

Aut-Talk



Oct / Dec
2007

NEWSLETTER FROM AUTISM SOUTH AFRICA—THE NATIONAL BODY FOR PEOPLE WITH
AUTISM SPECTRUM DISORDERS IN SOUTH AFRICA

12th Edition

Inside this issue:

Things To Do First After Diagnosis

We'll Do What We Have To Do

12 Important Needs Of Siblings and
Tips To Address These Needs

How does mindblindness show in the
behaviour of our ASD Children?

Dealing With Learning And Sensory

Thursday, 24th May 2007

A personal account written by
James Pendlebury

High Levels Of A Male Sex Hormone
In Foetuses Are Linked To A Higher
Chance Of Developing
Autistic Traits In Childhood, Scientists
Say.

Dietary Interventions

'Calendar And "Just To Let You Know"
Book / DVD Corner

Buzz Page

Young Sibling Corner

Teenage Sibling Corner

10 Things Every Child With Autism
Wishes You Knew

System Spots Autism In Toddlers

When Scott was around twelve years old (and talking in three and four word sentences), one of his pleasures was to go to our local Lunch Rooms (Dru & Bill's), sit on the same stool and order the same thing (hamburger with potato chips and a coke). Well, one day Scott put his order in and waited to be served, sitting between two other patrons. I turned to talk to someone else and suddenly heard "HEY, YOU LITTLE WISE GUY!!!!" The man commenced to grab Scott by the arm with the look of 'I'll fix you' on his face.

I jumped up, placed myself between Scott and the irate man and demanded he tell me why he was accosting my son. The not-so-gentle (at the moment) man went on to say that Scott reached over, grabbed his hamburger, took a big bite, and put it back in the man's dish right under his gaping mouth.

I tried to explain Scott's disability and offered what I'm sure was Scott's reasoning. 'I ordered a hamburger. There's a hamburger. I'LL EAT IT!!!!' So he did! By this time, the man was more composed and understanding. When Scott's hamburger came, I gave it to the gentleman. Scott just went on eating the man's hamburger, appearing oblivious to what was going on around him.

A happy ending, I might add. The man paid for our lunch!!!

Jean F. Butler

Main

Taken from Laughing and Loving with Autism

ISBN: 1-885477-04-x

Autism South Africa

The Memorial Institute for
Child Health and Development

(previously known as TMI)

Gate 13. Cnr Joubert Street
Ext

and

Empire Road Braamfontein.
2001

PO Box 84209

Greenside. 2034

Tel: + 27 11 484 9909 / 9923

Fax: +27 11 484 3171

E-mail

info@autismsouthafrica.org

Web Page :

www.autismsouthafrica.org

Show You Care
Be Autism Aware



THINGS TO DO FIRST AFTER DIAGNOSIS

A JOURNEY OF A THOUSAND MILES MUST BEGIN WITH A SINGLE STEP

Taken from *Facing Autism*
ISBN1-57856-262-7

The day we learned of Ryan's autism I did the only thing I knew to get help—I called the Autism Society and Dr. Sallows. But after I left my tearful messages, I didn't know what else to do. Where were we to go from there? Should we wait until the information arrived? I knew Ryan needed help, but what kind and from whom? I felt an urgency to begin combating his autism, but how?

Fortunately we had friends who were willing to show us the ropes and walk us through the beginning steps of our journey. Since not everyone has that option, this chapter focuses on where to start. There are many avenues to explore and so much that will be done over time, but these 'top ten' steps are practical ones you can begin to take the first month.

Understand your Child's Diagnosis.

Ironically Ryan was diagnosed during National Autism Awareness Week, and although we had been told autism was a possibility, we really weren't aware of what autism is. My experience had been limited to watching *Rain Man* on TV and knowing casually some families from our church who had children with autism. But Ryan wasn't like Dustin Hoffman or their kids. If they each had autism, why were they so different? Understanding the label your child has been given is an important starting point. Was your child diagnosed with autism, PDD-NOS, Asperger's, Landau-Kleffner Syndrome, or another related disorder? To learn more about the specifics of your child's disorder, begin with the professional who diagnosed your child. Ask the doctor to explain why that label fits. Our doctor took us step by step through the diagnostic criteria chart, explaining why autism fits and other disorders didn't. Feel free to call your doctor with questions.

Reading a book by a person with autism provides excellent insight. Temple Grandin's book *Emergence; Labeled Autistic* and

Thinking in Pictures and *Other Reports from My Life with Autism* are good ones to start with. Grandin is a remarkable woman with autism who has earned her PhD. in animal science. In *Thinking in pictures* she explains how her thought process difference, how she thinks in pictures instead of words. She also describes her sensory problem, her struggle to learn empathy, and the challenges of developing relations with people who don't have autism. Another book to consider is *'There's a boy in Here'*, written by Judy Barron about her son Sean. Since Ryan couldn't speak, we didn't know what was going on inside him and couldn't understand things like why brushing his teeth was so painful. Books such as these gave us a great insider's view that Ryan couldn't provide.

Talking to another family about their experiences can also be very helpful. The day after Ryan's diagnosis, Susie and Jeff, who have a child with autism, invited us for dinner. From the moment we walked in, we felt their empathy because they had walked in our shoes. We could talk honestly with them about the struggles we were just beginning to face. Through the course of the evening I realized that their son, Christopher was fascinated by movies and would watch them all day if allowed. When Susie showed me the hundreds of videos they had acquired, I even found myself laughing. I thought I was the only one who had a stockpile of movies! Both boys also had very limited diets. Christopher ate a total of five foods and drank only Sprite and citrus punch juice. Because he would eat only one breakfast bar and the company was discontinuing it, Susie and Jeff would drive hundreds of miles to buy as many as they could find. Although the following days would teach us more about Ryan's strengths and weaknesses, his needs and desires, and his autism, talking with Susie and Jeff that night and seeing the many parallels confirmed the diagnosis for me and allowed me to start moving forward.

Allow yourself to Grieve

While this isn't an item to check off a 'to do' list, it is important to give yourself permission to grieve. You haven't lost your child physically, but you may have lost many of your dreams and plans for your child, which can be extremely painful. In time you will develop new goals and dreams for him, but for now you need the freedom to grieve.

For the first few days I couldn't look at Ryan without crying. I forgot to eat, had difficulty sleeping, and lost seven pounds in a week. After that first week, my emotional meltdowns occurred about once a week, usually when I saw another child and realized that Ryan might never reach the typical milestones most parents take for granted. About three weeks after his diagnosis, Roger and I watched a grade-school choir perform. All I could think was, 'Will Ryan ever be able to stand up front and sing with a group?'. And the tears started to flow. Afterward, someone who knew our situation came up to me and said, 'are you still grieving! Wouldn't you be? Without intending any harm, people will say insensitive things because they really don't understand your grief. Trying to encourage us, one friend said to Roger, 'Don't worry. You'll have other children'. When such things are said—and it's usually at the worst possible time—try not to let their words or expectations upset you. Your friends have not walked in your shoes. Each person grieves differently. Some grieve without tears, dealing with their pain by keeping busy. Some grieve for a short time and then are able to move on. Others need much more time to process their feelings. Susan is the mother of Franke, a seven-year old boy with autism. For the first six months after his diagnosis, as Susan awakened each morning she would lie in bed in that half-awake state, thankful it was merely a nightmare. Her little boy didn't really have autism. Then reality would hit, and she grieved all over again. Be careful not to judge your spouse or others for how they grieve; instead, take time to talk honestly with each other about how you're feeling. You may feel you have to be strong for your spouse or someone else, but in order to be strong you first need to be honest with your feelings. I am very grateful that Roger felt free to cry with me. It brought me into his grief and him into mine.

Video your child

This may sound like common sense, but it can be very important and is often overlooked. Start today videotaping your child in his daily activities—eating, playing, talking. Tape him during good

and bad situations to document what your child is like before treatment begins. Once treatment starts, videotape on a regular basis to record progress. We had lots of family videotapes of Ryan before treatment started, but I wish I had taken more and had captured more fully the autistic traits in his life then. The video tape helps in three ways. First, they are wonderful for maintaining hope. Looking back at Ryan in the beginning, I can see the dramatic changes that have taken place. I could tell you about his progress all day long, but no words make the impression that watching him transform right before your eyes. I've put together a fifteen minute video of clips from pre-therapy to the present. Even though I've seen it dozens of times, I'm always amazed as I watch his progress. Without the videos, I might forget how far we have come.

Find other families

It is extremely important. It's easy to become isolated, wrapped up in finding help for your child. You may feel you're able to go it alone—perhaps even that doing so shows strength—but I encourage you to break free of that myth and seek support. The Autism Society in your area will give you contacts for ongoing support groups. Go to one of them and find out what the group is like. Each group will have a different focus, so you may need to check out more than one. When you go remember that each person is at a different place in the autism journey. Some may be brand-new to this and need more support and information, while others may have older children with autism who have different needs. Within the group see if you can find one or two families you're comfortable with. Get their names and phone numbers, and take the initiative to contact them soon. More than likely they would love to help you and get to know you better.

You may argue that you don't have time to meet with other families, and I'd argue that you don't have time not to. Networking not only gives much needed emotional support and strength, it provides essential information. Other families have walked farther down the path that you're just starting. They can help you avoid pitfalls they

encountered; they can point you toward good doctors and therapists; they can save you from having to learn everything firsthand and perhaps the hard way.

Continue Learning

Autism information is not stagnate, and treatments are always changing. By contacting the organisations as well as networking with other parents, you are well on your way, but it is critically important for you to stay as well informed as possible. Unlike treating a broken arm, there is no consensus on the treatment of autism. There is no single person who can give you all the answers for your child.

We'll do what we have to do

By Wendy Whipple
Taken from *The Autism Experience*
ISBN: 0-972-4682-4-2

In December of 2000, our daughter was diagnosed with autism, at the mild/moderate end of the spectrum. It was what my family had feared, but none of us admitted it to each other, afraid of the word. No one dared say it out loud, as if uttering the word would make it come true. The whole thing started in September 2000, when three-year-old Diana had her annual checkup, and her pediatrician insisted that we get her speech evaluated, because she still wasn't talking at an age-appropriate level. We'd had her hearing evaluated the year before for the same reason, and she tested normal. With that, we decided that it was not necessary to have her tested further because she was only two, and thought she'd catch up. We were wrong. The results of the speech evaluation put her 12–18 months behind what the average child should be able to do. That was alarming enough. It was recommended that Diana be enrolled in the school district, because the schools have programs for 'special needs kids' that could address her speech deficits. This really scared me. My baby was going to be entering The System, and receive a

Label.

Her pediatrician then insisted on a psychological evaluation, 'just to make sure there's nothing else going on'. (Never once did she suggest that autism might be what she thought was the problem). I enrolled her in the school district, and had phone conversations with the school psychologist, telling her that I was also trying to get Diana seen by a child psychologist for an evaluation. We decided that it would be in Diana's best interest to wait until we had results from the assessment before she started school, so that the school had all the information in front of them.

I managed to get an appointment with a highly respected and excellent child psychologist six weeks later. We were lucky; waiting lists are usually months long. After I completed a written survey / questionnaire and underwent a series of visits the doctor met with my husband and me in December to discuss his findings. Before he gave us his diagnosis, he told us what he'd found. It was not encouraging. Diana was delayed nearly two years in a number of developmental areas; fine motor skills, speech, and social interaction. Everything he said were things we had seen ourselves. He led us very gently to his diagnosis.

Hearing your baby has autism is devastating. I had decided earlier that afternoon that he was going to tell us that diagnosis, and even though I had prepared myself to hear it, I was shattered. I cried all the way to my brother's, who was watching Diana for us. I tersely told him what the doctor had said, and asked that he not make me talk about it. I took Diana and went home.

My husband sat me down before I called my parents and told them the diagnosis and told me that we were not going to treat Diana any differently. 'She's the same child she was a month ago', he told me. 'Now we know how to help her'. My folks were quiet as I told them, and they asked just one question, 'What can we do to help?'. At that point, I didn't know much myself, so I asked them to educate themselves about what we were dealing with. While I was on the phone with them, my husband was in his office, quietly ordering a stack of books on autism.

The next day, I searched the internet for information, and was quickly overwhelmed by it all. I called the school psychologist and told her what we'd learned, and she asked about the report.



We'll do what we
have to do

continued

The psychologist's report was being transcribed, and it would be a few weeks before I received it, I told her. She said it would be better to wait until the school had that before we put Diana in a class and made an IEP for her. After I finally got the report (in January) and sent a copy to the school psychologist, I met with teachers and school personnel to set up Diana in a classroom that best suited her needs. At the end of January, she started school in an early childhood class of about 10 kids. Her transition into the classroom went really well, and she displayed no problems with leaving me and staying with strangers. That made me both proud and sad, knowing she was her own person enough to do that, and knowing that she could leave me so easily. It also frightened me, because she didn't understand that she should be afraid of strangers.

In February, we tried to get Diana set up with speech and occupational therapy. The clinic sent in all the information and we waited for approval. Three weeks later, the insurance office called the clinic and said that services were denied on the grounds that they didn't cover speech delays. The speech therapist at the clinic was outraged; I was outraged. I called the insurance company. I was told that they didn't have the psychologist report containing the diagnosis of autism. I called the therapist back and told her what I'd been told. 'That's ridiculous! We sent everything in together!'. We decided we'd send it all in again, with a few extras. I got a 'letter of need' from Diana's doctor. The therapist sent in the DSM-IV's definition and classification for autism and the definition of autism from a respected medical dictionary, both of which included 'speech delay' as a symptom. In addition I drafted my own letter, pleading with them to grant the therapies my daughter needed to function in the world.

A week later, we were told that Diana's services were granted, with unlimited access to services, with the stipulation that she be re-evaluated in one year. Annual evaluations are recommended anyway, to fine-tune

therapies and track progress, so we certainly didn't have an issue with that. Diana had already started occupational therapy, since that service had not been denied, and she began speech therapy in March 2001.

She's doing very well in school, and with her therapists. Since she started school, and started getting therapy, sometimes Diana seems like a whole new kid. She's still has autism, and she still has limits with what she can tolerate, but those limits are expanding every day. Every January, we have a new IEP meeting. Every spring, I have to fight with the insurance company, as they review the policy and decide whether or not those services are needed (since they're also supplied by the school, for a few hours a week, in a classroom setting, with other kids). It's exhausting. It's depressing. It has to be done.

I met with the school social worker before the Christmas break (2002—3). She had me answer more questions so the school could identify strengths and weaknesses, so they'd know where to focus. She apologized, saying that she didn't write the questions. I told her bluntly that there was no question she could ask that hadn't been asked already, and that nothing she could do could upset me more than I already had been. She looked stunned. I don't think a parent had ever told her that this whole process was as devastating as it is.

I write a resource-oriented newsletter for the clinic where Diana sees her speech and OT. I read whatever I can. I am as involved with her education as much as I can be. There are days I feel my entire existence is defined by the fact that I am the mother of a child with autism. My mother-in-law tearfully told me in a phone conversation in 2001, 'You're so much stronger than I am' (she was very upset over Diana's diagnosis). I'm only as strong as I have to be. I still cry when I'm alone, and realise some of the things that will likely never be. Then I pick myself up; remind myself of the immense progress she's made already, in just two years. My own mother called me a hero. I'm not a hero!. I'm not even a runner-up! I have a daughter who needs me. And what she needs we will have, come hell or high water.

When I was pregnant with my daughter, I had dreams of playing dress-up, having tea parties, helping her grow into a strong

woman, and maybe I would one day become a grandmother. It hurts to know that these daydreams have shifted to 'I hope she can make it into inclusive classes. I hope she can live independently. I hope someday she doesn't need me as much as she does now'.

We have good days and bad days, like any family. Good days are amazing and gratifying. Bad days are hellish and discouraging. But my husband was right; she is still the previous little baby we brought home from the hospital.

Labeling is usually something I am opposed to, but with autism it can be a tremendous help. Getting that diagnosis means you usually have access to services within public schools. It means you have a name for what is happening in your child's head. And if you can name it, you can fight it. Not knowing what's wrong gives you no place to start. It's a difficult word to hear, but if you ignore the word, and focus on the love you have for your child and what she needs, 'autism' loses a little of its power to terrify.

Alex , like most kids I suppose, continually left his clothes on his bedroom floor. Being a well-trained parent, I sailed into him with my best shot, a line I had heard from my parents and one that the reader has also probably heard. This was the interchange:

Dad—"Alex, this is the last time I'm going to tell you to pick up your clothes".

Alex—(With a sign of relief) "That's good, Dad, because I hate when you tell me that!"

Taken from *Laughing and Loving with Autism*.

ISBN 1-885477-04-x



12 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. 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' ASD.** 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 whether 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.
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. 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 or a longer period several times a week. The important thing is to schedule specific "alone" time with a parent that siblings can count on.
5. **SIBLINGS NEED TO LEARN INTERACTION SKILLS WITH THEIR BROTHER OR SISTER WITH ASD.** Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings play skills to interact successfully with their brother or sister with ASD. Go slow and praise the sibling. Toys and activities should be age appropriate, hold both children's interest and require interaction. Teach siblings to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2003).
6. **SIBLINGS NEED CHOICES ABOUT HOW INVOLVED THEY ARE WITH THEIR BROTHER OR SISTER.** Be reasonable in your expectations of siblings. Most siblings are given some responsibility for their brother or sister with a disability. Show siblings you respect their need for private time and space.
7. **SIBLINGS NEED TO FEEL THAT THEY AND THEIR BELONGINGS ARE SAFE FROM THEIR BROTHER OR SISTER WITH AUTISM.** Some children with ASD 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. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their siblings' aggressive behaviors.
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. Make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with ASD.
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 what is being said. Validate the sibling's feelings, both positive and negative, as normal and acceptable. 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.
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, 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.** Siblings need to know that others are growing up in similar family situations. Opportunities to meet other siblings and/or read about other siblings are very valuable. Some might benefit from attending a sibling support group where they can talk about feelings and 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 ASDs. Discuss solutions to possible situations.



How does mindblindness show in the behaviour of our ASD Children?

Taken from How to live with Autism and Asperger Syndrome

ISBN: 1-84310-184-x

If a younger child on the autism spectrum does not have an understanding of the thoughts or motivations of others then she is less likely to use behaviours that communicate to the minds of others or to take into account the thoughts and feelings of others. He / she might have difficulty with the following:

- Pointing things out to others
- Making much eye contact
- Following another person's eyes when that person is talking about what they are looking at
- Using gestures to communicate
- Understanding the emotions on the faces of others
- Using a normal range of emotional expressions on her own face
- Showing interest in other children
- Knowing how to engage with other children
- Keeping calm when she is frustrated
- Understanding that someone else can help her
- Understanding how others feel in some situations (e.g. hurt, upset or fearful)

As he/she gets older mindblindness shows itself in more ways, including:

- A tendency to think about the world from his or her own point of view, which makes him/her appear very self-centered
- A tendency to engage in activities that do not depend on other people
- A focus on his/her own needs only
- A struggle to understand the emotions of others, and so a lack of empathy
- The need to be in control
- A lack of flexibility in interactions
- The use of rigid social rules rather than adaptable ones
- More take than give in the 'give and take' of relationships
- Problems with turn-taking
- A tendency to treat people as the same, with no variation for age or authority
- Being easily led by others due to her failure to understand the motives of others
- A tendency to relate better to adults. They are more predictable and may be more tolerant
- Difficulty with pretend play and an inability to understand about telling lies
- Difficulty understanding that his/her behaviour affects how others think or feel
- No understanding about sharing excitement, pleasure or belongings
- Talking excessively about a topic of his/her own interest without regard to the listeners opinion e.g. lack of interest or boredom

Exercise is understanding mindblindness

Along the sea from San Francisco, just outside a row of shops, a young man famously makes his living by hiding behind a few branches broken from nearby trees. Dressed in a monkey suit he watches and waits, unseen by most visitors who are busy chatting, shopping or just enjoying the sea atmosphere. Then he jumps out from behind his branches directly in front of someone passing by and shouts; 'Boo!'. Most people are startled and might jump or scream before laughing and joining in with the joke. Small crowds often watch from the other side of the road and then give him small change in appreciation of the street entertainment.

In order to make some money out of this, he requires good TOM. He needs to be able to predict the reactions of other people. He needs to think carefully about his chosen 'victim'.

Try to put yourself in his place for a moment. You are now the person waiting, hidden behind a few branches trying to make some money in the same way. You have to make decision about which people you will choose to jump out on and which you will not. Write the numbers corresponding to the four decisions given on the next page next to the descriptions of the people whom you see approaching to indicate your decision

When you have finished, ask a friend or relative to do the same exercise and then compare notes.

1—definitely will jump out on this person or these people. I don't have any worries about it.

2— It will be fun to jump out on them. There is a small chance of some trouble but I will take the risk.

3—I am very uncertain. There might be trouble

- Two teenage girls
- A teenage boy
- A middle-aged couple
- An eight-year old girl with a bleeding nose
- A boy with a small dog
- An elderly woman in a wheelchair
- A security guard who is protecting someone famous
- The local traffic warden
- A woman with a baby in a pram
- A mum with two children aged around eight and ten
- A blind man
- Your best friend
- Two men and a Rottweiler dog
- An elderly nun
- Your older brother



- A policeman
- A four-year-old child who is crying for her mum
- Your mum
- Your dad

Answer

There is no right or wrong answers. You will probably find that your answers differ when you begin to talk about why you made your decisions. You will probably have thought about the possible consequences of jumping out on the various people. For example, you may have thought that there was no risk in jumping out on the teenage girls because they might scream and then laugh about the incident, causing people in the small watching crowd to find the event amusing. This might then put them in a good mood and make them more likely to leave some money for you. However, you might have decided not to jump out at the blind man. You perhaps thought that he wouldn't get the joke because he wouldn't know what you have been hiding or know that you were wearing a monkey outfit, or you might have worried that the crowd might turn against you if they thought this was unkind. You are seeing things from his point of view but, more than this you are guessing what the crowd will think of you and what they think of the reactions and feelings of the person you jump out on. These are important social skills that we take for granted but with which people on the autism spectrum struggle. It is no wonder that the social world may be a challenge for them.

In order to make these decisions, you will have found yourself thinking about the thoughts and feelings of other people and trying to work out the likely consequences of your action on their behaviour. You may have been thinking not only about your 'victims' but also about the effect on the crowd. Intuitively you will have made a number of complex connections and decisions in a few seconds without even realising it at the time. People with ASD find this very difficult. They have mindblindness. They have great difficulty in understanding how other people might think or feel or how they might react.

Are there different aspects to Theory of Mind or mindblindness?

Yes, we know that an understanding of someone else's mind or point of view has different aspects. For example, when we try to understand what it will be like for a nun when a person in a monkey suit jumps out on her, we can consider:

- What she sees and what her sensory experiences are e.g. she sees something different from us
- What she is anticipating or expecting in any given situation or environment, and how that is different from what we anticipate or expect
- What her feelings are e.g. fear
- What her thoughts are e.g. 'I am in danger' or 'This is funny'
- How she brings all of this together in an interpretation of events e.g. 'A monkey has escaped from the zoo' or 'Another student rag week!'

Most typical nine-year olds understand that different people would react differently in the exercise above, and they would change their behaviour accordingly. Many nine-year old children with ASD may not. They might;

- Treat people as the same without making any variation for their age or authority e.g. jump out on all people indiscriminately or jump out on no-one.
- Focus on their own needs only e.g. their own enjoyment
- Have difficulty understanding that their behaviour affects how others think or feel and seem unaware of other people's reactions e.g. being upset.

However, as they grow older, they may develop more understanding. The difficulty seems to be that, for children not on the autism spectrum, understanding of other people's thoughts and feelings does not occur intuitively. It has, more often than not, to be taught.

Summary

Mindblindness makes it difficult for people with ASD to:

- Understand other people's thoughts and feelings
- Understand that they are expected to change the way they behave depending on where they are or whom they are with
- Predict what people might do next
- Interpret different facial expressions or gestures
- Understand how their behaviour might upset other people
- Understand social rules
- Express their own emotions appropriately.

It can make them seem self-centered and uninterested in other children and people.

Facilitated Communication

Taken from *Laughing and Loving with Autism*

ISBN: 1-885-477-04-x

My son David communicates very well and often bluntly through facilitated communication. Recently he was working with his facilitator and a visitor who was assessing his skills. After several hours, she had completed her work but wasn't sure how to end the conversation. One question followed another as she sought an appropriate close, without success. Finally, she said, 'David, is there anything else I should ask you?'

He quickly typed out, 'No, just open your mouth as say goodbye'.

Connie Deming

New York



Jessica had a great fascination with perfume from a very early age and an amazing ability to tell one from another. She always stopped by perfume counters and requested certain fragrances. A spray from a perfume bottle was a favourite reward.

When she was 5-years old she started attending a new school. She walked into the classroom, went up to the woman who would be her classroom aide, smelled her wrist and accurately announced "Estee Lauder." The aide was shocked and impressed by this charming but unusual skill.

Jennifer Brown

Ohio

Taken from *Laughing and Loving with Autism* ISBN: 1-885-477-04-x

Dealing with Learning and Sensory Differences

Taken from *Understanding Autism for Dummies*

ISBN: 0-7645-2547-6

Close your eyes and imagine what a cat looks like. Do you envision a generic feline with two ears, four paws, and a tail? Most people do, but Temple Grandin, the best selling author of *Thinking in Pictures* (Vintage) and other animal for that matter. She can remember what a cat looks like only by flipping through an imagery slideshow in her head of cats she's seen before. Learning sequential, nonvisual information is also challenging for Grandin and for others like her. Algebra is one concept she could never grasp, for instance, because she can't form pictures of what's happening; she can understand geometry, on the other hand. Although all people with autism may not see the world in exacting photographic detail, most people with autism experience the world differently. Their senses don't process information in the same way, so they experience seeing, hearing, smelling, tasting, and touching in a unique manner. In this article, we explain the unusual ways that people with autism experience their worlds, give you ways to handle their unique behaviour, and introduce some interventions that can help them in educational and social settings so they can communicate and process sensory information. An intervention is a system, therapy, or tool that serves to help people with autism overcome challenges that exist with the condition. Here are the three basic categories of intervention we discuss in this article:

- Communication and social interaction systems: Tools designed to aid people with autism in communicating their needs in ways non-spectrum people can understand.
- Sensory Integration aids: Interventions tailored to help the brain organize the information it receives from the senses.
- Neurotherapy; A therapy designed to retain the brain so it can calm down and maximize the benefits from and/or lessen its dependence on medications.

Not all the ideas in this article apply to every person with autism. Autism is a wide spectrum that includes people with mild to severe symptoms, and those symptoms vary. Thus, we continually stress individualized attention to your situation. We can't give you a one-size-fits-all formula that works for everybody.

Autistic Learning; Transferring Skills and Providing Structure

All children can learn, but each child learns in a different way. Understanding the unique way that your child learns and using that knowledge to your advantage can make the difference between frustrating failure and success. And with the latter comes continued motivation in learning. The brain—especially a young child's brain—is open to change, continually building new connections based on stimulation from one's environment. The autistic brain is no different in this respect. The newly formed connections occur across the autism spectrum, from the least to the most affected individuals.

Not all people with autism think in pictures, but many have trouble generalizing—something that comes naturally to a typical brain. When you generalize, you formulate general principles from particulars. When questioned about something he likes, a person with autism may list all the types of animals he knows instead of making a general statement, such as 'I like animals.' The autistic mind focuses on concrete, specific examples, not on the big picture. People with autism can exemplify the proverbial 'losing the forest for the trees'.

In the following pages, you find out how to help a person with autism take hold of the big picture, focusing on concepts and ideas, and you see how a structured routine can make a world of difference for the child's ability to learn.

Thinking conceptually and transferring concepts

You can help most people with autism to think conceptually by guiding them to put details together to form ideas—preferably with visual symbols. You can demonstrate abstract concepts like 'more' or 'less' with objects instead of explaining them in words. To teach a child fractions, for example, you can use a piece of paper or a piece of fruit that you can cut up to show quarters, thirds, and halves. And to teach the word 'fraction' you show the word with the pictorial example so that the child can form an association between the two.



Check out the animal example we present in the introduction to this section. Say that you want to teach a person with autism the categories of dogs. Whenever you go for a ride or a walk, point out the different types of dogs when you see them. Identify the dog as a dog and mention what kind of dog it is (Bulldog, Dalmatian, and so on). State what makes it a dog and not a cat or a bird. Picture books that show many kinds of dogs may be helpful.

A person with autism functions best with literal, concrete terms, not abstractly. Explaining a concept with detailed descriptions isn't as effective as showing a picture or the object itself. 'A picture is worth a thousand words' is quite true for a person with autism. And to complicate matters, a person with autism will take idiomatic expression is like the previous quote so literally that he may ask, 'What are the thousand words?'

Severe people with autism (or children with classic autism) may need to use touch as their most reliable learning method. You can walk a child with severe autistic symptoms through a new task by taking his hand and prompting him to touch the objects involved, because he may not understand the shape by sight if his visual processing is impaired.

A child with autism may also have trouble transferring a freshly learned skill, such as tying his shoelaces, to a new task if you alter the situation at all. For example, if you give him another pair of shoes that have, say, brightly coloured laces made of a different material, he may not be able to use the skills he recently learned to tie them. Although the two situations may seem identical to you, the person with autism doesn't realise that the laces are still shoelaces and that he can tie them in the same way, because they look different than the ones he's used to. You should also maintain touch consistency when teaching tasks such as lacing shoes to a severe child with autism. If you introduce new touches, you must take time to acclimate the person to the change.

When introducing a person with autism to a new situation, even if only one or two details have changed, you must take care to familiarize him with new aspects that may cause confusion. If he's going to a new school, for instance, you can help by taking him there before the first day to do a walkthrough, where you explain what will happen and show him where different items are located and how to use them. Perhaps you can even arrange for him to meet his new teachers.

Always remember to be understanding and compassionate. The normal anxieties a child faces in a new situation, like the first day of school, are increased by his difficulties in transferring behaviors to new settings—settings that seem conceptually similar but appear to him to be different.

Incorporating routine into daily life

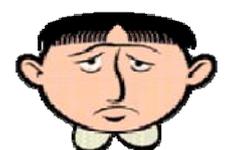
One of the hardest things to understand about an autism spectrum disorder is the great importance many people with autism place on structure and routine. Susie shrieks if she can't watch her favourite video all the way through each time, even though she's seen it countless times. Bobby insists on lining up his cars and trucks in order of size, and if another child 'messes up' his order, he can't relax until he returns each toy to its place. Will has to put on his shoes after his socks, and if his parents can't locate the shoes he likes best immediately, he asks for them repeatedly, sounding like a broken record, and won't put on anything else or stop asking until he gets them.

Dealing with the symptoms of autism isn't easy, and dealing with others' negative reactions just adds to the struggle. A person with autism may be battling feelings of chaos and anxiety. His world may be a confusing jumble of unrelated events, loud and painful sounds, or overly bright lights, like being in a funhouse where the entire environment is distorted.

In such a situation, the person feels the need to impose an order on the world just to survive and have a feeling of security. Not understanding or processing information from his senses and brain the way that others do, the person creates his own security. Nobody wants the feeling of security ripped away—particularly if you don't know why it's happening. You may not understand such behaviour (and you don't have to), but you can help by maintaining routines and helping the child deal with new and unfamiliar routines.

Advocates for autism believe that non-autistic people have caused much damage by arbitrarily imposing their judgments about what's logical and acceptable behaviour on people with autism. For the person with autism, his behaviour serves a need and seems right and logical to him—what he's doing isn't irrational. For this reason, when you implement an intervention you analyse the child's behaviour from a functional standpoint. To redirect a person's behaviour, you must first understand the motivation for the behaviour and what rewards the person gleans from it. You must assume that the behaviour makes sense to the person with autism, even if it doesn't to you.

Writer and artist Donna Williams, a person living with autism, points out that it's important to know the difference between a person with autism's involuntary responses and behaviors, and actions that are authentic reflections of who the person is. You want to help the person get past the former; you want to encourage the latter. Automatic behaviors may vary across the autism spectrum. High Functioning individuals may exhibit an intense need to organize or learn intricate detail about every day items, whereas low-functioning individuals may be resistant to physical change around them, such as chairs being moved around rooms.





Incorporating routine into daily life—continued

One global mantra you can keep to reduce the change of sensory overload when you attempt to introduce different routines is to keep things simple. Slow down the pace of your instruction, and simplify the information you give. Your child may have trouble attaching meaning to words you say, so give him time to make connections and don't ever raise your voice.

The following give you some more tips for different situations:

People with autism may fixate on certain activities, words, songs or objects. The fixation isn't a random, senseless act, but an attempt to compensate or adapt to their inability to effectively connect meaning to others' words or actions.

Try to introduce new things, people, or places gradually by talking about them first. For example, you can 'walk through' a visit to the dentist before it happens to identify people and items or to 'watch' another person's (mom, sibling) exam. You can also use pictures or other graphics to represent the new experience. Do the things you'd normally do to comfort a typical child, only do more of them. The familiar is comforting, and people with autism need more comfort for their jangled nerves.

Be sure to repeat simple questions you pose and remain patient. Many people with autism have slowed processing speeds, so you shouldn't expect immediate responses. Many people with autism also have trouble accessing their long-term memories; they can store the information they learn, but they can't recall facts in new situations when needed. Use simple, concrete, stripped-down language when giving directions without introducing extra information that can slow down the processing of a person with autism.

Try to teach new information to your child—even social skills, which Asperger children need help with—through scripts or 'social stories' that break down a process into easily remembered steps. For example, you can break down the process of getting ready in the morning into a series of steps, beginning with brushing your teeth and washing your face and ending with putting on your coat.

The person with autism can learn steps much easier if he or she can see them in pictures. Books are available with illustrated scripts for many common activities, or you can create your own social stories at home.

Bridging the communication Gap

Research conducted on families shows that language and communication deficits are the most serious and stressful aspects of autism. Communicating successfully is a major challenge people with autism face. Their ability to communicate dramatically affects how well they interact socially in a non-autistic world. Many people with autism lack the skill to even request a glass of water or to ask that the volume of a television set be turned down. Without the ability to communicate effectively, life becomes an exercise in frustration, tension and anxiety.

Because most persons with autism tend to have strong visual skills, a number of tools have been developed to help with communication and social interaction. In the pages that follow, we explain how you can work toward meaningful communication, implement technologies that can help with communication and use music as a tool for communicating.

Developing sign language as a communication bridge.

For children with autism with significantly delayed verbal skills, early introduction of sign language training can be important in developing functional communication skills. The development of signing skills can also, in some cases, be an effective bridge toward developing verbal skills. In low-functioning children, sign language can be the foundation of functional communication.

One common myth is that teaching sign language to a child with autism or encouraging the use of pictures will delay development in expressive verbal communication. However, many leading experts believe that introducing these modes of communication will, in fact, speed up the speech development for the children. At the very least, if a child can never gain verbal fluency, he or she will have some form of functional communication.

To determine the appropriateness of introducing sign language at an early age, consult with a speech and language therapist who's acquainted with training children on the spectrum.

Working toward functional communication.

People with autism can excel at data collection—gathering facts and figures like little computers. However, in an educational program, you want to include life-skill building that goes beyond data collection. The child should be able to use the data he collects, and the life skills you build should be able to use the data that he collects, and the life skills you build should be meaningful and have purpose in the real world. In other words, you want to practice functional communication. For example, a child should be able to do math, of course, but he also needs to apply the math he's learning to the world so that he knows how to use math to make change when shopping in a store, for instance. Often, even children on the lowest end of the autism spectrum have the potential to develop basic communicating skills that allow them to communicate their most basic needs to others.

A mistake parents make too often with programmed instruction is to focus on academic gains; they miss out on meaningful, functional communication. This result in children who can shoot through all the exercises in their programs with flying colours but can't ask for what they want to eat.



Children who are allowed to play video games for hours or watch television endlessly will disengage from the real world because their brains don't get enough stimulation. This troublesome fact is true for children with autism. So, you should pack your child's day full of meaningful interactions that keep his mind engaged with the world, not stimming or tuning out for long periods. Here are some ways you can promote engagement and connection (in other words, functional communication):

Turn off the TV after one video or program, and limit video games to one hour a day.

Talk to your child often, even if he or she doesn't seem to respond. Many people with autism have delayed sensory processing, meaning they may not respond immediately or even be able to respond, but they can understand what's happening. Like anyone else, people with autism don't like being ignored.

Encourage areas of talent, like drawing or computer programming. A common mistake is to focus on weaknesses to the exclusion of strengths.

Try to channel your child's passions or fixations, such as a love for trains or collecting, into something constructive. Kathy Grant, a high functioning person with autism, has turned her interest in maps (she collects maps, flags and items with foreign writing) into a vocation of traveling and writing about her experiences. She has a degree in political science and has visited Australia and Portugal, among other places.

Using assistive communication technology

Assistive technology is any device used to increase, maintain, or otherwise improve the capabilities of a person—whether the person has autism or not. Experts have created assistive technologies such as interactive language boards, visual schedules, and computerised communication systems to help people with autism—particularly those undergoing speech therapy—to communicate more readily while they work on improving their speech capabilities.

Most people use assistive technology; you just don't usually call the tools by that name. Day planners, PDAs, and shopping lists are the primarily text based equivalents of visual schedules. (People on the autism spectrum and otherwise who have difficulty processing text are usually helped by graphically based visual schedules using low, medium, or high technology to help remember routines, expected behaviors, and to organise their lives). E-mail, text messages, and instant messengers are computerized communication systems. Restaurant menus are interactive language boards.

Not all assistive technology devices relate to communication; the communication devices just stand out. Other common types of assistive devices include eyeglasses and hearing aids. Many of the assistive devices used by people with challenges are commonly employed by the majority of society and shouldn't necessarily be considered "special". Assistive technology has provided many new tools for autistic individuals to communicate visually, which can be their strongest sense. Some parents fear that these methods may hinder children from using spoken language, but researchers have no evidence to support this. If anything, helping children build communication skills lays the ground work for spoken language.

How does using a visual system help a child to learn language?

Understanding and performing nonverbal communication, such as gesturing and pointing, is a first step toward understanding verbal language for all humans. Using a keyboard to communicate doesn't stand in the way of talking; it helps language concepts form and develop so that a child can speak later when he's ready.

Research suggests that assistive technology positively effects reading and language skills. Some students have demonstrated greater frequency of spontaneous verbal utterances when a computer produced synthetic speech during learning tasks. Nonverbal people with autism also showed a reduction of challenging behaviors as their expressive communication abilities increased.

You often have many ways to skin the proverbial assistive-technology cat. For example, a person with fine motor control challenges may be helped by simply pointing to and moving Mayer Johnson pictures affixed to a piece of stiff cardboard. Others may find help in using magnetic cards that contain pre-recorded text with a Language Master. For another person, it may be easier to carry around a Dyna Vox or laptop with a touch screen to point at enlarged pictures that the machine verbalizes. It depends on the eh requirements of the person.

Furthermore, assistive technology isn't a cure-all answer. To have the greatest benefit for the child, proper training and support are necessary for integrating assistive technology into learning curriculum. Research suggests that teaching strategies for educators work best when they include a combination of workshops, modeling, practice in simulated and real settings, feedback about performance, and coaching during actual practice.

Taken from Understanding Autism for Dummies

Stephen M. Shore, MA

ISBN: 0-7645-2547-6



Thursday, 24th May 2007

A personal account written by James Pendlebury

It started on Tuesday. Well, actually, it started before that. The shortage of staff, the high pressure at work – that went back a while. So did everything else that was bothering me: like most people, I have quite a few worries.

But it was on Tuesday that Pat Lucas (our revise sub) first announced her intention to bring mulled wine to drink after work on Thursday (end of the week), and then called on the rest of us to bring snacks. Good idea, you might think. Some relief after all the stress – and the mulled wine fitted well with the cold weather. Thaw out a bit. That was the intention, and I suppose that was what it meant for most of us. But not for me.

I didn't think about it much at first. When the thing about snacks was raised, it struck me for a moment: What the hell am I going to do about this? But I went back to whatever else I was thinking about. Probably it was the work I was doing. Could have been that even if work was finished: it stays in my head for a while. The autistic brain is like that. We don't shift focus easily. And Thursday night's party was way down the list of priorities. That's part of the reason why I didn't initiate discussion with anyone on who was going to bring what. Other reasons as well: who would I have started talking to? And even if I had decided on that, actually starting to talk would have been difficult. It always is, and so much more so at the office, where there's always a lot to do and almost always a big rush. Starting any discussion takes time.

Not very big things, you might think. Surely I could get round all this? But that's my life.

It came back to me on Wednesday night. There had been some reminders. So it was

one of the things that disturbed my sleep (usually there's something or other). What snacks to bring? Not a difficult question, you might think. But I don't recall ever buying stuff for snacks like this before. There's the whole process of choosing...

Still, I thought I was doing pretty well. It came to me on Thursday morning: cheese is supposed to go well with wine. Some Camembert and/or Brie should go down well. And since I had to do the shopping anyway, might as well fit that in.

But when I was in Checkers it got rough again. I was looking at the Camembert and Brie and realised I'd never got such things for myself before. I knew there was this issue about the date. These cheeses go through this maturing process and (bearing in mind differences in individual taste) they're best eaten when they're pretty mature. In the past I'd seen dates on the boxes saying "Maturing process starts from..." I have some recollection that you give it some time (a week? two weeks?) after that date ... But there wasn't any such date on these boxes – not that I could see. Maybe all the noise and bright light in the shop was messing up my visual processing, but I don't really think that was it ... I couldn't see it. On some of them I could see best before dates, but they were quite a few weeks in the future, and I don't know how long before the best before date is a good time to eat it... There were quite a few different brands... So I gave up on the camembert and got quite a few Babybels.

Then the next thought came. What about biscuits? Savoury biscuits, of course. The kind that goes with cheese. Crackers or something. Why not? Until I got to the shelf. Why are there so many different kinds of biscuits? I never thought there could possibly be so many kinds. I couldn't even count them. How even to start? I can handle shopping if I know what I want and what the options are, but like this ... Just too much. I found some chocolates. Got lucky there.

I could ask, you might think. But ask what? Ask who? How many shop assistants know how to determine the maturing dates of camembert? And what kind of help can I ask for in choosing from three thousand five hundred and seventy-two brands of savoury biscuits without that much difference between them? I can't pretend all this went through my head. It never occurred to me. It wasn't a live option. Even if it had occurred to me, it would have been too hard. Initiating communication is difficult enough with people I know, in an easy environment, when I'm not particularly stressed and know what I want to say.

You might also say: it doesn't matter if you get it wrong. Just try anything. But it doesn't work like that. "Try anything" is the worst possible method for me. I need something to propel me to a choice. I need some sense of what I want. Especially under pressure. Imagine trying to do a backward somersault if you didn't even know what it looked like, let alone what the moves were.

(It's a lot easier when I go in knowing what I want and where to find it. That, together with the taste sensitivity that limits what I can eat, is why I buy a very narrow range of foods.)

I couldn't get it out of my head. That's the usual thing. First I couldn't get it in, then I couldn't get it out. The difficulty in shifting focus. So I was still pretty tense when I got into the mini-bus taxi to go to work.

And still tense when I got out to walk from the Bree Street taxi rank to 47 Sauer. The street is never quite the easiest thing. All those people and all that noise. It isn't usually the hardest thing either ... but this time I wasn't all that well co-ordinated. Probably swaying around a bit. Not surprising, perhaps, that when I tried to walk past these two guys I brushed against one



Thursday, 24th May 2007

A personal account written by

James Pendlebury continued

of them.

A couple of biggish, youngish, rather tough-looking guys. I don't know what I did. I can't recall if I forgot to apologise or if I tried and the words didn't come out. It's like that sometimes. He turned around and came after me. I couldn't read what he was at. I never can – certainly not with strangers. He said I should have apologized. I apologized. There was some kind of further exchange – something to the effect that he was letting me off the hook because I'm white – he got up close to me – I just had no way of knowing. Maybe it wasn't even unfriendly at all ... But I had to move.

Scary for anyone, of course. I wouldn't even say it was more so for me. But being autistic does make me a little more likely to land up in that sort of mess...couldn't tell anyone. I had to see Michael Schmidt anyway. He could see I was freaked out. I told him I'd had a bit of a shock, but I couldn't tell the whole story. The usual questions. Where to start? Starting is always complicated and difficult. There was no way of knowing what to say. Being able to say at all that I had had a shock was better than I usually do. I couldn't get further – not with Michael and not with Philippa at BR. It was clear I had to go home. Michael gave me a ride home, but I still couldn't tell him. I couldn't even tell my mother when I called her an hour or two later. It's hard on the phone. Maybe with some prompting I could have – I often need prompting to get started – but it didn't come. When I saw her in the evening I could tell her. And I've been talking to my mom about this stressful stuff for years and years. She understands as well as anyone. It still took hours before I could tell her.

I won't say all my life is like this. It isn't. It's not like every day there's one thing that totally freaks me out, let alone two things. But there's always the potential. It can be anything. Completely ordinary everyday stuff. All kinds of things push me close to the edge – and once I'm there, it's helluva difficult to stop thinking about it.

And no, I don't want to change it. Not really. Okay, I don't like it that dealing with people and shopping and walking in the street can be so stressful and risky. But holding a single focus is a big advantage – actually, that's what my life is made of. The cost of that is the difficulty in shifting focus. Not being tuned into people also has advantages. Lots of difficulties, of course – but I feel that it frees me from the drive to conformity and lets me go my own way. That's who I am. Some things might be improved, but I don't really want to change it.

Some references that may be useful:

Pendlebury, "Communication, Understanding and Autism: in Search of Common Ground". The paper I presented at the World Autism Congress in October 2006. Available on request.

www.autistics.org. Of particular relevance is Sullivan, "Inertia: from Theory to Praxis", <http://www.autistics.org/library/inertia.html>.

Kalen, "Dispelling some myths about autism", UK National Autistic Society, <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=120&a=2202>.

I can give lots of other pointers: these are just to start with. Lots of autistics have lots to say about our lives, and most of it is illuminating in one way or another – though of course all of us are different, and what one person says may not apply for others.

			7	5				
		8	1			5		
	7			6			3	4
						6	9	
4		5				3		2
	9	7						
7	2			3			4	
		3			7	9		
				2	4			

SUDOKU



Beyond the Wall

Personal Experiences with Autism and
Asperger Syndrome

ISBN: 1-931282-19-6

Advance Reviews of Beyond the wall

'A surprisingly warm journey into the psyche of an 'Aspie'. The reader is led on a wonderful excursion showing how personal courage and persistence mixed with an encouraging and unyielding family has allowed Stephen Shore to successfully deal with significant brain differences that are called Asperger Syndrome. His openness is refreshing and his love of music to contact and relate to himself and other 'Aspies' is remarkable. This is an invaluable guide and statement of hope for 'Aspies' and people who love them.

Stephen Shore was diagnosed with 'atypical development with strong autistic tendencies' and nonverbal until age four, Stephen Shore was viewed as 'too sick' to be treated on an outpatient basis. Stephen Shore is now completing his doctoral degree in special education at Boston University with a focus on helping people on the autism spectrum develop their capacities to the fullest extent possible.

www.autismasperger.net

I was quite fond of taking long soaks in the bathtub. Often, my requests to take a bath were turned down because they took too much time. I would argue with my parents that the 30 or so minutes they allocated for my bath were not enough. Soaking and playing in a tub of warm, soapy water was very relaxing.

I was afraid of dogs because of their relatively unpredictable habits of barking and licking my face. Kittens, however, were quiet didn't make loud noises and never slobbered my face. Often I would pretend to be a kitten whenever a bunch of children

got together to play house. I remember going with my parents to pick up a puppy from a farm where they were giving away a puppy. I vehemently proclaimed that he was 'their dog' not 'my dog', and was not enthusiastic about bringing the dog home. His name was Kippy because my brother could not pronounce the name 'Skippy' which my parents had originally planned for the dog. Gradually, Kippy and I became friends and I learned not to fear dogs, which was my parents' original intent in getting one.

Thunderstorms, the moon, and fireworks all produced fear. The flash of lightening along with the accompanying thunder was too much of a sensory overload. One year when my family went to a fireworks display, we sat close to the front. I had a good time running around and watching my sister dance to rock and roll music until the fireworks began. I was terrified of the sound and feared that the display produced by the rockets would float down and burn us. Assurance by mother that I wouldn't get hurt wasn't good enough. We finally left the lawn and watched the rest of the show from the car. The next year we watched the fireworks from an even safer distance—at home through a bedroom window.

Some time during my primary school days I somehow lost the fear of fireworks and thunderstorms and, now, I actually enjoy them. Perhaps this was a result of my increasing ability to admit less predictable events into my world.

Until the age of five or six, I couldn't stand anything wet lingering on my face or hands. As result, my face and hands had to be wiped with a napkin after every bite. Messy food was intolerable. A breakthrough occurred when I made a royal mess of myself eating barbecued chicken wings followed by a huge piece of watermelon. My mother never thought she'd be so happy to see such a messy kid. Perhaps the pleasure of eating the tasty food overwhelmed the sensory overload of bits of food remaining on my face.

But other food issues existed too. Brown or black food wouldn't be eaten as I insisted that they were poisonous. Canned asparagus was intolerable due to its slimy

texture, and I didn't eat tomatoes for a year after a cherry tomato had burst in my mouth while I was eating it. The sensory stimulation of having that small piece of fruit explode in my mouth was too much to bear and I was not going to take any chances of that happening again.

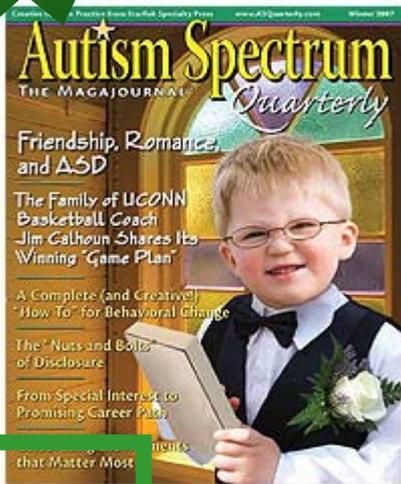
Carrots in a green salad and celery in tuna fish salad are still intolerable to me because the contrast in texture between carrots and celery or tuna fish is too great. However, I enjoy eating celery and baby carrots by themselves. Often as a child, less now, I would eat things serially, finishing one item on the plate before going on to the next. Issues with uneven sensory input extended to other activities too. One of these activities was learning to ride a bicycle. I had difficulty learning to ride on the street, so my parents put me and the bicycle on the grass in the front yard. Probably they felt I was afraid of getting hurt from falling. It worked. I could now ride on the grass but not the street. The bumpiness of the lawn may have forced me to be more aware of my body, which in turn enabled me to keep balanced on the bicycle. By six years of age, I had learned to ride on smooth pavement. Bicycles eventually became one of my many special interests. I have always liked climbing trees. I was especially fond of a maple tree in our yard that I would climb to the height of the second story window and sit there for extended periods of time. Often I climbed a particularly tall tree in my neighbourhood to the height of about 40 feet, where the trunk was about 2 inches thick. Hanging on, I would look down on the tops of the telephone posts as the tree and I swayed in an arc of 7 to 10 feet. Although I knew the top wouldn't break off, I would remain there swinging, utterly terrified. It made me feel more aware of myself in relating to the space around me. My brother sometimes joined me in climbing that tree.



Autism Spectrum Quarterly Magazine (ASQ)



R 200
SUBSCRIPTION PER
YEAR FOR FOUR COPIES



Only R 50
per copy
including
postage

Autism South Africa is a local distributor for a wonderful magazine from America called Autism Spectrum Quarterly.

Included in every issue of *Autism Spectrum Quarterly*

Articles by, for, and about individuals with ASD

A focus on families and family issues

Book and product reviews and recommended resources

Contributions by outstanding professionals in the ASD field

Spotlight on Best Practices to highlight an educator, clinician, or paraprofessional support person whose work on behalf of those with ASD has been exemplary

Tips and strategies to translate research into practice

User-friendly, cutting-edge information from the world of research.

And so much more!

Due to the financial implications, we will need potential South African subscribers to sign up, commit and pay up front for the period of a year for which you will receive four copies. Should you wish to subscribe for the ASQ Magazine please complete the form below and fax it to 011-484-3171 along with your deposit slip.

Phone: 011-484-9909

Fax: 011-484-3171

E-mail:

pauline@autismsouthafrica.org

Banking Details
Autism South Africa
Standard Bank
Sandton Branch
Branch code: 019205
Acc. No. 2207 312 33

Name: _____

Postal Address: _____

Phone _____

Fax _____

Email Address _____

Signature _____



By Rebecca Morelle
Science reporter, BBC News, York

High levels of a male sex hormone in foetuses are linked to a higher chance of developing autistic traits in childhood, scientists say.

The findings come from an eight-year study relating the development of 253 children to levels of testosterone they were exposed to in the womb.

The scientists said it was unclear whether the hormone was causing the traits or was a by-product of them.

autistic traits have been linked to levels of foetal testosterone
Simon Baron-Cohen

The research was presented at the BA Festival of Science in York.

The research team, from the University of Cambridge, looked at levels of foetal testosterone in the womb by examining samples taken from women undergoing amniocentesis for clinical reasons.

The children were then followed during their development.

At 12 months, 18 months and 46 months, the scientists used tests to spot autism-like traits, such as counting how often a child looked at its mother's face or how large its vocabulary was.

At these early stages, the team found a link between the traits and higher foetal testosterone levels.

But the scientists' latest research results came from a study undertaken when the children were eight years old.

The children's mothers filled in a questionnaire called the autism spectrum quotient. This is designed to test the number of autistic traits a child has by examining factors such as social interest and pattern recognition.

Typical questions included whether the child preferred social activities like parties or spending time alone, or whether he or she was quick at picking up numerical patterns, like remembering number plates or phone numbers.

The results were then compared with the pre-natal testosterone levels, which had a 20-fold variation, between 0.1 to 2.05 nanomoles per litre.

Bonnie Auyeng, who carried out the study, said: "The correlation is not perfect, but foetal testosterone will account for about 20% of the variability in [questionnaire] scores. Although this doesn't sound like a very high number, it is statistically significant."

Extreme male brain

Professor Simon Baron-Cohen, who was also involved in the study, said: "This is the first time autistic traits have been linked to levels of foetal testosterone, measured in the womb using amniocenteses."

Animal research has previously linked brain development to foetal testosterone levels, and some believe the hormone may play a causal role in autism.

However, the scientists stressed that the study only showed a link between autistic traits and the hormone, rather than a direct link to autism itself.

Dr Auyeng said: "We're still in the early stages of figuring out what actual role foetal testosterone plays. We don't know if it is causing autistic traits, if it is a by-product of them, or an indication of various interactions."

"We are just not sure yet."

Scientists currently do not know what causes elevated levels of foetal testosterone. Professor Baron-Cohen said previous research suggested that it could be a mixture of genetic and environmental factors.

He said that the hormone could be affecting the brain through altering neural cell connectivity and chemicals that carry messages, known as neurotransmitters.

The team is now planning to follow up their study to test direct links between autism and testosterone levels in foetuses. They will use Denmark's archive of 90,000 amniocentesis samples and its register of psychiatric diagnoses.

The work is connected to Professor Baron-Cohen's hypothesis suggesting that autism is a version of the extreme male brain.

He said that although researchers had tested this theory at the psychological level, the new studies meant it could now be tested at the biological level.



DIETARY INTERVENTIONS—Taken from Facing Autism

ISBN: 1-57856-262-7

WHAT ABOUT EATING OUT

It is not easy, but it is possible. We still go to McDonald's, but we order the hamburger patty in a box without the bun, having brought our own bun from home. French fries are usually all right as long as the restaurants don't coat the potatoes in wheat flour or fry them in the same oil they use for breaded foods. For safety's sake, as the manager of the restaurant.

Salads are okay, but leave off the croutons, cheese, and most salad dressings. Read the package closely to see if it's acceptable. Most hot dogs are free of gluten and casein, but they're full of nitrates and other additives and may have fillers that contain gluten. Broiled chicken and fish are good choices, but stay away from breaded or marinated entrees. Plain vegetables, baked potatoes and rice provide good side dishes, but if you are removing all butter, you'll need to verify that the restaurant used no butter in preparing them. Be sure to stay away from pasta and sandwiches. When we travel, we've learned where we can eat and what we can order. We also go prepared with additional food in our suitcase. If you're careful, you need not be trapped at home because of a special diet.

WHAT ABOUT THE REST OF THE FAMILY

You have to decide if your whole family will follow this new diet or just your child with autism. To a large extent our whole family follows the diet, but we eat certain foods that Ryan doesn't like anyway. Since our daughter eats yogurt and Ryan doesn't, we still buy regular yogurt. Ryan loves ice cream, so we buy only a nondairy ice cream replacement. Recently we got an ice-cream maker so we can make ice cream at home with our potato milk. Sorbet is also nice and easy to make, but Ryan refuses anything with fruit in it.

If your whole family doesn't follow the diet, be careful that your child doesn't get into the forbidden foods and isn't given any by a baby-sitter or relative. And don't overlook subtle things, like allowing crumbs of wheat bread to accidentally mix with his FG/CF bread if you share a cutting board.

'Calendar and

"Just to let you know"

It takes a very long time and incurs significant costs to send out information to the ever expanding database of Autism South Africa. May we therefore take the liberty of asking you to please check the web page (www.autismsouthafrica.org) on a regular basis?

Please ensure you visit the section **"Just to let you know"** as well as regularly checking the **calendar** that has been placed on the web page – these two areas will keep you to update on latest events and articles of interest that we have received.

We sincerely thank you for cooperation and hope that you will benefit from regular visits to our web page.

JOHANNESBURG SUPPORT GROUP

I am a parent of a six-year old gorgeous girl, Caitlin who is diagnosed with Autism.

I would like to get together with other parents whose children have been diagnosed with autism. I may be where you are today, or you may have already walked the road I am on and it would be wonderful to be able to share experiences, give and receive guidance, but above all, know that we are not alone as parents of children with autism.

My contact details are as follows:

Mobile: Abigail—073-605-2089

Or 011—764-5702



Book / DVD Corner

If you would
like to order any
of the books
listed in
the Book Corner,
please
contact
Pauline
on 011-484-9909 or
email
pauline@autismsouthafrica.org



The Eighth Colour
of the Rainbow

Publisher:

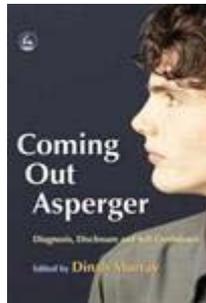
Jessica Kingsley

Written by

Florica Stone

Price:R 306.95

Through her questioning of traditional approaches regarding autism, and with determination and patience, Florica Stone has been able to develop a satisfying and supportive two-way channel of communication with her autistic son. In *Autism - The Eighth Colour of the Rainbow* Florica shows how shared meanings can be learnt and expressed between autistic and non-autistic individuals, though they experience radically different perceptions of reality. Through interacting with and listening to her autistic friends and son, she began to understand the autistic learning style and to decipher the various behavioural needs that arise from their particular sensory processing. In this inspiring, much-needed practical guide she presents ways of creating autistic-friendly environments, modifying habitual or traditional responses to autistic behaviour, using forms of literal learning, and provides many useful examples and exercises. This book will help parents, teachers and professionals to learn how to interact positively with autistic children and bring about long-lasting changes.



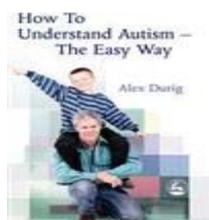
Coming Out
Asperger

Publisher: Jessica
Kingsley

Written by: Edited
by Dinah Murray

Price:R 238.55

Coming Out Asperger explores the complexity of diagnosis for Asperger Syndrome, the drawbacks and benefits of disclosing a diagnosis of a "hidden disability," and how this impinges on self-esteem. The contributors include some of the best-known and most exciting writers in the field of Asperger Syndrome (AS) today, and include individuals on the autism spectrum, parents and professionals. The broad range of the chapters, which draw on anecdotal, professional and research-based evidence, make this book a comprehensive and highly original consideration of the implications of an AS diagnosis. The ever-difficult question of who to tell and when once a diagnosis has been confirmed is discussed in great depth. Liane Holliday Willey and Stephen Shore examine the dynamics of disclosure, its risks and the possible effect on self-confidence. Jacqui Jackson looks at how a diagnosis impacts upon family life. Tony Attwood provides a clinician's view of diagnosing adults, and Lynne Moxon, Wendy Lawson, Dora Georgiou and Jane Meyerding discuss adult issues surrounding disclosure, including how to deal with relationships and sexuality, and disclosure in the workplace, as well as social and disability issues. A unique and fascinating insight into the important issue of diagnosis disclosure, this book is an essential guide for people with AS, parents, teachers, professionals and all those who have ever felt confused about revealing a personal issue.



How to Under-
stand Autism—
The Easy Way

Publisher: Jessica
Kingsley

Written
by: Alexander

Price:R 221.45

In this clear and accessible introduction to autism, Alexander Durig provides a host of ideas and examples that enable the reader to understand the phenomenon of autism, recognize different kinds of autistic perception and behaviour, and prepare for interaction with autistic people. To help 'normal' people understand and lose their fear of autism, Durig discusses the notions of 'slight' autism, being or becoming 'autism-friendly', and the mental well-being of autistic people. The author explains how autistic perception 'works' and how it yields autistic behaviours', to enable readers to see the world through the eyes of an autistic person, and thus change the way they perceive autism.



Some of the Books available from the Library at the Outreach Resource Centre at Autism South Africa

A mind of ones own
A miracle in the making
A miracle in the making
A parents guide to Asperger Syndrome and high functioning Au-tism
A parents guide to Autism
All Cats have asperger syndrome
Approaches to autism
ASA's 37th National Conference
Ask and Tell - SELF ADVOCACY and Disclosure
Asperger Syndrome A guide for parents and professionals
Asperger Syndrome and Adolescence; Practice
Asperger Syndrome and Difficult Moments
Asperger Syndrome and Sensory Issues: Practice
Asperger Syndrome and the Elementary School Experience
Asperger Syndrome and the Elementary School Experience
Autism - An Inside out Approach
Autism - Whats for Dinner
Autism An Inside-Out Approach
Autism and Asperger Syndrome preparing for adulthood
Autism and creativity
Autism and Personality
Autism and severe learning difficulites
Autism and the school aged child
Autism as a metabolic Disorder
Autism diagnosis and after
Autism for Dummies
Autism From theoretical understanding to educational intervention
Autism from within
Autism Has Many faces
Autism in the School - Aged Child
Autism Medical and educational aspects
Autism Meeting the needs of an individual
Autism Society of America - Revealing our Placement on the Au-tism Spectrum
Autism through the lifespan
Autism, Play and Social Interaction
Behavioural Concerns and Autistic Spectrum Disorders
Beyond the Wall; Personal Experiences
Biological Treatments for Autism and PDD
Blue Bottle Mystery
Building Social Relationships
Child development & Teaching pupils with Special Educational Needs
Children in difficulty
Children with Autism Spectrum Disorders
Commonsense methods for children with Special education needs
Constructing Autism
Cure Autism Now Advances
Developing a good Autism Programme Autism Society of Kenya
Developing Talents
Disability for Professionals
Disability Rights Wrong
Educating children with Fragile X Syndrome

Enzymes The Fountain of Life
Establishing Long Term Goals
Exiting Nirvana
Facing Autism
Finding our way
Leading Inter-professional Teams in Health and Social Care
Learn to Move and Move to Learn
Making it a success - Practical Strategies and Worksheets for teaching students with Autism Spectrum Disorder
Making Visual Supports Work
Managing Care in Context
Managing Care in Pracrice
Managing in Health and Social Care
Mental health issues and the media
Mixed Blessings
MMR and Autism
Mothering
Multiplex Development Disorder
Mum, is that a human being or an animal
My Best Friend Will
My book full of feelings
My Book Full of Feelings ; How to control ..
Pathways to Play
Peer Play and the Autism Spectrum
Peer play and the Autism SpectrumL The art..
Planning for Life
Power Cards; Using special interests
Practical Solutions to Everyday Challenges
Pre-Schoolers with Autism
Pre-Schoolers with Autism - for parents
Problem Girls
Sensory Perceptual issues in autism and asperger syndrome
Simple Strategies that Work
Social Skills traing for children and adolescence
SOS Social Skills in our schools
Space Travelers An interactive Program for Developing Social Understanding,
Space Travelers Student Manual
Super Skills
The Autism Experience
The child in mind
The complete guide to Asperger Syndrom
The Handbook of Autism
The Hidden Curriculum
The Incredible 5-point scale
The Managing Care reader
The power of excile
This is Asperger Syndrome
Toilet Training
Toward New Diagnostic System for Child Psychopathology
Understanding special educational needs
What about me
When my worries get too big



Sibling Corner



AUTISM

My brother was, is and will forever be Autistic.
 His mind is somewhat of a separate entity
 To his body; a tool only called upon to rationalise
 With the truth.

If you tell me to jump, I say, "how high?"
 If you tell him to jump, he does it and asks why.

A simple command like this is critically analysed
 By the complex system of crossed wires in his head,
 Maybe that's the problem? His wires are crossed!
 No, there's no cure because there's no problem to be found.
 It's true, "the research shows no chemical imbalance...
 No head injuries...
 No ...
 ...Problems."

Richard is also Autistic, like my brother.
 He is in his class; 'The Senior Autistic Class'
 "Rich, look at me when I speak to you"

I wonder what it must be like in his head.
 Vaults of information, variations of every detail
 That he records when he studies your face
 And not your words.
 Alas, of all these vaults he has lost most keys.

Some say if you treat them normal,
 They will become normal.
 If you treat a bonsai normal;
 Give it all the water a real tree needs,
 And plant it out in a field
 It would die,
 As would a child with Autism Spectrum Disorder.

Stuart has a mind like you and me
 Except he acts out all the memories,
 Visions, dreams and imitations
 That lie dormant for future reference,
 In a library of confusion
 That he is too scared to enter at most times.
 You try it; act out everything that you think,
 Every thought and image that you conjure.
 Then you are one step closer to becoming
 Autistic.

Written by Kyle Pratt.



Teenage Sibling Corner

Advice from Adult Siblings to Teenage Siblings—Taken from <http://www.wikihow.com>

...I'd encourage them to do whatever they can to promote good experiences with their sibling. It's not always easy, it takes work sometimes to "connect" with them.

...Don't feel a huge sense of responsibility. Live your life the way you feel you should. I'm glad to be independent, yet there is a part of me that feels I should be more in his life. And there's another part of me that knows I really don't want that.

...Keep it in perspective. No blame to anyone. Take care of yourself and your needs so as to stay strong and CLEARLY realistic for your sibling and those around you.

...Join a peer support group. Learn everything you can about the disorder.

...I would tell them to be patient and spend large amounts of time trying to connect with their sibling.

...Try and learn more about your sibling. Find out what he/she likes and how you can spend more time with them. Also, understand that people with autism have a hard time relating to other people. Lastly, laugh! Because if you focus only on the negative, you'll never respect/understand your sibling.

...Have open communication. If not with your family, then with professionals. Talking about fears, anxieties, etc., helps, rather than retreating into embarrassment or denial.

...Love your brother or sister—be there for your parents—understand why they do negative or positive behavior and realize they are not DOING IT TO you, only to express themselves with the way they can.

...Don't take things too serious. Try to be positive about things and involved in things as do other people. Try to treat your sibling as "normal" as possible. He/she needs attention just as does everyone else.

...It is difficult to grow up with a sibling who naturally required more attention—try not to limit yourself because of your family situation, i.e.-going away to college. Your family may be reliant on you somewhat to help care for sibling—but try not to forfeit life experiences.

...Don't regard your relationship with your autistic sibling as negative, or weird, or impossible. It can really be a unique learning experience. The more you get to know him/her, the more he/she will give you. The older you get, the easier it will get. I think that is, until your parents aren't able to provide/handle decisions regarding his/her care anymore. Try to bond with your brother/sister sooner than later. Don't pretend he/she doesn't exist because he/she will always be a part of your life in one way or another.

...Don't ever feel embarrassed! Your sibling is a human being with thoughts and emotions and is not trying to embarrass you. Have compassion and be proud of who you both are. It can be a confidence building experience. Other people are probably not judging you, even if they are ignorant of your sibling's situation.

...Develop your own peer group and pursue your own interests. Find a way to express your feelings, especially if your family cannot cope with your needs on top of your autistic sibling. Plan for an adult life where you can be an advocate and support person for your sibling without sacrificing your well-being.

...Hang in there. Things can get better. Remember that your sibling with autism has as much right to life, happiness and your parents' time as you do.

...Your brother or sister is more like you than different than you. He/she needs love, even though it's hard to try to stick by your brother or sister. If you were the one with autism, would you want to be alone? Find positives in your relationship and remember that you need to talk about it with someone- don't keep your feelings inside.

...Live your life to the fullest and appreciate the opportunities that you have that your sibling does not. Stand beside your sibling at all times. Support him/her and love your brother or sister. You will need to find a delicate balance in managing your life and your sibling's life. Lean on other family members and let them lean on you. Take time to be fully a part of your sibling's life. Know that you play a critical role in their future. Don't be held back, because of it. But know that family is always the priority.

...I would have to tell them don't be afraid of what you can teach them, or show them. Also, any of your prize possessions, keep out of their reach.



HOW TO COPE WITH A SIBLING WITH AUTISM

Taken from

<http://www.wikihow.com/Deal-With-an-Autistic-Sibling>

If you are reading this, then you probably have a sibling who is autistic. Often, autistic children can get on someone's nerves with their actions, and so this how-to has been created to help those who have trouble with this.

Learn about autism If you just found out your sibling has autism, you should first take a few weeks to get used to that fact. Research what autism is and visit web sites that can tell you how to cope.

Talking to them. Now that you're used to it, you have to deal with it. In severe cases, people with autism sound like they're speaking gibberish, BUT they are not stupid. Talk to them as if they were a friend. If your sibling is high-functioning, then it will be easier for you to talk with them. Do not yell or shout at them. Also, do not speak to them as if they were babies, this will hurt their feelings.

Spending time with them. Do what they want you to do, even if it sounds ridiculous or embarrassing. Never, ever let them do something that could hurt them or anyone else. However, this is your sibling, just go with the flow. If your friends find out and ask what you're doing, you might have to tell them that your sibling has autism. It also might help if you tell them a bit about autism.

Helping them with homework. Most children with autism have difficulty with homework and may require help from you. Speak in a gentle tone and don't rush. If they get frustrated and go into a fit, get an adult to calm them down. Explain things simply.

Getting along with them. Children with autism normally do awkward things like tell people they don't know the answer when they do. If you ask them a question that they don't answer when you know they do know, keep in mind that even scientists don't know everything about autism. For now, all you can do is try and calm them down. Solutions will vary from person to person.

Autistic behavior. When children and teenagers with autism get stressed, they often may act stranger than normal. The best you can do for them at these times is talk to them gently and be there for them. Your sibling with autism loves you, even if it is not noticeable. They do love you and need you.

Understand Your sibling didn't choose to have autism and you should treat them as you treat other children of their age. Children with autism may say inappropriate things, or things that aren't very tactful. They also may like to smell or feel some odd things. This is just another part of who your sibling is, and soon, you'll get used to it. Don't take what they say *too* seriously, they may just not understand when to be quiet or keep their opinions to themselves. Remember, because you are living with and caring for your sibling, it is making you a really great and strong person.

Be there for them. This is extremely important. If the kids at your school find out about your sibling's autism, no doubt they will tease them. Stick up for your sibling and if they cry comfort them. Treat them as you would treat your best friend.





10 THINGS EVERY CHILD WITH AUTISM WISHES YOU KNEW By Ellen Notbohm

(Every parent, teacher, social worker, therapist, and physician should have this succinct and informative book in their back pocket. Framed with both humour and compassion, the book defines the top ten characteristics that illuminate the minds and hearts of children with autism. Ellen's personal experiences as a parent, and autism columnist, and a contributor to numerous parenting magazines coalesce to create a guide for all who come in contact with a child on the autism spectrum.

Don't buy just one of this book – buy one for everyone who interacts with your child! **Give the gift of understanding!**



THIS IS A SHORT TRANSCRIPT TAKEN FROM THE BOOK TO OUTLINE THE TEN THINGS EVERY CHILD WITH AUTISM WISHES YOU KNEW.

WRITTEN THROUGH A CHILD'S EYES, IT SO BEAUTIFULLY DESCRIBES AND EXPLAINS THE IMPORTANT ISSUES EVERYONE HAS TO UNDERSTAND. EACH OF THE TEN THINGS ARE FURTHER DISCUSSED IN MORE DETAIL IN THE BOOK. EXPLAINING HOW THESE THINGS AFFECT THE CHILD. **GET THE BOOK!**



ONE

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 individualized by one trait? Are you 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 or 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 that I "can do it," my natural response will be: why try?

Everyone sets the bar at a different place, but it's dangerous business. Whether too low ("You don't think I can do it – why try?") or too high ("I'm never good enough – why try?"), should we force the child to travel the extra distance to meet what might be naive expectations? The road is long enough as it is. So run the word 'autistic' through your reality-checker and ask yourself if in any way limits your view of what the future holds for your child or student with autism and the value he brings to your world. If it does, remember that nothing – *nothing* – is predetermined and that your time together is filled with open-ended opportunity.



TWO

My Sensory perceptions are disordered

This means that ordinary sights, sounds, smells, tastes and touches of every day 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 one. 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 the line ahead of us has a poppy diaper, they're mopping up pickles on aisle three with ammonia – I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented, this may be my first sense to become over stimulated. 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 are too many items for me to be able to focus (I may compensate with "tunnel vision"), like glares from windows, moving fans on the ceiling, and so many bodies in constant motion. All this affects my vestibular (balance) and proprioceptive (position) senses, and now I can't even tell where my body is in space.



THREE

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

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, approach me and 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.

Do not shout, it hurts my ears and upsets me. Tell me calmly, do not overload my emotions.



FOUR

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, "Its pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me, "Its raining very hard."

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



FIVE

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 those 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, television, or the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just now that it gets me off the hook for coming up with a reply.



SIX

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

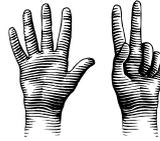
Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn.

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 a smooth transition between activities and 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.



SEVEN

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.



EIGHT

Help me with social interactions.

It may look like I don't want to play with 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, I might be 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 is funny. It's that I don't know the proper response. Teach me to ask, "Are you okay?"



NINE

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, and activities. A pattern may emerge.

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

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



TEN

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. It may be true that I'm not good at eye contact or conversation, but have you noticed the I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? It's also true that I probably won't be the next Michael Jordan. But with my attention to fine details and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They had autism, too.

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.

CHAPTER ONE...../

The book goes on to explain each one of these ten points in greater detail. There is very important information contained in it.



System spots autism in toddlers

Leigh Dayton, Science writer | *October 04, 2007*

CHILDREN as young as 14 months of age can be reliably diagnosed with autism, according to an Adelaide psychologist who has devised a tool to help experts detect the telltale signs of the lifelong disability.

Robyn Young, head of the Early Intervention Research Program at Flinders University, said the assessment tool could even be used to identify risk in children as young as 12 months.

Until now, there have not been widely available systems for accurately assessing autism because there are no biological markers or tests. People with the disorder have impaired social interaction, communication and imagination, and often engage in repetitive patterns of behaviour.

Associate Professor Young's system - called Autism Detection in Early Childhood - is the first method to assess 16 behaviors linked to the core brain deficits driving autism.

"I had two little ones, 12 and 14 months, this week," Professor Young said. Using ADEC, she found the older child had been misdiagnosed as autistic, while the younger was very likely to have the disorder.

According to Professor Young's colleague, psychologist Carrie Partington, very young children with autism spectrum disorders frequently displayed three types of behaviors: they didn't recognise their name, they didn't imitate adult facial expressions and they didn't switch their gaze.

"Most kids will look around the room to share their experience of, say, a new toy," she said. The inability to do that, "gaze switching", is a predictor of ASD.

The exact causes of autism remain unknown. One in every 160 children has the disorder or related conditions such as Asperger's syndrome, according to recent findings from the Australian Advisory Board on Autism Spectrum Disorders.

Using Centrelink data, the board found that 10,625 children aged six to 12 had an ASD.

It also found most Australian youngsters were not diagnosed until they were two or three.

That meant children missed out on early interventions known to improve their functioning, Mrs Partington said.

"Age at diagnosis is an important predictor of how well children will do," she said. "If we can get them early, we can make a lot more significant changes."

The type of intervention is also critical. Comparative international research has consistently indicated that the only effective evidence-based approaches are based on behaviour modification.

Such programs cost \$40,000 to \$60,000 a year for each child because they require 14 to 40 hours a week of one-on-one work. To overcome the cost barrier, Professor Young in 2003 established the EIRP, a research body aimed at making home-based therapy possible by providing information, training and services to parents or caregivers.

The EIRP has an eight- to 10-month waiting list for the program, which is free. It consists of a two-week clinic-based program for each autistic child and their parents, during which parents are trained to provide the therapy, and follow-up support for 18 months.

In a forthcoming report on the first 87 of 150 children and their families, Professor Young's team claim their approach works as well as conventional behavioural modification programs.

Taken from:

[/www.theaustralian.news.com.au/story/0,25197,22527952-23289,00.html](http://www.theaustralian.news.com.au/story/0,25197,22527952-23289,00.html)

USE YOUR ABSA CREDIT CARD TO HELP AUTISM SOUTH AFRICA!



If you bank with ABSA, you can apply for a "Rewards" Credit Card and you can then accumulate points as you use your credit card. These points are then "cashed" in purchase something from their extensive list of products.

The Rewards Company who manage this promotion have selected Autism South Africa as one of three beneficiaries to receive Rewards points that people would like to give to charity.

For those of you who bank with ABSA, please consider helping Autism South Africa through ensuring that you have a Rewards Credit Card and then if you do not want to utilise the points you accumulate, please consider donating them to Autism South Africa.

We use these points to purchase items such as printers, TVs etc for the schools around the country.

For more information on the ABSA Rewards system, please phone 0800 600 059 or visit their web page: www.absa.co.za

Thank you for your consideration.



Autism South Africa Database

We would like to keep our database running efficiently and to ensure that we are constantly in touch with you, please could you re-update your details below and fax it to 011-484-3171.

Tel: 011-484-9909

Fax: 011-484-3171

Email: pauline@autismsouthafrica.org

www.autismsouthafrica.org

PLEASE CHECK THAT MY DETAILS ON YOUR DATABASE IS CORRECT

Name:

Address:

Province and Postal code:

Country:

Email:

Tel:

Fax:



MEMBERSHIP/ DONATION

Name:

Address:

Province and Postal code:

Country:

Email:

Tel:

Fax:

I enclose my cheque/postal order /deposit slip made payable to: **Autism South Africa** for:

Individual Membership R 50

Family Membership R 60

Or I prefer to give:

Or donation of: R 100 R 200 R 500 Other amount R

Autism South Africa does not receive any government assistance and therefore your support will really be most appreciated and will facilitate the provision of desperately required services for those affected by autism in South Africa.

**BROCHURES
AVAILABLE
FROM
AUTISM
SOUTH AFRICA**

Autism South Africa
Standard Bank—Sandton Branch
Branch code: 019205
Account No: 2207 312 33

