior can be perplexing and downright difficult.

Autism was once thought an "incurable" disorder, but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism's most challenging characteristics. Equipping those around our children with simple understanding of autism's most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly -- every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am first and foremost a child. I have autism. I am not primarily "autistic." My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don't think I "can do it," my natural response will be: Why try?

2. My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It his means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a "simple" trip to the grocery store may be hell for me:

My hearing may be hyper-acute.
Dozens of people are talking at once.

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The loudspeaker booms today's special. Musak whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia....I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented (see more on this below), this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

3. Please remember to distinguish between won't (I choose not to) and can't (I am not able to).

Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "*&^%\$#@, Billy. #\$\$%^*&^%\$&*....." Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch."

This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

4. I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is "this will be easy for you to do." When you say "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me "It's raining very hard."

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

5. Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, I am very visually oriented.

Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations. Here's a great website for learning more about visual schedules:

www.cesa7.k12.wi.us/sped/autism/structure/str11.htm .

I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

7. Please focus and build on what I can do rather than what I can't do.

Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

8. Please help me with social interactions.

It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or

shooting baskets, it may be that I'm delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

9. Try to identify what triggers my meltdowns.

Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge.

Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment.

Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.

10. If you are a family member, please love me unconditionally.

Banish thoughts like, "If he would just....." and "Why can't she....." You did not fulfill every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not

you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for

extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They had autism too.

The answer to Alzheimer's, the enigma of extraterrestrial life -- what future achievements from today's children with autism, children like me, lie ahead?

All that I might become won't happen without you as my foundation. Think through some of those societal 'rules' and if they don't make sense for me, let them go. Be my advocate, be my friend, and we'll see just how far I can go.



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Ellen Notbohm is author of the book **Ten Things Every Child with Autism Wishes You Knew**, winner of iParenting Media's Greatest Products of 2005 Award, and co-author of **1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders**, winner of *Learning Magazine's* 2006 Teacher's Choice Award. A columnist for *Autism Asperger's Digest* and *Children's Voice*, she is also a contributor to numerous magazines and websites. Your comments and requests for reprint permission are welcome at ellen@thirdvariation.com.

Reacting to a Diagnosis

When an individual receives a major diagnosis, he or she may go through the well-studied five-stages of adjustment (Kubler-Ross, 1969). When the diagnosis is given to a child, his or her caregivers often go through those five stages. You may find that you go through all of these stages, or just some of them, or possibly none of them. Whatever reactions you do feel are perfectly fine and acceptable. Think of receiving a diagnosis as a starting point and acceptance of your child's diagnosis as your destination; whatever road you take to reach your destination is okay. There are an endless number of routes you can take to reach your destination, and any one of them will get you there; you will simply take the route that best works for you. The five stages listed below represent one commonly taken route, but certainly not the only one.

Denial

Many parents may try to deny their child's diagnosis immediately after hearing it. They may believe that there has been a mistake, they may believe that their child will outgrow the diagnosis, or they may simply think they must be having a bad dream. Learning that your child has an autism spectrum diagnosis can be overwhelming and it is very common to believe that there is no way the diagnosis could be accurate. It may be easier to go home after hearing the diagnosis and pretend like it did not happen, to avoid telling anyone what you've learned, or to simply hope it will all go away. All of these reactions are typical of the denial stage. However, as time passes, it may become harder and harder to deny the existence of your child's difficulties. As you start to realize that the diagnosis is accurate you may move on to the next stage...

Anger

You may begin to think it is unfair that your child has this problem when other children do not. You may look at people who failed to take good care of themselves while pregnant and be angry that their child turned out fine while yours has difficulties. Some parents will watch their child struggle with tasks that come easily to other children and feel that it is unfair. These reactions are typical of the anger stage. You simply cannot understand why this happened to you or to your child, and you wish you could make it all go away. As you begin to work through this stage you may start to move on to the next stage...

Bargaining

Parents in the bargaining stage try to work out ways to fix their child. They may think thoughts such as, "If I am the perfect parent and do X, Y, and Z, then my child will be cured." They may say prayers in which they promise to never do another bad thing in their life if God will cure their child. While in the bargaining stage, parents try to find ways to exchange their behaviors for the complete recovery of their children. As they begin to realize that nothing will completely cure their child, parents may move on to the next stage...

Depression

Once they realize that the diagnosis is accurate and that they cannot bargain their way out of it, parents often feel depressed. Parents in the depression stage may feel sadness that their child cannot be cured. They may feel upset that they cannot do anything to make the situation different. While in this stage, parents may feel like the rest of their life will be focused on helping this child and they may feel overwhelmed or hopeless. Eventually, parents in this stage will discover what works best for their child and create routines that work for them and their family. Once these realizations begin to occur, the parent has moved into the final stage...

Acceptance

Parents in the final stage, acceptance, have generally worked through all of their emotional reactions to their child's diagnosis. They understand that their child is just as wonderful, sweet, lovable, and precious as before the diagnosis. They know that they can handle raising their child and have generally sought out whatever additional supports they will require. Parents in the final stage know that although their child may never be cured, they can show improvements and learn many new skills. They know that although their child may not be perfect, no child is perfect. They have learned to accept their child for who he or she is.

Reference

Kubler-Ross, E. (1969). On Death and Dying. New York: MacMillian Publishing Company.

Enjoying your Child

Although your child has been diagnosed with an Autism Spectrum Disorder, the reality of the situation is that your child is the *exact* same child you've loved and known since the day he or she was born. The only real thing that has changed is that you now have a label to explain some of your child's differences or difficulties. You may feel stress or anxiety now that you have a label for your child, but remember this is still your child. Try not to let the stress of the diagnosis outweigh your love for your child.

Because your child was recently diagnosed, you may find that much of your time over the next few months will be spent seeking out more information about your child's diagnosis or finding the best services and treatments for your child. Those pursuits are absolutely important uses of your time, but it is equally important to be sure you continue to take time each day to enjoy your child.

Be sure to take time every day to play games with your child, to read to your child, to talk and to interact with your child. Take your child to the park. Take your child to the zoo to see animals. Roll a ball back and forth. Play chase or peek-a-boo. Get to know your child and the type of things that interest him or her, and then select activities that match those specific interests.

Remember although your child has an autism spectrum diagnosis, he or she is still a child and still wants to laugh and have fun. Be sure to enjoy your time together!

Enjoying Your Child in Play

My Child Likes To...	Suggested Toys	Suggested Activities
Listen to music/make sounds	Instruments, music box, keyboard, sound books, talking tolls	Parade, singing songs, musical chairs
Bang on things	See n' Say, drum, xylophone, workbench	Pounding clay
Watch things spin	Spinning tops, yo-yo, pinwheel, helicopter	
Feel motion	Rocking horse, swing, slide, sit n' spin, trampoline, tricycle	Dancing, chase games, rough-housing
Smell things	Scratch & sniff books, markers that smell, scented playdoh	Cooking
Touch things	Playdoh, stuffed animals, bristle blocks, books with textures, koosh ball, finger paint	Water play, make playdoh, cooking
Look at lights/color	Sand/rice/water table, Lite Brite, bubbles, electronic games, flashlights, mirrors, picture books, spin toys	Painting, dress up in front of the mirror
Look at/play with letters/numbers	Computer, alphabet blocks, playdoh cutters, puzzles, telephone, books	Read signs, alphabet songs, art activities with numbers/ letters
Play with mechanical things	Tinkertoys, legos, train tracks, lincoln logs, cash register, toys with keys/locks	Chores- e.g. use dustbuster
Line up, sort, arrange things	Dolls to put to bed, in car, legos, trains and tracks, shape sorter, puzzles	Setting the table, sorting jobs, putting clothes away
Feel different temperatures	Playdoh (warmed or cooled), ice/heat packs	Water play (ice), cooking, washing baby dolls

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*Grandparents: Focus on the Child
Special Needs*

Special Needs

Every grandparent hopes and prays that a new grandchild will be healthy. We count our grandson's fingers and toes after he is born. We keep an eye on our granddaughter to make sure she is developing 'normally.'

Most of the time, we breathe a deep sigh of relief because our grandchild is just fine. But sometimes there are challenges. We may find out that the newest addition to our family has a disability. This news can be very hard to hear. We feel shocked and sad. We are angry. We find it hard to understand how this could have happened to our family. We ache for our grandchild—and for the child's parents.

These feelings are painful. As grandparents, we need to take time to grieve the loss we are feeling. And then we need to get busy. That's because we have many special gifts to offer our families right now. They need us more than ever.

Tips for Dealing with Disabilities

You may be helping the child's parents cope with the child's special needs or you may be raising your grandchild yourself. In either case, you can't take away the pain that you or your grandchild's parents are feeling right now. You can't change what has happened to your grandchild. But you can offer your support to the child and to the rest of the family.

- Show your grandchild every day that you love him for the special person he is.
- Listen when the child's parents need to talk.
- Support the decisions they are making, even if you don't agree with all of them.
- Show that you are interested in the special programs and therapies they have found for the child.
- Offer to help with household chores.

You can also do a few things to help yourself cope with your grandchild's disability. Even if you are not raising the child, it's important to stay as involved as you can in the child's life. This will help you become more comfortable with his or her condition. Talk to other grandparents who have grandchildren with disabilities. Join a support group for families of children with disabilities. You will feel better when you can share your feelings with people who know what you're going through. You can learn more about the disability. And, you may pick up some tips on how to support your family. You might even encourage the grandchild's parents to join a support group too.

Learning About Disabilities

Learn as much as you can about your grandchild's condition. This will help you cope with what is happening. A number of conditions can affect young children. Each has its own causes and treatments. Some of the more common disabilities include:

- **Down syndrome.** Children with Down syndrome have an extra chromosome 21. This gives them some physical traits that are easy to recognize. Children with Down syndrome grow at a slower rate than other children. They usually are small. Many suffer from mild or moderate mental retardation. Most have problems with hearing and heart disease. Children with Down syndrome do best in a caring home. They can benefit from special services and learning programs.
- **Autism.** Autism is a very complex brain disorder. It usually appears by age three, and the causes are largely unknown. Autism affects the way a child interacts with others and his or her world. Many children with autism have trouble socializing with others. They may be slow to talk. They may be very sensitive to sound or to being touched. Some therapies can help children with autism. The sooner these therapies begin, the better a child will do.
- **Fetal Alcohol Syndrome (FAS).** Unborn babies can develop FAS when their mothers drink alcohol while they are pregnant. This hurts the child's central nervous system. Children with FAS grow at a slower rate than other kids. They also can suffer from mental retardation. Some may have learning disabilities. They often have serious behavior problems. There is no cure for FAS. But special services that can help these children cope.
- **Attention Deficit Hyperactivity Disorder (ADHD).** Children with ADHD have trouble sitting still or paying attention. Some experts say that these children may not have enough of certain brain chemicals that help everyone pay attention and control their behavior. Medication, counseling and various therapies are used to treat ADHD. Your grandchild probably won't 'outgrow' ADHD. But he or she can learn to adapt to it and do well in school.
- **Learning Disabilities.** A learning disability may make it hard for your grandchild to listen, think, speak, read, write, spell, or do math. One of the most common learning disabilities is dyslexia. People with dyslexia have trouble reading and understanding words, sentences and paragraphs. Learning disabilities don't go away. People live with them their whole lives. But children who get the right support can become good students and successful adults. That support includes tutoring and various therapies.

Fighting for Your Grandchild

Finding out that your grandchild has a disability is difficult. And raising a child with a disability is challenging. You and your family can meet this challenge if you work together and support one another.

There are many professionals who are ready to help your grandchild. You or your grandchild's parents can find these professionals by calling the local public school. All schools have special services for children with disabilities. The Individuals with Disabilities Education Act (IDEA) sets the rules for who can receive these special education services. If qualified, it ensures an Individualized Educational Program (IEP) is designed especially to meet that child's needs. And your grandchild may be able to get services even before starting kindergarten.

Parents and grandparents must be strong advocates for a child with special needs. It's often up to you to make sure the child gets the help that he or she needs and deserves. Grandchildren with disabilities can't fight for themselves. We have to do it for them. These children need extra support. But they can be happy and healthy—and a special gift to their families!



Autism Society of America™
improving the lives of all affected by autism

Sibling Issues

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

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

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

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

Explaining Autism to Children

Common sense tells us and research supports the idea that children need to understand what autism is all about. The rule of thumb: Do it early and do it often! It is important that your children know about autism and that the information you give them is appropriate for their developmental age. From early childhood, they need explanations that help them understand the behaviors that are of concern to them. For the preschooler, this may be as simple as, "Rick doesn't know how to talk." While for the adolescent, it may involve a conversation about the possible genetics of autism.

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

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

Helping Your Children Form a Relationship

Because of the nature of autism, it is usually difficult for a young child to form a satisfying relationship with a brother or sister who has the disorder. For example, your child's attempts to play with his/her brother with autism are probably rebuffed by his ignoring him/her, and fall flat because of his lack of play skills, or end abruptly because his tantrums are frightening. How many of us would keep trying to form a friendship with someone who turned her back when we spoke to her, or, even worse, seemed angry when we approached?

It is not surprising then that young children may become discouraged by the reactions they encounter and seek their playmates elsewhere. The good news is that young children can be taught simple skills that will enable them to engage their brother or sister in playful interactions. Research has shown that siblings can learn basic teaching strategies to engage their brother or sister with autism. These skills included things like making sure they had their brother's attention, giving simple instructions, and praising good play. One research study showed that videotapes made before and after the children learned these skills showed that, after training, they played together more and seemed much happier than they had been prior to training.

Special Times

Along with ensuring that the child with autism is a fully integrated member of the family, it is just as important to remember that the other children in the family need their times to be special too. Families are often urged to find some regular, separate time for the children in their family who do not have autism. It may be one evening a week, a Saturday morning, or even a few minutes at bedtime each night. If your child with autism has a home-based program or exhibits serious

management problems, you will have neither the stamina nor the energy to give your other child exactly the same amount of attention. It is not necessary that everything in childhood be exactly the same. What is important is the opportunity to feel special to your parents and to feel that there is an overall atmosphere of equity in your home.

Not Everything as a Family

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

Adult Siblings

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

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

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

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

your wishes.

Sibling Groups and Other Resources

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

The Sibling Support Project of The Arc of the United States, based in Seattle, Washington, is one example. They offer a range of information on siblings of children with disabilities, including: reading lists for children and adults, information on local sibling group meetings, information on facilitating sibling discussion groups, or online resources. Their Web site address is:
<http://www.thearc.org/siblingsupport>

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

Most Siblings Cope Very Well

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

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

Siblings Perspectives: Some Guidelines for Parents

Contributed by Marci Wheeler M.S.W.

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

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

It is also important to note from Lobato's research that a mother's mental and physical health is probably the most important factor in predicting sibling adjustment regardless of the presence of disability in the family (Lobato, 1990). Positive outcomes that siblings frequently mention are learning patience, tolerance, and compassion and opportunities to handle difficult situations. These opportunities also taught them confidence for handling other difficult challenges. Research by Susan McHale and colleagues found that siblings without disabilities viewed their relationship with their brother or sister with autism as positive when: 1) they had an understanding of the siblings disability; 2) they had well developed coping abilities; and 3) they experienced positive responses from parents and peers toward the sibling with autism (McHale et al., 1986).

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

Wheeler, M. (2006). Siblings perspectives: Some guidelines for parents. The Reporter, 11(2), 13-15.

family that need information, reassurance and coping strategies just as parents do.

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

Twelve Important Needs of Siblings and Tips to Address These Needs

1. **Siblings need communication that is open, honest, developmentally appropriate, and ongoing.** Parents may need to deal with their own thoughts and feelings before they can effectively share information with siblings. Children may show their stress through their withdrawal or through inappropriate behaviors. Parents should be alert to the need to initiate communication with their son/daughter. Siblings may be reluctant to ask questions due to not knowing what to ask or out of fear of hurting the parent. While doing research on siblings, Sandra Harris found that developmentally appropriate information can buffer the negative effects of a potentially stressful event (Harris, 1994).
2. **Siblings need developmentally appropriate and ongoing information about their siblings' Autism Spectrum Disorder.** Anxiety is most frequently the result of lack of information. Without information about a sibling's disability, younger children may worry about catching the disability and/or if they caused it. The young child will only be able to understand specific traits that they can see like the fact that the sibling does not talk or likes to line up their toys. School aged children need to know if the autism will get worse, and what will happen to their brother or sister. Adolescents are anxious about the future responsibility and impact of the disability on their future family.
3. **Siblings need parental attention that is consistent, individualized, and celebrates their uniqueness.** Many families make a major effort to praise and reward the child with the disability for each step of progress. This same effort should be considered for the siblings even if an accomplishment is somewhat "expected." Self esteem is tied to this positive recognition by parents. Remember to celebrate everyone's achievements as special.
4. **Siblings need time with a parent that is specifically for them.** Schedule special time with the sibling on a regular basis. Time with the sibling can be done in various ways such as a 10 minute activity before bed each night or a longer period of ½ hour to an hour 3-4 times a week. The important thing is to have some specific times with a parent that siblings can count on having just for them.

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5. **Siblings need to learn skills of interaction with their brother or sister with an Autism Spectrum Disorder.** Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings necessary play skills to interact successfully with their brother or sister with an Autism Spectrum Disorder. It is important to go slow and generously praise the sibling for his or her efforts. Toys and activities should be chosen that are age appropriate, hold both children's interest and require interaction. The sibling needs to be taught to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2003).
6. **Siblings need to be able to have some choice about how involved they are with their brother or sister with an Autism Spectrum Disorder.** Be reasonable in your expectations of siblings. Most siblings are given responsibility for their brother or sister with a disability at one time or another. Show siblings you respect their need for private time and space away from the child with the disability. Make every effort to use respite services, community recreational programs, and other available supports so that you are not overly dependent on the sibling.
7. **Siblings need to feel that they and their belongings are safe from their brother or sister with autism.** Some children with an Autism Spectrum Disorder can be destructive and hard to redirect. They can also be quick to push, bite, or engage in other challenging behaviors with the sibling as a target. Siblings must be taught how to respond in these situations. Generally this would include asking a parent for help in handling the situation. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their siblings' aggressive behaviors. Thomas Powell and Peggy Gallagher offer ideas on teaching basic behavior skills to siblings (Powell & Gallagher, 1993).
8. **Siblings need to feel that their brother or sister is being treated as "normal" as possible.** Explain differential treatment and expectations that apply to the child with a disability. As they mature, siblings can better understand and accept the modifications and allowances made for the brother or sister with a disability. For various reasons, parents sometimes do not expect their child with an Autism Spectrum Disorder to have chores and other responsibilities around the house. Attempts should be made to make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with the Autism Spectrum Disorder.
9. **Siblings need time to work through their feelings with patience, understanding, and guidance from their parent(s) and or a professional, if appropriate.** Listen and acknowledge you hear what is being said. Validate the sibling's feelings both positive and negative as normal and acceptable. Repeat back what you have heard the sibling say and check for accuracy. Sharing your positive and negative emotions appropriately is also important. Remember parents are important models of behavior. Help siblings learn ways to cope with and manage their emotions.

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10. **Siblings need opportunities to experience a “normal” family life and activities.** If needed, draw on resources in the community both informal and formal. Some families are uncomfortable in asking for help. For the sake of everyone in the family, it is important to find and use resources available such as respite care services and other community programs for persons with disabilities and their families. Most families would be overwhelmed without some breaks from the ongoing demands of caring for children with a disability. Siblings and parents need opportunities for activities where the focus of energy is not on the child with special needs.
11. **Siblings need opportunities to feel that they are not alone and that others understand and share some of the same experiences.** Parents should recognize the need for siblings to know that there are others who are growing up in similar family situations with a brother or sister with a disability. Opportunities to meet other siblings and/or read about other siblings are very valuable for most of these children. Some children might benefit from attending a sibling support group or a sibling event where they can talk about feelings and feel accepted by others who share a common understanding while also having opportunities for fun.
12. **Siblings need to learn strategies for dealing with questions and comments from peers and others in the community.** Parents should help prepare siblings for possible reactions from others toward their brother or sister with a disability. Make sure the sibling has facts about Autism Spectrum Disorders. Discuss solutions to possible situations. They may even benefit from carrying their own information card for friends which they can hand out as needed.

Siblings have a unique bond with each other which is usually life long. Having a sibling with a disability impacts this bond and will impact each sibling differently. The information presented here highlights some of the limited research and the most significant factors influencing a positive experience for siblings of a child with a disability. As a parent of a child with an Autism Spectrum Disorder you can directly influence and support positive relationships for siblings. Just as you have learned to be proactive for the sake of yourself and your child(ren) with an Autism Spectrum Disorder, siblings need you to be proactive in helping them, too.

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A Summary of:

Psychosocial Adjustment in Siblings of Children with Autism
Laura Kaminsky and Deborah Dewey
Journal of Child Psychology and Psychiatry, 2002, 43, 225-232

Having a child with autism affects everyone in the family. A lot of research has studied the effects on parents, but little research has studied siblings. The research that has studied siblings has found mixed results. Some studies found that siblings were more likely to feel depressed and to “act out” than other children. Other studies found that siblings of children with autism are well-adjusted, do well in school, and have good self-esteem. One reason for these opposite results is that these studies included very few children. Results based on larger numbers of people are more likely to hold true when tested again than are results based on smaller numbers of people. A result from a study of 100 siblings is more likely to hold true in future studies than a result based on only 10 siblings.

Many studies compare families of children with autism to families of children with Down syndrome. Both types of children tend to have learning difficulties, but children with autism also have social difficulties. Any differences between the groups are likely due to the social problems common in autism. The goal of this study was to see whether siblings of children with autism are as well adjusted as siblings of children with Down syndrome. A second goal was to see whether having social support (friends, teachers, family, etc) affected adjustment levels.

The study included 90 children between 8 and 18 years old. One third had a sibling with autism, one third had a sibling with Down syndrome, and one third had a sibling with no known disability. Five types of surveys were used, some filled out by the child and some by their parent. Parents filled out surveys about the child’s behaviors, about the skills of the child with the disability, and about family income, the number of children in the home, and other information specific to the family. The child completed surveys about social support about how lonely they feel.

The results of all the surveys were then studied. Results revealed that siblings of children with autism are *not* at higher risk of adjustment problems or loneliness. One reason may be that many of these families went to support groups. This study also found that siblings of children with autism who came from large families were better adjusted than those from smaller families. Children with higher levels of support from classmates felt less lonely. They also found that siblings of children with autism did not have any problems with social skills. One drawback of the study is that most of the children in the study were older than their sibling with the disability, which makes it hard to know whether the results would be the same for younger siblings. Overall, this article found that siblings of children with autism are well-adjusted, and those from larger families appear better adjusted than those from smaller families.

**Summarized by Stacie Pozdol, M.S., LMHC and Naomi Swiezy, Ph.D., HSPP,
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Step Two Summary

It can be overwhelming to learn your child has a PDD. Caregivers may feel many emotions after the diagnosis. Although any emotion you feel is normal and okay, many people go through a set of 5 emotions. This set includes denial, anger, bargaining, depression, and acceptance. Although it may be hard to accept the diagnosis, as you begin to accept it you will see that you can still enjoy your child. Once you change your expectations for your child, you will find many activities you can still enjoy. It often helps to focus some activities on your child's specific interests.

Receiving a diagnosis of a PDD for your child can greatly impact you as a parent. The impact of the diagnosis on parents has been widely studied. In families with two caregivers, it is important to keep communication open and to take time to nurture the relationship between the caregivers. Each parent may react differently to the diagnosis, so it often takes some effort to understand the others' reactions. Receiving a diagnosis for your child can be overwhelming for many people. Don't be afraid to seek supportive counseling to help you through this process.

When a child has a diagnosis of a PDD, more than just the primary caregivers are affected. A diagnosis also affects siblings, grandparents, and the whole extended family. Be sure to give each person in the family time to react and adjust to the diagnosis. Be sure to also take time for yourself and for your other children. Some days may be harder than others, but that is true in all families. Take time for a break on harder days, and take pleasure in your life and your child on the better days. You, your child, and your family will survive this diagnosis.