

Aut-Talk



November
2006

NEWS LETTER FROM AUTISM SOUTH AFRICA—THE NATIONAL
BODY FOR PEOPLE WITH AUTISM SPECTRUM DISORDER IN
SOUTH AFRICA

10th EDITION

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WELCOME!

We would like to welcome a new team member to Autism South Africa!

Sandra Miller joined us on 1st October 2006 taking the post of Incoming National Director. We wish her every success and hope she will enjoy many years with Autism South Africa.

In 2003 Autism South Africa won the bid to host the 2nd World Congress on Autism in 2006. The event was opened on Monday, 30th October with a warm Capetonian welcome to over 900 delegates from over 50 countries. Pat Matthews, President of the World Autism Organisation, (WAO), highlighted key points of WAO's odyssey and focused on the essential rights of people with Autism.

Paul Pratt, Chairman of Autism South Africa, offered a local welcome from Autism South Africa.

The delegates enjoyed an outstanding and moving display of drumming and dancing by learners with Autism from Alpha and Vera Schools, based in Cape Town.

Dancers from Debbie Turner Cape Dance Company entertained the audience with an African expose` providing a wonderful ambience as the congress launched into the "Autism Safari".

Riaan Visser, a parent of a son with autism sang Josh Grovan's hit "You raise me up" which touched everyone's heart.

Jill Stacey, National Director of Autism South Africa introduced the first speaker, Margaret Golding.

MEC, Cameron Dugmore, Provincial Minister of Education Western Cape Province, presented a message of support and hope to learners with Autism Spectrum Disorders saying that whilst parents often feel that services for learners with ASD are being neglected, he assured the audience that this is not the case. Ground work that has been implemented over the last couple of years will show positive benefits over the ensuing 2—3 years. MEC, Dugmore urged parents to maintain contact with the Department of Education and continue lobbying for services for their children. He emphasised his commitment to learners with ASD when he related a brief story of how he and his family home hosted a young girl with Autism and how much he enjoyed and learnt from the experience.

Autism Safari

The Autism Safari DVD and / or the Congress Documentation is available through the office of Autism South Africa.

A CD of the photographs taken throughout the congress is also for sale.

If you would like to order any of the above please complete the form on page 17 of this edition of Aut-Talk and fax it to the office on 011-484-3171.

WE HAVE MOVED!

Autism South Africa

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Billy

What's going to happen to my brother Billy?

The boy who everyone thinks is so silly,
Is he going to relish the wonders that we will?
Well nobody knows what the future will spill.

Most people think "Oh, he won't be that
clever,"

But actually he will be, for ever and ever

His talents are greater than you could
imagine,

A top one is his magnificent grin

He is so kind and benevolent,

So if there ever occurs an accident,

Billy will always be on the scene,

Wiping the wound so your fresh and clean

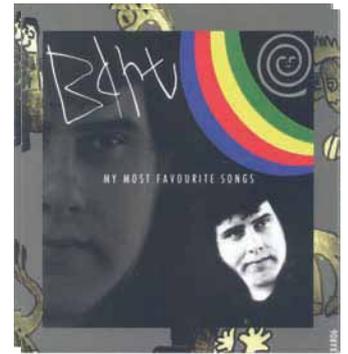
But Billy is also a Rally Car King,
He wins and wins until finally he sings,
His joy echoing through the house,
Until everyone in the family is up in a
rouse!

My brother Billy has autism you know,
And I'm not really sure when it I going to
go,

So even when it's time to call it quits,
I obviously still love him to bits!

Written by Bella Tommey

Taken from The Autism File Issue 21 - 2006



MY MOST FAVOURITE SONGS
- Sung by a learner from UNICA.

Price: R50

Contact person:

Liesl du Plessis

Cell: 082 373 5423

E-mail:

lieslduplessis@xsinet.co.za

Siblings

Siblings in a family with a child with ASD often have slightly different experience of being a sibling than their peers. They may be expected to be on their best behaviour a lot of the time, perhaps to compensate for the difficulties their sibling might be experiencing. They may miss out on special trips or parties as their sibling may not be able to cope. Being a sibling in a family with a child on the spectrum is not all hard work, but they may need information to help them understand why their family is different to others.

When is the best time to start discussing ASD with them?

Use the children themselves as a gauge of when and what they need to know. You might be hearing questions like 'why doesn't Sam get told off when she hits people?' or 'why does Sam have to go to a different school?'/ When they start

noticing that things are a little different for their sibling with an ASD, it is probably a good indication that it is time that you told them why. It is important that they understand from an early age that their brother or sister is not naughty or silly—just that they see the world differently to us and that they might need special help to learn.

What do we tell them?

This can change over time, you might like to start with something like 'Sam's brain works a bit differently to ours', then, as they grow up, explaining in more details about the triad of impairments. Explaining that ASD is something that their brother or sister was born with, and that they can't catch it, might be important for them to know too. Using metaphors like 'Sam's brain is tuned into a different channel of the TV' or 'he has a different computer in his brain than us' might work for young children. For older children, it is important to let them ask the questions and go from there. Reading a book pitched at

their age level might be appropriate.

Friends Questions?

Siblings may get asked 'what's wrong with your brother/sister?' by friends or other children at school. It is important that they are armed with the right information to be able to provide an answer in potentially difficult situations. 'My brother has autism which means he has difficulty talking and playing with other kids' or 'my sister has Asperger syndrome, which means that she is clever but needs help making friends and mixing with other kids'. You will know the best language your children will relate to and feel comfortable using.



My daughter has started to notice that her old brother is 'different'. What's the best way to explain his autism to her

Written by Tamara Oxley, NAS Autism Helpline Advisor taken from Communication Autumn 2006



Square Peg, Round Hole

Josh Muggleton, a 16-year-old student with Asperger syndrome—and proud of it—tells us what it was like for him in a mainstream school.



Inclusive education promotes the idea of all children being educated together in mainstream schools. But what happens to people like me who discover it doesn't always work?

I wasn't a troublesome student. I never go a single detention. My behaviour was exemplary. I was keen to learn, always did my homework and was never late for school. It is not as if I went to bad schools. Both my primary and secondary schools have good records for academic achievement and excellent Ofsted reports.

So—What went wrong?

First of all, soon after I started school I realized that I was a bit different from other children. I was repeatedly bullied, teased, and soon discovered I was a misfit. Apparently, not many kids walk around the lines on the playground in the middle of summer with a thick coat zipped up to the hood. Being diagnosed with dyslexia also didn't help.

Somehow I survived primary school. I treated my depression and low self-esteem with my own 'chocolate therapy'. I hoped that secondary school would be different. Before I started, my parents wanted to meet with

the school to discuss the additional support I would need. They refused. It seemed that they first wanted to see how far I would sink. Unfortunately, I sank too far and never recovered.

True Inclusion only works when schools can give enough support

At secondary school, I was bullied more than ever. The school did nothing. I became more depressed. After making serious threats to commit suicide, I received help from the Child and Adolescent Mental Health Service (CAMHS). After four years of secondary school hell, I had a complete breakdown. My psychiatrist decided that I could not cope any more and signed me off on medical grounds.

So what was it that caused the breakdown?



It wasn't just the bullying, it was the lack of understanding of the staff at the school. Nobody seemed to listen to what I was saying. I needed a place of sanctuary when things got too much for me. I needed encouragement from the teachers, not threats. If the teachers had been properly trained in ASDs, they might have been able to help me cope.

I'm studying for A levels, using a home-based study programme. I would like to go to sixth form college, but is there anywhere that can give me the support I need?

Recently, I have been giving talks to groups about my experiences, the way my mind works and what people can do to help me. It started by accident, when my dad was asked if he knew of anyone who could speak to a small group of teachers about Asperger syndrome. I volunteered. People said my talk was insightful and I got more and more bookings. It's one of the few positive experiences I have had.

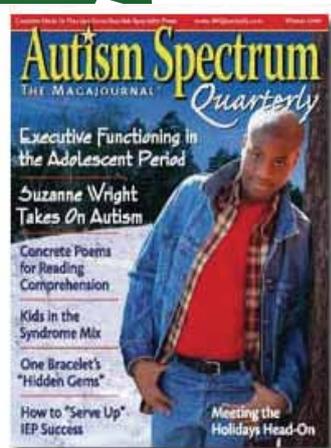
Inclusion didn't work for me. I tried my best to adapt, but true inclusion only works when schools can give enough support. If they can't do that, then inclusion becomes very damaging. I'm only just beginning to rebuild my shattered confidence and self-esteem.

Taken from Communication Autumn 2006

Autism Spectrum Quarterly Magazine (ASQ)



**R 200
SUBSCRIPTION**



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per copy
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postage**

Autism South Africa is acting as a local distributor for a wonderful magazine from America called Autism Spectrum Quarterly. We need your urgent response should you wish to receive copies.

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. 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.

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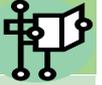
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Rain and Snow

SINCE IT'S RELEASE 18 YEARS AGO, THE INFLUENCE OF THE FILM RAIN MAN ON PUBLIC PERCEPTIONS OF AUTISM HAS BEEN HUGE, ENCOURAGING A BELIEF THAT MAY PEOPLE WITH AUTISM HAVE EXTRAORDINARY OR SAVANT ABILITIES. ANGELA PELL IS THE SCRIPTWRITER OF A NEW FILM, SNOW CAKE THAT SHE HOPES WILL HELP TO GIVE A MORE REALISTIC VIEW OF THE CONDITION

Shortly after my son Johnny was diagnosed as 'severely autistic', someone gave me a poem about have a child with special needs. The essence of the poem was as follows: getting pregnant is like preparing for a trip to Italy. Many of your friends have already been and it seems that everyone has a tale to tell about what a great time they've had there. So you start collecting the guidebooks and counting down the days before you finally arrive at this, almost mythical, land of culture and beauty. Then nine months later, just as the plane touches down, the pilot makes his announcement; 'Welcome to Holland'. 'Holland! Holland!' you shriek. 'No, I'm supposed to be in Italy I know all about Italy I've prepared for Italy'. The poem ends by saying that we have a choice. We can either spend the rest of our lives wishing we were in Italy—or we can start to appreciate the different, maybe a little less highbrow, things that Holland has to offer. It is, after all, a country with tulips, windmills and chocolate.

In 2004, I wrote the script for a film called *Snow Cake*. In a nut-shell, the film is about one week in a man's life, as he learns to live in the present, to exorcise his demons, to move on. The reason I am writing this article is because he happens to be spending this particular week in the

company of an autistic woman.

Of course, while writing the script, I drew upon my experience of being a parent of an autistic child but I didn't initially set out to write a film about autism. The seed for the film came from the idea; what would happen if you picked up a hitch-hiker and then had an accident which killed them? I thought that this could be an interesting place to start a movie. What I then wanted to do was to put my protagonist somewhere he was completely out of his depth, somewhere surreal where the normal rules of engagement didn't apply. I looked around at my son who was banging me (lovingly) on the knee with a plastic bottle whilst excitedly and repetitively shouting the words 'be careful potatoes', and that's when I thought aha!

Although the character of Linda, played by Sigourney Weaver, has several traits in common with my son, she is very different to Johnny. I am not an expert on autism—O am merely an expert on my son's autism. Even then, there are days when I doubt that. To be honest, after I'd written the first draft of *Snow Cake*, I didn't know if Linda was autistic or had Asperger syndrome. I phoned the NAS to ask for guidance and was so desperate to make sure that I had written a believable character that I even tracked down Ros Blackburn, an autistic adult who I had seen give a talk just after Johnny was diagnosed. Ros was extremely supportive of the project, even coming on board to advise myself and the director and eventually spending a great deal of time tutoring Sigourney Weaver, both on the delights, the physicality and, in her words, 'the pig of being autistic'. She helped both to mould and inspire the final shooting script.

As a rule of thumb, the central characters in all movies should experience an emotional journey which changes them in some way. But I didn't want Linda to have to change, to 'improve'. I wanted the audience to accept and like her, without her having to make 'progress'. This has been the hardest lesson I have learnt with Johnny. To embrace his au-

tism not just on the 'easy' days, the days when he says a new word or does something that resembles 'normal' play, but to embrace it on the days when he bites, or he won't get out of the car on a particular level of the car park, or spends the entire day with his hands over his ears.

After one preview screening of the film, a woman said that what she liked about the film was that at the end, when Linda was in the kitchen doing 'her thing' (which involves snow ... won't give it away!) that what she's doing just feels so commonplace, that we accept it without batting an eyelid. I was really pleased to think that if nothing else maybe someone somewhere will leave the cinema feeling a little less judgmental of other people's more unusual 'passions'. That maybe they'd start to see, and even attempt to share, the joy. Of course I know that there are some people out there who find living with autism an overwhelmingly negative experience, but I'd like to believe that *Snow Cake* gives a balanced view. I know that it can be hellish at times, but I also know, from my experience, that amongst the heartbreak, frustration and fear we parents sometimes feel, it is actually possible to get a great big gawp of Heaven.

I really hope that, if you see the film, you enjoy it. One of the less agreeable characters in *Snow Cake* states, after the protagonist Alex, played by Alan Rickman, tries to apologize for Linda's lack of social graces, 'Oh, it's alright, I know all about autism. I've seen that film. 'If nothing else, perhaps it will raise the profile of the condition a little more and maybe, after all these years, offer up an alternative point of reference to *Rain Man*!

Taken from *Communication Autumn* 2006



REDUCING HOLIDAY STIMULATION

Holidays can be a stressful time, especially for children with autism and other pervasive developmental disorders. Following are some helpful tips to lessen the inevitable increased stimulation associated with the holiday season:

- Try to establish as much of a routine as possible.
- Try to limit the number of stores to which you expose your child/children.
- Have your child/children help plan and organise the decorating process.
- Some families find it helpful to only have one color of lights on the tree (the non-blinking variety may be less stimulating).
- Holidays are associated with delicious smells; however, some fragrances are more calming than others; vanilla, chamomile, and lavender are best.
- Add decorations to the inside and outside of your house slowly.
- Use social stories as needed to prepare your child/children for upcoming events and/or changes in routine.
- Limit the number of visible gifts.
- Incorporate sensory activities into family functions (i.e., let them sit on a bouncy ball at the kid's table for dinner, make snow angels, etc).
- Discuss realistic expectations for holiday events and family functions prior to their occurrence to avoid stress and disappointment.
- It is all right to say "no" to anything that you think may cause undue stress to you, your family, and/or your child/children.

Enjoy the holidays.

Taken from www.Fraser.org

NEW BOOK WRITTEN BY HILDE DE CLERCQ AVAILABLE THROUGH AUTISM SOUTH AFRICA

AUTISM FROM WITHIN— a hand book

BY HILDE DE CLERCQ

Price: R 200

Ever since her fourth child was born, Hilde De Clercq has been involved with autism. She decided to dedicate herself entirely to try to understand the essence of the enigma.

Hilde dared to explore and analyse the 'different' behaviour of her son. She found an approach through language and the attribution of meaning, where she, as a linguist, could observe the pervasiveness of this developmental difference. The extreme attention to detail and the effects of hyper selectivity were explored in her first book. This time Hilde goes further and explores, in depth, the qualitative differences of autism in every day life. This book is a practical guide as well as a reflection on pragmatic language issues.

One could say that there are indeed two cultures, one autistic and another non-autistic. This book builds bridges between two perspectives on reality. It is intended for students, professionals and parents, but could very well be read by anyone interested to know more about the autistic syndrome.

The author's frequent references to the writings of autistic people themselves will open the reader's eyes to the 'world of autism' and provide a philosophical and educational framework.

Should you wish to buy a copy of this book, please contact the offices of Autism South Africa on 011-484-9909 or email info@autismsouthafrica.org.

FOREST TOWN SCHOOL

Due to financial reasons Forest Town School has had to retrench 18—20 staff members. These have included therapists, teachers and general assistants.

This has effected the school badly and will also effect the intake of pupil numbers.

The general assistants are desperately seeking work and have an excellent track record with Forest Town School. They are used to working with children and families with disabilities.

If you know anyone looking for such staff please contact Carol at the school on 011-6946-0131/2/3 or 082-454-7619



“Autism is the inability to single out people as special,
separate, unique entities - different from bits of the
furniture, different from even the family pet dog.”

“I have to work out theoretically
all the things that you just land yourselves at instinctively.”

“To me the outside world is a totally baffling incomprehensible
Mayhem which terrifies me. It is a meaningless mass of sights and sounds,
Noises and movements, coming from nowhere, going nowhere.”

Ros Blackburn.

Taking things literally: Ryan aged five

Ryan’s mother reported:

Ryan got wet and muddy when he was playing outside in the back yard.. I told him to take off his socks and put new ones on. A bit later I said: ‘Ryan, put your socks in the washing machine please.’

I went to the laundry to do the washing after lunch and when I lifted the lid on the washing machine I was surprised to see about 20 pairs of socks in there. Ryan had put all of his socks in the washing machine. I couldn’t be cross, could I? He had done exactly what I said ... he put his socks in the washing machine. Next time I’ll remember to be more specific and say ‘put your wet, muddy socks in the washing machine’.

Taken from Pre-Schoolers with Autism—Manuals for parents.

Using Photographs and offering choices: Jessica aged three and a half.

Jessica’s mum reported:

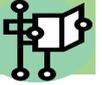
Jessica and I were at the market buying fruit and vegetables. She likes to be out shopping and helps to carry things in the basket. She can’t speak yet but she and I can understand each other most of the time and she uses photographs to show me what she wants.

I took a basket, a new, bright red one, and started off down the aisle when Jessica began to scream and threw herself on the ground. I was a bit shocked and surprised because shopping is usually a happy time for us both. I was about to growl at her for being naughty but stopped and thought for a moment. Because I had been learning about ABC approaches to behaviour problems I stopped to think whether I had done anything to provoke this crying.

Of course ... I chose a different basket ... we always have a blue basket at this shop. I bent down and showed Jessica the red basket and the blue basket and said, ‘Which basket?’, offering her a choice. She looked at me, then took the blue basket and put the red one back on the stack.

We then took the blue basket and did the shopping. Next time we were at the market Jessica had photographs of the baskets and showed me which one she wanted by pointing to the photograph ..I. Yep, it was the blue one.

Taken from Pre-Schoolers with Autism—Manuals for parents.



Address by Minister of Education Naledi Pandor, MP, at the closing ceremony of the second Autism World Congress, Cape Town

2 November 2006

"Autism exploring new territories"

National Director of Autism South Africa Jill Stacey,
International scholars and specialists in Autism Spectrum Disorder,
South African professionals and specialist in Autism,
Educators,
Parents,

I would like to congratulate Autism South Africa for organising this second World Congress of Autism International. We are impressed by this gathering of eminent scholars and dedicated researchers and professionals in the various disciplines that deal with diagnosis, treatment, and management of education and support for individuals with autism spectrum disorder.

I recognise the exceptional role played by parents of affected individuals in providing enlightenment with regard to knowledge about autism spectrum disorder as well as the unselfish love and dedication that only mothers and fathers understand and never tire of providing.

To see specialists and scholars from over 50 countries, demonstrates the commitment towards facing the challenges that autism spectrum disorder poses to the global community as a whole.

From presentations made during the past three days, as well as interviews in the public media, it has emerged very clearly that autism spectrum disorder is indeed a "hidden disability". This explains the small number of institutions in the country catering for children with the disorder.

Because autism spectrum disorder, to a large extent, unlike the commonly known sensory disabilities such as blindness or deafness, manifests itself in unconventional social behaviour, it often leads to negative reaction, stereotyping, censorship and rejection in the environment of the affected individual. Aggressive behaviour and flouting of social conventions, such as saying sorry or staying interested in the conversation of people around us, all has serious negative effects in the schooling environment of a learner.

The learner with autism spectrum disorder is vulnerable in early childhood, especially at risk during the teenage years, and may remain vulnerable even as an adult later in life.

Yet, I am told that the typical characteristics of a young person with autism spectrum disorder set them apart as potential candidates for certain professions, because of their meticulous attention to detail, their love of animals and not people and their particular tendency to keep an open mind.

The majority of sufferers, therefore, if diagnosed early, and exposed to appropriate treatment, support and education, stand a chance of not only leading productive lives, but also of making a meaningful contribution to society and humanity in general.

The theme for this congress is "Autism Safari, Exploring New Territories."

The rich information that has been shared and deliberated upon with passion over the past three days adds to the body of knowledge that already exists on this subject matter. The research findings give credence to certain theories and dispel certain myths.

This is well and good!

The challenge that remains is information management and information dissemination. It is the outreach programme that Autism International needs to explore to reach the average undiscovered autism sufferer who is vulnerable to rejection and possible expulsion.

How much of information shared this week will reach the thousands of learners who are estimated to suffer from autism spectrum disorder?

How do we manage this information so that it serves the lives of those affected positively and enable them to take their place in mainstream society?



How much knowledge about the condition is built into the professional training for education, health and social welfare students in institutions of higher learning the world over?

How much information and support is routinely made available to parents to enable them provide support with homework, with social skills, with life skills in general for children?

South Africa is a young democracy. It is a developing nation. It is a nation with a mission to reverse the effects of our divided past. It is a nation seeking to promote a culture of inclusivity. It is a nation in a process of supporting social cohesion and unity in diversity among all its citizens, young or old. It is with this background in mind that we seek to support the development of strategies to assist parents in attaining early diagnosis and identification of conditions that impact on the development of the child.

This cannot be achieved by the education sector alone.

As a matter of fact, the health sector has to join hands with the education and social development sectors in moving towards new frontiers in coping with autism spectrum disorder.

There are seven schools in the country for learners affected by autism spectrum disorder.

Building special schools is a costly exercise. I believe we have children with autism spectrum disorder in some of our 390 special schools that cater for other disabilities. We have children with autism spectrum disorder in our private schools! We have children with autism spectrum disorder in our mainstream public schools.

The Department of Education is currently engaged in field testing inclusive education practices that ensure learners with disability are able to access quality education in schools closest to their homes.

While the sample where this trial is being conducted is miniscule in comparison to the number of public schools in the country, every province is involved in the programme. This will ensure that the norms developed from the research findings are suitable for application to the entire system.

Over 4 750 teachers, school management teams and school governing bodies have been trained on the draft strategy for assessing learner support needs in schools. Over 4 000 educators have been trained on the draft guidelines for ensuring inclusive learning programmes that take into consideration the diverse needs of our learners.

Over 30 district based support teams have also taken part in the training mentioned above.

The challenge is in ensuring that every district in the country possesses the expertise to ensure that autism spectrum disorder does not go undiagnosed and untreated among learners in our schools.

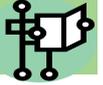
In February 2006 the Minister of Finance approved an additional budget of over R140 million to the provincial treasuries for the programme for recapitalisation of special schools. This allocation was made so that over 66 special schools would, in the next three years, be upgraded in terms of infrastructure. Transport would be provided so that learners who have to travel long distances to attend special schools would continue to have access to education.

The programme for strengthening special schools is aimed at ensuring that special schools are not neglected.

The appointment of school counsellors to serve a cluster of schools will indeed complement the work of the district-based support teams as well as ensure that the services offered to learners and educators are integrated.

Opportunity for research of this transformative process abounds. Contextual issues may differ from Denmark, Norway and India, but the challenges posed by Autism for the child, the teenager and the young adult who is trying to integrate into society are similar for all.

In closing, it is important to state that our history of discrimination and exclusion has created a challenge for Autism South Africa. You need to consider ways of supporting and informing families that may be totally uninformed and that deny affected children support that could enhance their opportunities in life. Given our key role in African affairs, you could also consider links in Africa and the development of working relationships with similar organisations. Specific attention should be given to rural based communities as they have often been left behind in terms of support for learners facing barriers to learning. I wish you all a safe journey as you travel back to your countries, and as you begin preparations for Mexico 2009!



Tactful Responses to Challenging Questions or Comments

Taken from Autism for Dummies ISBN 0-7645-2547-6

Sadly, people with autism often face social disapproval—not because they look different, but because they look so “normal.” Unlike other disabilities, autism doesn’t clearly disable a person on the outside. People with autism are expected to behave “normally”, which can make life difficult for them and for their parents. Parents face unwanted, awkward choices: do you explain to others that your child is special, or do you hope that they won’t judge you or invade your privacy if your child does something disruptive? We’re here to help ease your discomfort, if only momentarily. This section gives you tips for handling some common uncomfortable situations you may encounter, whether you’re a person with autism or the caregiver of one.

“Why Can’t You Control Your Kid?”

Variations on the control-your-kid theme are numerous: “What kind of parent lets his/her child misbehave that way?” “Didn’t you teach her any manners?” “Let me have your child for a weekend ... I’ll straighten her out!” Or just a plain-old, Judgmental Bad-Parent Look.

People with autism often perceive the world very differently from others, which results in unexpected differences in behavior. Although the lighting in a department store may simply seem garish to some, it may be totally over-whelming to a person who sees florescent lighting like a strobe light. The result is a sensory-overload tantrum. Can you blame the person? Most people would be uncomfortable shopping in a store lit with strobe lights.

Also, most people can filter and prioritize incoming sensory data, which allows you to ignore sounds, lights, and other information that isn’t important in a given situation. Many people with autism lack this ability. They have an experience comparable to watching a television set that receives all 500 or more channels at once with the volume at full blast.

When someone asks, “Why can’t you control your child”, the implication is that you’re a failed, weak, negligent parent, which is why your child doesn’t behave. Please don’t be tempted to believe this is you get this kind of feedback. When other people misunderstand or misjudge you, it can be painful and frustrating. However, if you know that you’re doing the best job you can for your child, you don’t have to let these emotions get to you.

Who Did He Inherit It From?

A person who asks “Who did he inherit it from?” reveals ignorance more than anything else. This question makes you feel defensive, as if you must explain something you don’t even fully understand yourself. You wish others would think about the implications of what they say before opening their mouths.

You can say, “Yes, current research indicates that autism has a strong genetic factor, which then gets triggered by something else”. But you’re not responsible for explaining the causes of autism to the world, especially because research hasn’t established causation anyway. You have enough on your plate. Just say, “I don’t know,” and leave it at that. You can also go for a humorous response if you like. Both parents can eagerly claim genetic responsibility. Or if only one spouse is present, you can state—with a smile—“Although my spouse claims responsibility, I know that the genes from MY side”.

“Is She Still in Her Own World?”

The question “Is she still in her own world?” is an all-time candidate for insensitivity. In fact, due to sensory hypersensitivities, many people with autism are so much more aware of the world around them that it’s painful. Imagine being able to hear the ticking of every electric clock in the house or being driven to distraction from the crinkling of a plastic bag that someone is stuffing under the kitchen sink. Our friend Kassiane Sibley, a person on the autism spectrum, recommends a couple routes to take in response, each with a bit different tone. Here’s the first, more ... ahem ... bold response (staring blankly) “Who else’s world would she be in? I mean, really. It’s not like they beam us all off the planet at age 22. Do they? If they did I missed my flight. Darn”.

She takes a more educational approach with this response. “or alternatively, you can explain how autistic people tune out because they are overwhelmed by a world that is too loud, too bright, talks too fast with weird figures of speech ... and so as a protective mechanism, people on the spectrum often tune out. People with autism like precise language. Asking if a person is in his or her own world has a pretty good chance of getting hackles up. That’s why he or she is glaring at you silently instead of answering although he or she may be perfectly verbal.

You have multiple ways to answer the same question, so have fun!



GLUTEN FREE HOLIDAY RECIPES.

CHICKEN CASSEROLE

This recipe has been handed from friend to friend so many times that we have no idea where it originated. My wife, Joanna, as usual, has made her own improvements.

Ingredients:

1.5kg chicken pieces (for best flavour, leave the skin on)
4 teaspoons oil— 2 large onions OR dried onion—4 cloves garlic OR garlic powder
2 teaspoons oil, extra—4 teaspoons lemon juice—2 teaspoons grated lemon rind
2 cups gluten-free tomato sauce (ketchup) - 2 teaspoons brown sugar
2 teaspoons dry mustard—2 teaspoons gluten-free curry powder (some isn't GF)
4 teaspoons wine vinegar (NOT malt vinegar) - 2 teaspoons teryaki or gluten-free soy sauce (may be hard to find) - salt and freshly ground pepper

Method:

Sauté chicken in hot oil until golden brown, remove from pan, drain. Pour off oil from pan, add all other ingredients. Stir until pan browning are dissolved. Add chicken. Cook on low heat until tender.

Nice served with rice.

TIP OF THE DAY

Wheat-free baking powder

Make your own gluten-free baking powder as follows: sift 18ml corn flour, 12ml bicarbonate of soda, 9ml cream of tarter and 8ml tartaric acid together. Store in an airtight container and use as needed. Taken from www.Food24.com

RICE PUDDING CAKE!

Ingredients:

3 cups cooked rice
4 eggs, beaten
1/2 cup brown sugar)
2 medium bananas, mashed
2 apples, finely chopped
500g (1 pound) cottage cheese
2 cups mixed dried fruit
1/2 cup dried apricots, chopped
1/2 cup mixed nuts OR almonds, roughly chopped
grated rind of one mandarin OR orange
1 teaspoon nutmeg
1 teaspoon cinnamon

Method:

Combine everything and mix well. Place mixture in a greased tin. Joanna uses a fancy fluted ring (one with a hole in the middle). Bake at 220 C (400 F) for about half an hour until firm and cooked through. When a skewer comes out clean, the cake is cooked. Allow to cool in the tin.

BOOK CORNER

SOUTH AFRICAN BOOKS AVAILABLE ON AUTISM



Product details

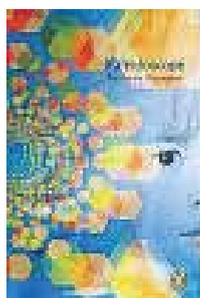
Publisher: [The Penguin Group \(SA\) \(Pty\) Ltd](http://ThePenguinGroup(SA)(Pty)Ltd)

ISBN: 0143024485

Format: Softcover

Publication Date: 2004/4

Kaleidoscope is a novel about shifting perspectives within a family, brought about by the birth of an autistic child. Primarily about relationships, insights are given into the difference between early infantile autism, Asperger's Syndrome and social phobia

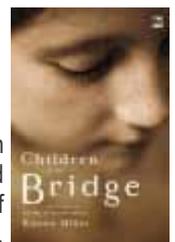


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Publisher: [The Penguin Group \(SA\) \(Pty\) Ltd](http://ThePenguinGroup(SA)(Pty)Ltd)

ISBN: 0143024485

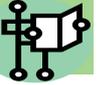
Children on the Bridge is a dramatic story of a journey through the world of autism in South Africa, but it is also a personal and very real account that offers insight into the experiences of someone touched by this complex and unpredictable disorder.



Autism has recently become extremely topical in the media. Autism South Africa estimates that 1 in 165 children may be affected by some degree with autism. However, very little has been published that relates specifically to autism in South Africa, and there are many parents who have nowhere to turn when their children are diagnosed.

This story provides a way across the bridge between our world and that of the people and families affected by autism, and helps us to identify and respect the differences between the ways our different brains work.

"After so many years in this line of work, now I know that there is something about standing on one side of a bridge and calling to a child on the other side, coaxing her day in and day out to join you and the rest of the world on your side. There is something in hearing your own voice calling, and then seeing that child's eyes flicker upwards to notice you, to look at you as if for the first time. There is something in being part of even the tiniest spurt of growth that binds you to that child forever."



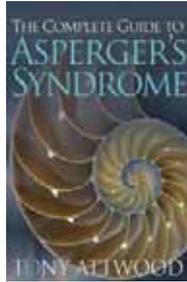
BOOK CORNER

**BEST SELLERS AT
THE AUTISM
CONGRESS**

**ALL BOOKS
AVAILABLE FROM
AUTISM SOUTH
AFRICA
AT THE
CONGRESS PRICES!
(Prices valid until
15 December 2006)**

Tony Attwood

The Complete Guide to Asperger's Syndrome



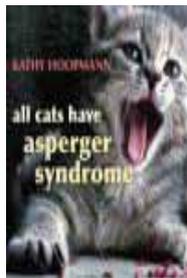
The Complete Guide to Asperger's Syndrome is the definitive handbook for anyone affected by Asperger's syndrome (AS). It brings together a wealth of information on all aspects of the syndrome for children through to adults.

Drawing on case studies and personal accounts from Attwood's extensive clinical experience, and from his correspondence with individuals with AS, this book is both authoritative and extremely accessible.

1843104954 R275.00

Kathy Hoopmann

All Cats Have Asperger Syndrome!

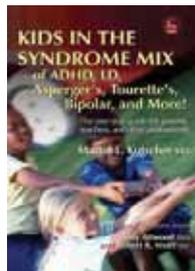


There is a great deal of truth in humour. If you have only just begun to discover why someone with Asperger's syndrome is different, this book will inform and entertain you. The...

1843104814 R155.00

Martin L Kutscher

Kids in the Syndrome Mix of ADHD, LD, Asperger's, Tourette's, Bipolar and More!

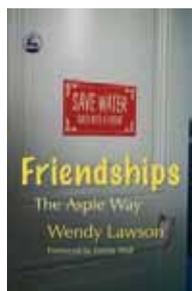


Kids in the Syndrome Mix is a concise, scientifically up-to-date, all-in-one guide to the whole range of often co-existing neuro-behavioral disorders in children-from attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder, and bipolar disorder, to autistic spectrum disorders, nonverbal learning disabilities, sensory integration problems, and executive dysfunction.

1843108100 R230.00

Wendy Lawson

Friendships – The Aspie Way

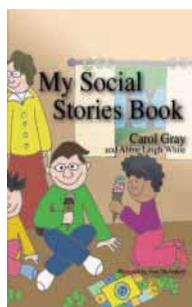


People with Asperger's Syndrome have difficulty with interpersonal relationships, yet are well known to be loyal and dependable friends. Wendy Lawson felt she had a knack for upsetting people and was surprised to be told that she 'did friendship rather well'. In her frank and thoughtful analysis of what makes and breaks friendships, she explores what it means to have friends or be a friend – even a friend to oneself.....

184310427x R200.00

Carol Gray

My Social Stories Book



Carol Gray's social stories have been found to be very effective in teaching social and life skills to children on the autism spectrum. Taking the form of short narratives, the stories in *My Social Stories Book* take children step-by-step through basic activities such as brushing your teeth, taking a bath and wearing a safety belt in the car. These stories are written for preschoolers aged 2-6 and form a useful primer for non-autistic as well as autistic children. 1853029505 R200.00



BUZZ PAGE

Introducing **AUTISM SINETHEMBA**, a non-profit organisation (included under section 21) associated with the Autism Support Group of East London.

Antionette Bruce-Alexander said "One Saturday afternoon in October 2003, a group of parents and professionals got together for a workshop on Behaviour Modification and Tutoring for children with autism. It became clear from the onset that we needed a support group for parents, caregivers and families of children with autism and we have held monthly support group meetings since then. We have invited various professionals to inform parents on specific topics / areas of concern and interest.

Antionette said 'based on information supplied and needs expressed, parents identified an early intervention and formal education options as the most problematic and long-term need in the East London area".

Autism Sinethemba was established to provide an accountable opportunity for the public and corporate sector to contribute financial support though fund raising and donations to help us realize our goal.

Autism support group of East London meet every second Tuesday of the month 18h00 to 19h00 at Ground Floor, St Dominics Medical Suites, St Dominic's Hospital, 56 St James Road, East London.

Contact details of Autism Sinethemba: Antionette 072-678-2452 or Bonnie 083-751-5994 or Fax: 043-748-3992



I am a fully qualified, SACE-registered teacher, with 40 years' experience at all levels of the educational spectrum. I have a BA Hons degree in Applied Linguistics and also a Diploma in Special Education. I am currently employed at Bellavista Remedial School as a remedial therapist and librarian. I will be leaving there at the end of this year and would like to teach from home, teaching learners with learning difficulties or problems which make school-attendance / placement difficult. I have had many years of experience in the remedial field and whilst at Bellavista in the past five years, I have had experience and training in working with children with ASD. I have managed to build up and foster good relationships with such children. As I have also taught at High School and post-Matric level, I am well-equipped to teach older learners. My name is Frances Butler and I live in Atholl, Sandton and would welcome teaching in the vicinity of my home, or in my own home. I can be contacted on 083-783-0223 or 011-440-5359. Email: prbutler@iafrica.com.

LOOKING FOR AUTISM FRIENDLY DENTISTS AND HAIRDRESSERS

Can you recommend an autism friendly Dentist and or Hairdresser. Please contact Autism South Africa on either 011-484-9909 or email pauline@autismsouthafrica.org.



CONGRATULATIONS UNICA SCHOOL AND THE ASSOCIATION FOR AUTISM.

The Unica Christmas Market was an absolute success again this year.

We know you all did an outstanding job. Well done and congratulations.



Christmas Puddings for sale

Small—500g	R 32.00
Medium—900g	R 48.00
Large—1500g	R 70.00

All proceeds go to the following organisations:

Herschel School, Leliebloem House, Vera School, Tembaletu School and Day Centre, Woodside Sanctuary and Bel-Porto School.

To order please contact:

Anita 021-6962844 or email: vera@vera.wcape.school.za

Syringa Child Clinic

Syring Health Centre
4 Wembley Avenue
Plumstead
7800

Contact: Dr Raoul Goldberg
Tel: 021-762-2364
Fax: 021-761-1973

Email: syringe@netpoint.co.za
Syringa Child Clinic is a newly established children's clinic for vulnerable children including children with Autism.

New National Executive Committee Members of Autism South Africa

- Paul Pratt—Chairperson—KZN
- Petra Dillmann—Vice Chairperson—Namibia
- Margaret Golding—Cape Town
- Dr. Lorna Jacklin—Johannesburg
- Fanie Minnaar—Western Cape
- Joan Jorritsma—Eastern Cape
- Jill Stacey—Johannesburg
- Pauline Shelver—Johannesburg



ACORN KIDS

Angel Powder

Only R29 each – 125ml

Transforms the bath water into a magical blue, yellow or red play-ground. Mixing the primary colours will give you green, orange or purple. This is educational and fun – what an experience for your little people

Surfs Up Fun Foam

Only R44 each – 250ml

This is a highly concentrated foam bath with sea creatures in a floating solution. Your children will love hunting for the little fish and stars in the bath. As they track them down you will notice the development of their hand/eye co-ordination and fine motor skills

Gloop

Only R44 each – 250 ml

Gloop is a jelly-like substance that is designed to replace soap and shampoo. Use it and you will be amazed at how your child's hair shines. Squeeze it into your kiddies hands and let them feel it squish through their fingers – now get them to rub it all over themselves, from top to toe. Washing hair and grubby bodies has never been this enjoyable!

KaleidoFoam

Only R55 each – 150 ml

This product offers a tactile experience that turns bathing into an enormous amount of fun. Kaleido-Foam is an all over body wash with natural active ingredients. Create bath designs and wall art that will rinse off easily.

This is literally fun in a can!

Contact:

Jason Simpson
Acorn International
Florida Branch

Artism for Autism

Exhibition

V & A Waterfront Cape Town.

We would like to congratulate all the artists who put their paintings forward for the Artism for Autism Exhibition held at the V & A Waterfront during the 2nd World Congress. Your art was absolutely amazing and we would like to sincerely thank you all once again.

We would also like to sincerely thank Autism Western Cape for their hard work in making the Artism for Autism exhibition such a successful event.

Kind regards from
The Team at Autism
South Africa

THANK YOU!

We would like to take this opportunity to thank Pieter and Rosemary Viljoen for their kind donation of a children's playhouse for the children to use in the playground at The Key School, Parktown.

They also very kindly donated two couches, a microwave and washing machine for the residents to use a Lethabo Le Khotoso.

Childrens' Disability Centre

Affiliates:

The Memorial Institute for Child Health and Development (TMI)

Johannesburg Hospital School

University of Witwatersrand

The Childrens' Disability Centre (CDC) is situated at The Memorial Institute for Child Health and Development (TMI), in Gauteng. The Centre is currently the only Centre in South Africa that caters for the needs of blind, visually impaired and learners with Autism Spectrum Disorder (ASD).

The service originated thirty years ago as a service for children with visual impairment and included children with autism as the need developed. The Unit, which is affiliated to Johannesburg Hospital and Witwatersrand University, caters for pre school children referred by assessment clinics or similar institutions within the region.

A retrospective study, done at TMI supports the drastic increase in numbers of children presenting with autistic features. The study observed over the 10 years, shows an increase from 1.5% of cases in 1996 to 5% in 2004 and a jump to 8.2% in 2005.

Whilst specialized in visual impairment there was a desperate need to diversify and accept learners with ASD. Thus the development of the CDC and our services

Intended Services for 2007

- 6 classes from preschool to foundation phase - a ratio of 6 learners to educator and a shared practitioner. Classes include both VIP and ASD learners.
 - Individual Educational Programmes based on the Revised National Curriculum with adaptation for all learners
 - Individual speech assessments and therapy for all learners
 - Individual occupational therapy and assessments for all learners
 - Dietary intervention for all learners.
 - Early Intervention programmes complimented with individually designed home programmes.
 - Application of Alternative and Augmentative intervention techniques
 - Teacher training
 - Autism awareness groups and community education
 - Parent support and training
 - Support and intervention groups for Mothers and children awaiting school placement
 - Sustainability projects for parents to promote entrepreneur skills
- Outreach programmes

The CDC strives to co ordinate services to serve the needs of the community.

CDC: "Ordinary people doing extra-ordinary things"

For further information, please contact;

Poppy (011) 643-3050

Autism Spectrum Disorders, Culture and Sexuality—written by L.J. Moxon for 2nd World Autism Congress Autism Safari 2006

I have noted an increasing number of consultations about young people with ASD who are experiencing difficulties because of inappropriate sexual behaviour. Much of this behaviour appears to happen because the individual has failed to grasp (or has not been taught) the sexual rules of society or who has not taken context into account. This paper will reflect on how we can support people with Autism Spectrum Disorders (ASD) to attach importance to culture, society, rules and more associated with the relationships and sexual behaviour going on around them. How and when do young people acquire their understanding of what it means to be a boy or a girl or to have a relationship, especially when language powerfully constructs the way people see the world and the way they make sense of their experiences of themselves and others? Friendship skills and interpersonal understanding need to be taught but the young person's personal motivation and emotional involvement in the process are vital; one must be involved in the process of being a good friend. Most of the (limited) research into sexuality and ASD has used a narrow definition of sexuality and has focused on observable sexual behaviour. We need to broaden the definition to include intimacy, emotional aspects of sexuality and relationships, self-esteem, attitudes and cultural values (Gray et al, 2000; Koller, 2000, Harpur et al 2003). The experience of being male, female, gay, straight, sexually active or celibate is mediated by the society and cultures in which we live. How then do people with Autism Spectrum Disorders absorb and learn the rules and rituals of their culture, and link their behaviour to the relationships and sexual behaviour going on around them? Behaviour which does not conform, is often subject to sanctions and I have had to work with increasing numbers of young people who are in trouble due to inappropriate sexual expression. In Britain and many other societies young people with ASD are bombarded with sexual images and attitudes via the media which they find difficult to integrate with the rules they are taught. (Jackson 2002).

In the past, many parents and professionals denied the importance of sexuality and reproductive health education and services for persons with autism, believing these individuals had no sexual feelings or desires and were not suited to have families of their own. Fortunately, many changes in social thinking have taken place, (Schwier and Hingsburger 2000) and the focus now is on promoting the reproductive and sexual dignity and autonomy of persons with developmental disabilities including autism spectrum conditions. This document aims to allow readers to consider the essential approaches and ideas about relationships, sexuality and vulnerability when working with children and young people with ASDs. Biology, social and cultural, interactional paradigms have been suggested in order to understand the development of gender and these point to the areas of socio-sex education needed in autism (Stainton Rogers and Stainton Rogers 2001). It will also look at the need to teach to cultural norms so that problem sexual behaviour does not develop.

A focus on language and functional skills development without a linked focus on emotional and social interaction has been a limitation in many educational interventions with people with an ASD. How and when do young people acquire their understanding of what it means to be a boy or a girl or to have a relationship, especially when language powerfully constructs the way people see the world and the way they make sense of their experiences of themselves and others? Friendship skills and interpersonal understanding need to be taught but the young person's personal motivation and emotional involvement in the process are vital; one must be involved in the process of being a good friend. A gender stereotype is a rigid set of beliefs about what men and women are like and labels those who deviate from these expectations as odd or unusual. Groups vary considerably in their expectations of appropriate behaviour in terms of gender. Some young adults with autism are unaware of the differences between men and women. Many boys with Asperger syndrome find a safe haven in mixing with girls at school and some girls with AS prefer the games that boys play and both may mimic the actions and behaviour of the opposite sex. All experience a 'culture lag' with their peers (Jansen 2005) missing out on learning the skills of adolescent relationships. Young people should have the chance to explore gender difference and how ethnicity and sexuality can influence people's feelings and options.

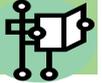
Young people can be exposed to a wide range of attitudes and beliefs in relation to sex and sexuality. These sometimes appear contradictory and confusing. For example, some health messages emphasise the risks and dangers associated with sexual activity and some media coverage promotes the idea that being sexually active makes a person more attractive and mature. In AS socio—sexual skills can be well known in theory, but sometimes give rise to problems in practice, (Henault and Attwood 2002). Teaching communication skills is vital including non-verbal communication. To be able to fit in young people with ASD need to learn the language of the teenage subculture, so that they can fit in more easily but also to prevent them from being teased. Filipinos know the soft handshake as welcome or goodbye greeting. But take into consideration that the initiative for handshaking has to come from the woman. A firm handshake is more the norm in the west. Which arm and finger movements are going to upset someone? If someone puts his hands on his hips, he is looked as arrogant or that he is angry. In some cultures it is regarded as impolite—even offending—if a person is beckoned with curled index finger or a pointing index finger is used. To show the outstretched middle finger is in many other parts of the world, an obscene gesture.

Individuals with AS and high functioning autism have levels of sexual desire and imagery comparable to those of the general population. The Asperger Syndrome sexual profile differs in several respects from that of the general population. The Asperger Syndrome sexual profile differs in several respects from that of the general population.. The body image, sense of belonging to one's sex and the erotic imagery of individuals with AS seem to be less influenced by social norms. Adults with Asperger syndrome would appear to act according to their internal desires regardless of whether they are directed to a person of the same or the opposite sex.

Can be very vulnerable to inappropriate approaches, suggestions from others. Consent issues are difficult to understand for many adolescents. "I said no but he did not stop".

Misunderstanding of friendship, 'I thought he wanted to be a friend but all he wanted was sex'.

Make sure that behaviors which are fine as a child are no longer carried out as an adult e.g. stroking women's hair or feet as severe penalties will be imposed.



Current research (Stokes and Kaur 2005) suggests that there is a difference between typical adolescents and able adolescents with autism in sexual behaviour that is consistent with the nature of an autism spectrum disorder. Adolescents with autism tend to display poorer social behaviors and more inappropriate sexual behaviors. They engage in fewer behaviors related to privacy, have poorer knowledge regarding privacy issues and have had less sex education.

In the most recent studies (Henault 2006) it is suggested that children and adolescents with an autism spectrum disorder need sexual education in a structured, systematic and concrete way but that it must also include socio-sexual skills and rules on behaviour and relationships (Couwenhoven 2001). Although it is problematic to teach a certain set of rules, to judge certain values and behaviors to be 'better' than others, all people who work with young adults with ASD are aware of the problems if rules are not taught. Unfortunately teaching young people the facts about friendship or sex is not in itself an effective means of promoting healthy friendships or sexual relationships. They need to have the experience of having friends. This can also be confusing. Each year at college I have young men who think they might be gay as they like going to the cinema or a football match with another male student from college. I have to say that this is the enjoyment you have with a friend which they have not experienced.

Bodies

- Women's and men's bodies
- Naming of private parts, the differences and similarities
- Puberty changes—menstruation and wet dreams

Depending upon their level of understanding:

Sex—Physical and practical aspects

- Touch, public touch—identifying boundaries and appropriate behaviour
- Masturbation
- Heterosexual activity—including consequences. Information on pregnancy
- Same sex activity—including consequences. Sexual health information
- Contraception
- Sexual health information

Sex—Social Aspects

- What does sex mean?
- Why do people do it?
- How do we learn about sex?
- Who can/can't we have sex with and why? Discussing laws and social rules
- Right times and places—public and private
- Keeping safe—discriminating between appropriate and abusive relationships
- Learning about others attitudes, opinions and beliefs

It is vital to teach friendship skills and as your child gets older so should his or her friends.

If people with an ASD are sexually active, what do they need to know?

- Consent
- Contraception
- Saying no and coping with people saying no to them
- Consequences (physical, emotional, social)

Can only be done with certain people in certain places (has rules)



MEMBERSHIP/ DONATION / PURCHASE ORDER

Name:

Address:

Province / Post code:

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Email:

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

Membership R 30

Family Membership R 40

Autism Safari CD of Papers Presentations R 250

Autism Safari Handout of CV's and Abstracts R 250

Autism Safari Photo CD—photos taken during Congress R 100

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.

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