



Autism Practical Aspects

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BROCHURES AVAILABLE FROM ASA

Information for Parents

Information for Teachers

Information for Doctors

Thoughts of a Sibling

Information on Asperger Syndrome

Dietary Intervention










4 books written by Michael MacGregor, an Adult with Autism

"I am growing up" – a book on Sexuality Issues.



This brochure was made available due to sponsorship from The National Lottery Distribution Trust Fund.

Some common characteristics of autism.

- 
 Little awareness of others.
- 
 Imaginative play may be poor. E.g. cannot play with a wooden block as if it is a car.
- 
 Minimal reaction to verbal input and sometimes acts as though deaf.
- 
 Changes in routine or the environment, may cause distress.
- 
 Pursues activities repetitively and cannot be influenced by suggestions of change.
- 
 Inappropriate attachment to objects.
- 
 Displays of extreme distress and or tantrums for no apparent reason.
- 
 Difficulty in interacting with others and little or no eye contact.
- 
 No real fear of dangers.
- 
 Prefers to play alone.
- 
 Self-injurious behaviour, e.g. head banging, scratching or biting.
- 
 Unusual habits such as rocking, hand flapping, spinning of objects etc.
- 
 Indifference to, or dislike of being touched, held or cuddled.
- 
 Sense of touch, taste, sight, hearing and/or smell may be heightened or lowered.
- 
 Sudden laughing or crying for no apparent reason.
- 
 Uneven gross/fine motor skills.
- 
 Abnormal sleeping patterns.



AUTISM SPECTRUM DISORDERS (ASD)

Autism Spectrum Disorder (ASD) is a genetic condition which results in abnormal brain development and function. A lot of research is being done to try and find the cause of autism, but as yet there are no definite answers. There is agreement however that autism is **no-one's fault**. It is **NOT** a psychological or emotional disorder. It is **NOT** the result of bad parenting and children with ASD do **NOT** choose to misbehave. Misbehaviours are often reactions to the environment and are expressions of the difficulties they experience.

The incidence of Autism Spectrum Disorders (ASD) is on the increase worldwide with international statistics implying that it now affects 1 per 158 children under the age of 8 years. ASD affects 4 times as many boys than girls.

It is important to remember that there is **NO social disgrace in having a child with autism or any other form of a disability**.

NOTE TO PARENTS: You have not made any mistakes. It is not your fault that your child has been born with autism.

Very simply, there are 3 main types of ASD

- 1. ASPERGER SYNDROME**
ASD does not always result in intellectual impairment. People who are affected by ASD can have a normal or above normal intellectual level with close to normal speech development. These people are referred to as having Asperger Syndrome. Approximately 25% of people with ASD have Asperger Syndrome.
- 2. CLASSIC / KANNER AUTISM**
When ASD is accompanied by intellectual impairment and/or learning disabilities, these people are commonly referred to as having "Classic" or "Kanner" autism. 75% of people with ASD have intellectual impairment or learning disabilities.
- 3. SAVANT FORM OF AUTISM**
Approximately 5% of people with ASD have the "Savant" form of autism. This subgroup of people can be described as individuals who have an almost "superhuman" skill in one area, along with extreme impairments. For instance, a person may well be able to play a full piece of music on a piano, after only having heard it once and never actually been taught to play the piano, but are unable to perform simple daily tasks.

"TRIAD OF IMPAIRMENTS"

Regardless what type of ASD a person has or how they manifest their particular form of ASD, it must be remembered that **ALL** people correctly diagnosed with ASD, are affected by the "Triad of Impairments". The Triad causes delays in development and ongoing problems in Language and Communication, Social Interaction and Imagination.

- 1. LANGUAGE AND COMMUNICATION**



- The development of speech and language may be abnormal, absent or delayed;
- There may be minimal reaction when people talk to them or they appear to be deaf;
- They may not understand tone of voice, gestures or facial expressions, e.g. frowning or grinning;
- They may take similes, metaphors or jargon literally (e.g. they may think 'daft as a brush' and 'throwing the baby out with the bathwater' are about brushes or babies);
- They may find it difficult to hold a conversation;
- They may repeat words, questions or phrases over and over again;
- People with ASD may speak clearly and properly but they can lack full understanding of what is being said to them;
- They may seem argumentative, stubborn, angry or over-compliant, agreeing to anything even if untrue;
- They may speak in a formal, stiff or stilted way;
- They may seem not to be paying attention or be unresponsive;
- They are known to be honest to the extent of being blunt or rude.

2. SOCIAL INTERACTION

People with ASD:

- May seem isolated or apparently not really caring about others;
- Find it difficult reading body language or understanding the need for politeness;
- Often behave inappropriately or oddly;
- May avoid eye contact when feeling worried or under pressure;
- May dislike physical contact;
- May prefer to play or be alone;
- Their apparent independence can disguise their isolation and social disability;
- May behave unpredictably because they have difficulty understanding social situations and language.

3. BEHAVIOUR AND IMAGINATION

- They play with toys inappropriately e.g. they line their toys up instead of playing with them;
- They cannot foresee the consequences of their actions;
- Changes in routine or environment, e.g. a change of route to the shops, or altering the position of furniture within the home, may cause distress;
- They may like set rules, and may overreact when people break or change them;
- Some may have special interests that become obsessions;
- They find it difficult to see or imagine another person's point of view;
- Some may have unusual habits such as rocking, spinning, finger-flicking, continual fiddling with objects, spinning objects, feeling textures, or arranging objects in lines or patterns etc;
- They may hold onto objects, e.g. carrying a piece of wool for the whole day;
- Tantrums may occur for a reason that those around them cannot see or understand;
- Interests and range of activities may be limited, e.g. only interested in puzzles.

You may well observe the following features:

- Little or no eye contact;
- No real fear of danger;
- Poor learning skills or resistance to normal teaching methods;
- Odd responses to noises, lights, smells etc, e.g. covering of ears, eyes, dislike to being touched;



- Crying or laughing for no apparent reason;
- Self-injurious behaviour, e.g. head banging, scratching, biting;
- Abnormal sleep patterns.

Heightened / Increased Sensory Perception

In addition to the "Triad of Impairments", people with ASD may well also have **HEIGHTENED OR LOWERED SENSORY PERCEPTION**. For instance, their sense of touch, taste, smell, sight and hearing may be more or less sensitive than normal.

This aspect differs from person to person and not all people with ASD have the same sensory disturbances. For instance, one person may have a heightened sense of smell and touch, whereas another person may only have heightened hearing and sight.

The effect that these sharpened senses has on a person with autism can be that their environment becomes a **bombardment of painful stimuli** that results in them reacting or behaving "differently". One can compare this to spending your life in a busy market place or nightclub where the music is too loud, the lights are always flashing, people are bustling around and there are many strong smells etc.

This aspect of ASD is a very important factor that must always be considered when trying to understand behaviours. Remember that the presentation of ASD in individuals can vary greatly.

DIAGNOSIS AND ASSESSMENT OF A PERSON WITH A SUSPECTED AUTISM SPECTRUM DISORDER

There is no physical test available to confirm whether a person has ASD. It can only be diagnosed through observation by a multi-disciplinary team that includes a Doctor, or during a full assessment by a single, but well-informed Doctor. This person bases a diagnosis on criteria as set out in several diagnostic manuals i.e. the International Classification of Diseases, 10th edition (ICD10, World Health Organisation 1992) and the Diagnostic and Statistical Manual, 4th edition (DSM IV, American Psychiatric Association, 1994).

In structured situations and in a limited time frame, an individual with autism may show no obvious signs of "autistic behaviour". Less obvious signs can be missed and therefore an incorrect diagnosis made.

The pattern of abnormal behaviour unfolds with time. The correct diagnosis can only be made by taking a **detailed developmental history from infancy** and obtaining equally detailed information concerning behaviour in different settings and at different ages.

We suggest that if you suspect that ASD is the diagnosis, you need to refer to the child to a Doctor who has good knowledge of ASD or developmental delays.

CHECKLIST FOR AUTISM IN TODDLERS (CHAT) (copyright of MRC/SBC1995)

The checklist for autism in toddlers (CHAT) is a brief screening instrument that is intended to detect possible Autism Spectrum Disorders in toddlers. Since it is a screening test, the CHAT provides a first level of evaluation leading to a "yes/no" decision that, at the current time, ASD is either unlikely or is possible (and requires further evaluation). The CHAT was published in 1992 by Baron-Cohen, et.al.. CHAT takes only about five to ten minutes to administer and score. Specific training is not required, and it can be administered by a variety of individuals. The CHAT is designed to be used with toddlers as young as 18 months of age.

The chat consists of nine "yes/no" questions to be answered by the child's parent. These questions ask if the child exhibits specific behaviours, including: social play, social interest in other children, pretend play, joint attention, pointing to ask for



something, pointing to indicate interest in something, rough and tumble play, motor development, and functional play. CHAT also includes observations of five brief interactions between the child and the examiner, which enables the clinician to compare the child's actual behaviour with parental reports.

Recommendations

1. It is important to identify children with ASD as early as possible. CHAT is a useful first-level screening method for children from 18 to 36 months of age in which there is any level of concern about possible Autism Spectrum Disorders.
2. If screening using CHAT suggests a possible Autism Spectrum Disorder, further assessment is needed to determine a diagnosis.
3. If screening using CHAT suggests ASD is unlikely, it is still important to:
 Assess the child for other developmental or medical problems that may have caused the initial concern.
 Continue regular periodic surveillance for problems that may be related to the cause of the initial concern.
4. It is important to remember that not all children with ASD can be identified early.
5. Because the time of onset and severity of symptoms vary, it is recommended that screening be repeated at various age levels when concerns as regards ASD persist.

CHAT – to be used by GPs or Health visitors during the 18 month developmental check-up.

Section A: Ask Parent

Does your child enjoy being swung, bounced on your knee, etc?	YES	NO
Does your child take an interest in other children?	YES	NO
Does your child like climbing on things, such as up stairs?	YES	NO
Does your child enjoy playing peek-a-boo/hide-and-seek?	YES	NO
Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?	YES	NO
Does your child ever use his/her index fingers to point, to ASK for something?	YES	NO
Does your child ever use his/her index finger to point, to indicate INTEREST in something?	YES	NO



Can your child play properly with small toys (e.g. Cars or blocks) without just mouthing, fiddling or dropping them?	YES	NO
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Does your child ever bring objects over to you (parent) to SHOW you something?	YES	NO
--	-----	----

Section B: General
Practitioner or Health

During the appointment, has the child made eye contact with you?	YES	NO
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* Get the child's attention, then point across the room at an interesting object and say 'Oh look! There's a (name of toy)!' Watch the child's face. Does the child look across to see what you are pointing at?	YES	NO
--	-----	----

Get the child's attention, then give the child a miniature toy cup and teapot and say "Can you make a cup of tea?" Does the child pretend to pour out tea, drink it, etc?	YES	NO
---	-----	----

Say to the child 'Where's the light?', or 'Show me the light'. Does the child POINT with his/her index finger at the light?	YES	NO
---	-----	----

Can the child build a tower of bricks? (If so how many?) (Number of blocks)	YES	NO
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CASE CONFERENCE – A SURVIVAL GUIDE FOR PARENTS WRITTEN BY PARENTS!

For parents, feedback meetings, a visit to the doctor or a team meeting can be a traumatic experience for parents. So here are a couple of hints that should make these meetings a little more understandable and less intimidating:-

1. **Be prepared**

- For a couple of days or so before your appointment, have a pen and paper close at hand, so that you can write down questions you would like to ask. All too often, we try and store questions in our heads and our nervousness causes us to forget them.
- Keep all your child's reports, test results and ages at which milestones were obtained etc in a file, in date order and take this information with you.
- If possible make sure that both parents attend these appointments, or if this is not possible, consider taking along a relative or a close friend for moral support.

2. **On the day**

- Take writing paper with you, to write notes as the interview takes place. Wear clothing that is comfortable and makes you feel emotionally strong and confident.
- If both parents attend the meeting, try not to sit next to each other. Sit opposite one another, so that you can visually communicate and exchange glances of reassurance and comfort.

- As far as it is possible as a parent, listen objectively and carefully to what the professionals are telling you. Do not be afraid to ask questions or ask for explanations of medical terms. If you have a list of questions, make sure you immediately write down the answer next to your question.
- If two of you are present at the meeting, both of you should take notes as this will ensure that you have an accurate record of the meeting.
- If time is running out and you have not asked all your questions, either book another appointment for as soon as possible, or leave behind your list and ask the doctor, therapist or teacher to please contact you with the outstanding answers.
- When you leave a doctor's room, X-ray department or any other meeting, take home the reports and films etc. If this is not possible ask if you can collect a copy. These reports could be required at a later stage and this may well prevent your child from possibly having to go through repeat procedures.
- Remember that the professional or the assessment team in front of you is there to help you and your child. They are on your side!

3. After the meeting

Read your notes soon after the meeting when the information is fresh in your mind as you may have missed something that you should have written down. What you can then do is write a summary of what you understood from the meeting and send this to the doctor or assessment team, asking them for confirmation of what you think you understood.

Remember you are not alone. There are many other parents who have gone through, or you are going through what you are experiencing.

Please contact the National Body for people with autism in South Africa (Autism South Africa) as they can offer you support, information and guidance. They can also put you touch in parents, schools, regional bodies, support networks and professionals in your area.

Even though you may feel shy or nervous, it really does help to speak to other parents of children with autism. You can share your feelings, swap ideas and form new friendships for both you and your child.

TIPS FOR DAILY LIVING

The following excerpts are taken from "Autistic Spectrum Disorders: Understanding The Diagnosis and Getting Help" by Mitzi Waltz, copyright 2002 by O'Reilly & Associates, Inc. Permission is granted to print and distribute this excerpt for noncommercial use as long as the above source is included. The information in this article is meant to educate and should not be used as an alternative for professional medical care. www.patientcentres.com (Some words have been slightly altered to match the South African way of life, and additional information has been added).

Haircuts



If you can figure out what it is about haircuts that upsets your child, try to remove those particular factors. If you can do this you may be able to get the job done at a regular but understanding hairdresser. Common problems and solutions

include:

- **Sensitivity to hairdressing salon odours.** Look for an old-fashioned hairdresser that does not use many highly perfumed shampoos. Unscented products are often available, but you may have to buy them yourself and take them with you. Try not to book an appointment at the same time that someone is having a perm or colour added to their hair as these products have very strong smells. Also try and get the first or last appointment of the day.
- **Sensitivity to the sound of buzzing clippers or snapping scissors.** Some people can tolerate one noise but not the other. You might consider taking along ear plugs, or a Walkman to drown out the surrounding sounds. Your hairdresser should happily work around headphones if it keeps your child in the chair! You might also choose to accept a longer hairstyle if hair-washing and brushing is not a problem as this would mean less frequent visits to the hairdresser!
- **Sensory sensitivity in general.** Try brushing your child's hair often and with a medium-soft hairbrush in an attempt for them to get used to their hair being brushed or washed. You could let your child sit on your lap during a haircut. Another solution is to get someone who knows how to cut hair to come to your home if the child strongly dislikes going to the hairdresser. Make sure you or your hairdresser uses a neck strip and a cape to keep hair off their skin and clothes as heightened sensitivity could really cause them a lot of discomfort and unhappiness.
- **Extreme hyperactivity.** One false move in the hairdresser's chair can result in strange hairstyles!! For this reason many parents cut hair whilst their child is asleep. Scissors work rather than noisy clippers should be used. Keep a brush and comb handy, and work slowly.

Toenail and fingernail clipping/cleaning



It may be an exaggerated fear of being cut, a desire to not lose a part of oneself, or the sound of the clippers, but many children with ASD hate having their finger or toenails cut. Large curved toenail clippers are easier to operate than smaller fingernail clippers. This is another job that parents can do while their child is asleep.

Bathing



If a child with ASD does not like bathing make bathing fun with bubble-bath, coloured soap pencils and toys.

It can be quite a challenge to get a child or adult with ASD to wash themselves independently mainly because they rely heavily on seeing things. A person with ASD may well wash mud off their hands and feet, but may not understand to wash their skin and underarms etc, because they cannot see any dirt so they do not see a reason to wash that area.

Some children who fear or dislike a bathtub may enjoy swimming. Encourage a child to get used to water by letting him run through a lawn sprinkler in a pair of shorts. The novelty of pools and sprinklers sometimes helps them get over the fear of getting wet.

Toilet Training



How do I know if my child is ready to be toilet trained?

Children with ASD may be delayed in learning toileting skills. Even the most able child may have difficulties recognising the sensations of needing to go to the toilet. The developmental level of the child may also be a factor in whether the child is ready to be toilet trained. Some literature on toilet training suggests waiting to start a toileting programme until a child is at least four years old for weeing and four and half for pooing.

The first sign that a child might be ready to start toilet training is when they start to become aware of needing to go to the toilet. For example, this may be displayed by changes in behaviour patterns, appearing distracted or fidgeting. Some children may become aware of a wet or dirty nappy and be able to inform their parents/carers of this situation. To know whether a child is ready for toilet training a good indicator is whether a child is able to remain clean for one to two hours at a time and during naps. If not, it is unlikely that a child is physically ready for toilet training yet.

When thinking about developing a toilet training programme it is important for the child is able to associate toileting with the privacy of the toilet/bathroom. Even prior to developing a programme, changing your child's nappy in the bathroom can help the child to realise this is where all the toileting happens. When introducing a potty, try to ensure that the use of it takes place in the bathroom.

Identifying at what time your child goes to the toilet

Observe your child over a few days or a week to see when he/she does a poo or wee. It is quite usual for a fairly regular pattern to emerge especially if mealtimes and drinks are provided at about the same time every day. Identifying a pattern can help to establish when to take your child to the toilet or put them on the potty as this will result in an increased likelihood of them using the toilet successfully.

Developing a toileting programme

When developing a programme and if possible, increase your child's liquid and fibre intake to increase their need for the toilet. Once you have identified specific times of the day when it is more likely that your child will need the toilet, developing the programme can be relatively straightforward. The idea is to take the child to the toilet prior to when they will usually need the toilet e.g. if your child usually soils their nappy at 9.00am, 11.15am and 1.00pm etc, take him / her to the toilet or sit him/her on the potty five or ten minutes earlier. Encourage him/her to sit for a set period of time to increase success. It can also be helpful to provide a drink 10-15 minutes before carrying out the toileting routine to increase the likelihood of them doing a wee or poo.

The bathroom needs to be a friendly environment for a child with an ASD. Providing your child with something to do while he/she is on the toilet can help to increase concentration and relaxation e.g. giving them a favourite book or toy to play with. Using timing devices such as an alarm clock or egg timer can help your child to identify when they have sat for the required length of time.

Rewarding is essential. Only you as parents will know what your child will feel is a reward. For some children it may be a favourite sweet, for others it may be five minutes playing with the water in the sink. If your child is able to sit on the toilet for the set amount of time, rewarding this behaviour will increase confidence and co-operation. It is also essential to reward your child after he/she has done a wee or poo. Once the toileting routine is established, gradually reducing the rewards will be necessary, but do not withdraw them too quickly as this may cause regression. Using visual information, (such a series of pictures that show what needs to happen during toileting time) may also improve the success of the toileting programme. This applies to even the most able of children.

(Taken from *The National Autistic Society – UK* www.nas.org.uk)

Clothing



What do you do with a child who strips off his/her clothes at every opportunity? First, try to find out why. The most common reason is a touch sensitivity as some children do not like the feel of the material, wool, labels, seams etc.

It is a challenge to see what can be done to make a child stay dressed for longer. There are several options such as using softer material, cutting off labels, even turning the item inside-out so the seams do not rub the skin. Children who cannot tolerate regular waistbands can often handle elastic-waist pants and shorts, especially those made with soft fabrics such as tracksuits.

For children needing to wear nappies, the nappy itself may be the problem. Check for and treat any nappy rash. Experiment with different types of nappies; try toweling, material or different brands of disposable nappies, or even try a larger size in case tightness around the waist and legs is the problem. Loose tracksuit pants can be comfortable over the nappies.

Many people with sensory problems prefer soft fabrics, such as cotton jersey or terrycloth, under stiff fabrics like denim. It can help to wash new clothing a few times before giving it to the child to wear as this can remove the stiff feeling and any unfamiliar smells.

If a child suddenly refuses to wear certain clothing, make sure you have not changed your detergent or fabric softener. Your child may not like the new smell or they may even have an allergy to the new washing-powder or softener.

Remove labels from inside the clothes if necessary and if name tags are required, do not sew them on the neck area, but rather on a side seam that is unlikely to the child's skin.

One solution that will save you money and problems is purchasing second-hand clothes instead of new ones. These pre-softened garments may already feel "just right." Again, they may need to be washed a few times to take away any bothersome smells.

Decorating for autism



When shopping for new furniture, pay extra attention to strong, easy-to-clean pieces. You may want to use sticky-back Velcro or Prestick to secure ornaments to shelves. It may be wise to put precious items out of reach.

Bunk beds and other items of furniture that encourage the child to climb or balance may not be a good idea for a child with ASD, especially as they often have no fear of danger and poor gross motor skills and abilities.

Shelves are often used as a ladder and therefore must be securely attached to a wall, or removed.

Some children seem to have a compulsion to move furniture around, often using pieces to build ramps up to places

they cannot reach or have been told not to go. Solutions include:

- Removing wheels or plastic sliders from furniture legs
- Choosing very heavy furniture
- Weighting or blocking the movement of furniture with heavy concrete blocks hidden beneath stuffed couches and chairs
- Literally attaching furniture to walls or the floor could be a solution.

If you want to have one or more nice rooms, either lock them or be prepared to stand guard at all times. Experienced parents can tell you that trying to keep an unlocked room supervised is almost impossible.



Childproofing dangerous items

Parents of crawling babies and toddlers take pains to remove hazards from their reach and this is something years.

Items that can be very dangerous include:

Glass items and windows. Some children seem to enjoy the sound of breaking glass and it may be worthwhile ensuring windows are covered with a specially designed film, or that a piece of foam covers the inside of the window is an inexpensive solution. Replacing the glass in windows or picture frames with unbreakable plastic may save accidents.

Window blind cords. These present a danger of hanging if the child puts her head inside the loop. Simply cut through the loop or cut the cords very short so they are out of reach.

Take a walk through your house with your child's size and interests in mind. If you notice and remove potential problems before your child sees them, you've done well. Here are some things to watch out for:

Exposed electrical plug points. You can buy plug covers from most hardware stores.

Exposed electrical wiring and extension cords. Any exposed wires should be covered with insulation tape or at least safely protected. Extension cords can either be eliminated by adding additional wall outlets or if necessary it may be better to secure them to the wall.

Electric fans. Box fans are less dangerous, but little fingers may still fit through the gaps. Experiment with fan placement. You might consider using ceiling fans rather than stand-alone fans.

Stove burners. Fire-guards can eliminate the attraction of touching fire, flame or glowing coals, but fire-guards can also cause burns if touched when hot. Some parents remove the knobs from their stoves and place a barrier in front of it. Add a disconnect valve for gas behind the stove or unplug it when not in use. Add locks to kitchen doors and keep the key hidden.

Matches, lighters, and combustibles. Lock these up, and watch out for guests who carelessly leave lighters



or matches on tables.

Household cleaning supplies, paints, solvents, and other chemicals. A securely locked cupboard is a must to keep household chemicals away from your child. Some young children with ASD have incurred serious brain damage by repeatedly sniffing gasoline, glue, or other solvents.

Medications, including herbal remedies and vitamins. Keep everything that is a medicine out of reach. Securely locked bathroom cabinets can work, but storing medications in the bathroom is not a good idea because of moisture levels. You should consider installing a similar cabinet in another room or use a simple lock-box. Small cash boxes work well and are available at office supply stores for a reasonable price. For convenience's sake, you may wish to keep one week's medications, supplements, and vitamins counted out in a plastic pill box, then keep that pill container in another secure location. Be especially wary of leaving chewable medications and vitamins within reach.

Cigarettes. You would think they'd taste too horrible to eat, but some children have been known to eat them. Tobacco is dangerous when eaten. Keep cigarettes, snuff, cigars, chewing tobacco, and full ashtrays away from children.

Alcohol. It's dangerous to mix even a little alcohol with many of the medications used for people with ASD. If you like to keep a selection of different alcoholic drinks at home, you must consider a locked cupboard, or keep a separate refrigerator in a locked garage.

Knives. Sharp knives are common household tools, but of course they are very dangerous. You should think of installing a lock on the knife drawer. Watch out for knives and other sharp kitchen tools that may be left in the sink, on kitchen counters or in the dishwasher.

Safety precautions



Some children with ASD seem to have a special skill at being able to escape from their rooms, homes and gardens. This "talent" and the common lack of a sense of danger can obviously result in some very serious accidents.

Security options that parents have tried, with varying degrees of success, follow:

Installing key locks or doorknobs with twist-locks facing outward on bedroom doors can keep a child securely in his room at night. Obviously, toileting could be a problem in a child is in a locked room. An intercom or buzzer to summon parents can solve this problem (as could a potty for those willing to try it). Never leave a heater unattended in the room.

Latch-style locks, hook-and-eye hardware, or chain-locks installed at the top of interior doors can limit access to certain rooms, or keep a child in one room. Of course, these can be opened easily when a child gets taller, becomes strong enough to force the door, or figures out how to stand on a chair to reach the latch.

Double or triple-bolt security doors on the outer doors can slow down a person with ASD who likes to run away. Keep the keys well hidden but where others know where they are in case of fire.

Windows can be nailed or latched shut, taking into account the fire-hazard this causes.

Bars can also be placed on windows and alarms are available that will warn you if a door or window is opened.



Depending on your child's speed, this may not give you enough time to catch the child before he/she gets to the roadside or pool etc. Strong high fences and gates are a good idea for the perimeter of your property.

A bracelet or necklace can be made with the parent or carer's mobile phone number that the child wears at all times. Information you might want to have engraved on this item **include**:

- I have Autism
- I cannot speak
- I do not really understand words
- I do not have a sense of danger
- Please contact

THE SENSORY WORLD OF THOSE WHO HAVE SENSORY DISORDERS. Taken from the National Autistic Society (UK) Webpage (www.nas.org.uk) Adapted slightly for the SA community.

Introduction

To function and participate in the world around us, we need to use our senses. Senses help us to understand the environment around us and to respond to it. Senses play a significant role in determining what actions we take in a particular situation. Imagine what could happen and how it would feel if one, or all, of your senses were much more acute or where not present at all. This is particular dysfunction is called "Sensory Integration Dysfunction" and is found in most people with ASD.

Everyday functions (which the majority of us take for granted) for people with ASD can be painful and upsetting experiences. **Behaviours presented by someone with ASD will often be a direct reaction to their sensory experience.** It is therefore understandable why people with ASD create rituals, or have self-stimulatory behaviours such as spinning, flapping and tapping, as this makes them feel that they are in control and safe in their unique and often frightening worlds.

The sensory system consists of 6 senses and these fall into two main areas; hyper (high) and hypo (low) sensitivity. It is important to remember however that both of these difficulties may be experienced by some people with ASD.

Sensory Difficulties

1. Balance (vestibular) system

For a person with ASD, difficulties/differences may be:

Hypo (Low)	The need for rocking, swinging, spinning. activities which include movement such as gross motor skills.	Hyper (High)	Difficulties	in
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Helpful Hints

Hypo (Low)	Encourage activities which help them develop their balance – rocking horse, swing, roundabout and see-saws.
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Hyper (High)	Break down activities into small steps, use visual cues such as a finish-line or physical or visual prompts.
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2. Body awareness (proprioception) system

For an individual on the spectrum difficulties/differences may be:

- Hypo (Low) Proximity - standing too close to others/not understanding personal body space and therefore bumping into people unintentionally.
- Hyper (High) Difficulties with fine motor skills, e.g. manipulating small objects (buttons, tying shoe laces) and moving the whole body to look at something.

Helpful Hints

- Hypo (Low) Position furniture around the edge of the room to make navigation easier and put coloured tape on the floor to indicate boundaries. Use an "arm's-length" rule.
- Hyper (High) Encourage threading activities and lace boards.

Smell (olfactory) system

- Hypo (Low) Some individuals have no sense of smell and fail to notice extreme odours or may lick things to taste them instead to make up for their lack of smell.
- Hyper (High) Smells can be intensified and overpowering, there may be toileting problems or a dislike of individuals with distinctive perfumes, shampoos, etc.

Helpful Hints

- Hypo (Low) Use strong nice-smelling products as rewards and to distract your child from inappropriate strong-smelling stimuli such as faeces.
- Hyper (High) Use unscented detergents or shampoos, refrain from wearing perfumes, make environment as free as possible from smells.

Sight (visual) system

- Hypo (Low) May see objects clearly, lose features or lines. For some they may concentrate on their peripheral vision because their central vision is blurred; others say that a main object is magnified and things on the periphery become blurred. There can be poor depth perception like problems with throwing and catching as well as clumsiness.
- Hyper (High) Distorted vision occurs and objects and bright lights can jump around. Fragmentation of images, as a consequence of too many sources. Focusing on particular detail (sand grains) more pleasurable than looking at something as a whole.

Helpful Hints

- Hypo (Low) Increase the use of visual cues, prompts and pictures.



Hyper (High) Reduce fluorescent lighting by using deep-coloured light bulbs instead, provide sunglasses, and create a work station in the classroom: a space or desk with high walls or dividers on both sides to block out visual distractions from the front and sides. Use blackout curtains.

Hearing (auditory) system

Hypo (Low) Sounds may only be heard with one ear, the other ear either only having partial hearing or none at all. The person may not acknowledge particular sounds, yet enjoy crowded noisy places, kitchens and banging doors and objects together.

Hyper (High) Volume of noise can be magnified and surrounding sounds distorted and muddled with an inability to cut out particular sounds - difficulties concentrating, or may have a lower hearing threshold, which makes them particularly sensitive to auditory stimuli, for example hearing conversations in the distance.

Their hearing impairment can have a direct effect on their ability to communicate and may also affect their balance.

Helpful Hints

Hypo (Low) Use visual cues to back up verbal information.

Hyper (High) Shut doors and windows to reduce the external sounds. Prepare the person before they go to a noisy place or crowded situations and offer ear plugs or a walkman.

Touch (tactile) system

Hypo (Low) Holds others tightly, has a high pain threshold for instance as regards temperature/pain. There can be self-harming and they enjoy heavy objects on top of them.

Hyper (High) Touch can be painful and uncomfortable and they will often withdraw from aspects of touch, which can have a grave effect on their relationships with others. A dislike of having anything on hands or feet, difficulties in brushing and washing hair and only likes certain types of clothing or textures.

Helpful Hints

Hypo (Low) Weighted blankets / sleeping bags.

Hyper (High) Warn the person if you are about to touch him or her; always approach him or her from the front. Remember a hug may be painful rather than comforting. Gradually introduce different textures - have a box of materials available. Allow the person to complete the activities themselves, enabling them to regulate their sensitivity (e.g., hair brushing and washing).

Taste (gustatory) system

Hypo (Low) A like for very spicy foods, eats everything - soil, grass, materials.

Hyper (High) Some flavours and foods are too strong and overpowering for them and certain textures also cause discomfort; some children will only eat smooth foods such as mashed potatoes or ice-cream.



Possible strategies - A greater understanding of the sensory world of individuals on the spectrum allows you to help them develop in a more comfortable environment. The following ideas and strategies should help when trying to create a comfortable environment for an individual on the spectrum to avoid their senses being overloaded.

Awareness - Knowing that sensory dysfunction may be the reason for the problem, always examine the environment.

Prepare - Always warn the individual of possible sensory stimuli they may experience, e.g. vacuum cleaners, electrical tools, loud crowded places.

Examples of problems, followed by the possible sensory reason and ideas:-

Picky eater - sensitive to taste or texture, maybe unable to feel the food around mouth - slowly introduce different textures around the individual's mouth, e.g. flannel, toothbrush, foods, introduce small portions, change texture of the food, purée it. Encourage activities that involve the mouth, such as whistles, bubble wands, straw painting.

Chews on everything, including clothing and objects - may find this relaxing, enjoys the tactile input of the item - latex-free tubes, straws, hard gums (chill in fridge).

Smearing - may like the texture in their hands or be hypo sensitive to smells - try and introduce similar materials such as jelly, cornflour and water.

Refuses to wear certain clothes - dislike the texture or pressure on their skin, turn items inside out so there is no seam - remove any tags or labels; allow them to wear clothes that they are comfortable in.

Difficulties getting to sleep - may have difficulty shutting down senses, in particular visual and auditory - use blackout curtains, allow child to listen to music to cut out external sounds, use weighted blankets.

Finds concentrating in the classroom difficult - may have too many sensory distractions: too noisy (talking, bells, chairs scraping the floor), lots of visual stimuli (people, pictures on the wall), may also find holding a pencil uncomfortable (hard/cold) - position them away from the doors and windows, use furniture in the room to create an area free from distraction or if possible an individual workstation, try different textures to make the pencil more comfortable.

UNDERSTANDING OBSESSIONS, ROUTINES AND REPETITIVE BEHAVIOURS Taken from the National Autistic Society (UK) Webpage (www.nas.org.uk) Adapted slightly for SA community.

Obsessions, repetitive behaviours and routines are key features of Autism Spectrum Disorders. The way these characteristics present will vary from person to person.

Understanding obsessions, routines and repetitive behaviours

These may include arm or hand flapping, finger flicking, rocking, jumping, spinning or twirling, head banging and complex body movements. They may also include a preoccupation with parts of objects (such as the spinning wheels of toy cars), repetitive use of a particular object, such as the flicking of a rubber band or the twirling of string, or repetitive activities involving the senses (such as repetitive smelling, feeling of particular textures, and listening to different noises). (Howlin, 1998).

The exact nature and function of repetitive behaviours will vary according to the individual; however several reasons for these behaviours have been suggested including:



- An attempt to gain sensory input (e.g. rocking may be the individual's attempt to gain necessary stimulation for the balance system, hand flapping or finger flicking may provide visual stimulation).
- An attempt to reduce sensory input and environmental stimulation (e.g. focusing on a particular sound may reduce the impact of a loud and distressing environment).
- Repetitive behaviours are usually a coping strategy for dealing with stress and anxiety and to block out uncertainty.
- A source of enjoyment and occupation.

Obsessions

Obsessions can cover a diverse range of topics such as dinosaurs, computers, trains, historical dates or events, car registration numbers, bus or train timetables, postal codes, traffic lights, numbers, shapes or particular body parts such as feet or elbows.

Some people will remain interested in one area for their entire lives; others develop interests in new areas after particular time periods. Obsessions can be very intrusive in an individual's life and limit the person's involvement in other activities.

Another common characteristic of ASD is an attachment to particular objects. These may be particular toys such as figurines or model cars, or more unusual objects such as milk bottle tops, stones, shoes or bath plugs etc.

There may be several reasons why an individual with ASD may develop particular obsessions. The following are some possible reasons:

- Particular subjects or objects may provide structure, order and predictability to a person with an autistic spectrum disorder, which can assist the individual to cope with the changes and uncertainties of daily life.
- A person who experiences difficulties engaging with other people socially may refer to their area of special interest to facilitate conversation and to gain a sense of assurance in these situations.
- Obsessions may assist the individual to relax.
- The individual may gain extreme enjoyment from learning about a particular subject or gathering together items of interest.

Routines and resistance to change

Many people with an autistic spectrum disorder, of all ages and levels of ability, have a strong preference for routines and sameness. The individual may have a need for routine around particular daily activities such as mealtimes or bedtime, and may experience great distress if the routine is disrupted. Routines can become almost ritualistic in nature needing to be followed very precisely, with attention paid to the tiniest details. There may be a need to engage in a series of behaviours in an exact and almost compulsive way and the individual may become extremely distressed if interrupted before the completion of the ritualistic routine.

Some individuals may develop compulsive behaviours such as constantly washing their hands or checking locks; others may have obsessional thoughts regarding distressing topics such as death, illness or making mistakes (Howlin, 1998). Rituals may also be verbal in nature, and may involve the individual repeatedly asking the same question and requiring a specific answer.

The individual may find changes to their physical environment (such as the layout of furniture in a room) or the presence of new people/absence of familiar ones very difficult to manage. Even those changes to routine that others may enjoy such as holidays or birthdays can cause anxiety for a person with an autistic spectrum disorder. Sometimes minor changes such as transitions between two activities can be distressing, for others unexpected changes are the most difficult to manage. Some individuals can have very specific and rigid preferences when it comes to the food they



eat (such as only eating foods of a particular colour), the clothes they wear (egg only wearing clothes made from specific fabrics) or objects used on a day-to-day basis (such as the type of soap or brand of toilet paper they will use).

An individual's dependence on particular routines can increase during times of change, stress or illness and may even become more dominant or elaborate at these times (Attwood, 1998).

Attwood (1998) also suggests that an individual's dependence on routines may increase or re-emerge during adolescence in particular as a result of the personal, physical and environmental changes to which the individual will be exposed.

Routines can be highly intrusive in the lives of the individual, their family and carers. They can also cause extreme distress and limit the individual's experience and opportunities. However, it is important to remember that these behaviours often serve a very important function for the individual - to introduce order, structure and predictability and to assist the person to manage anxiety levels.

Responding to obsessions, routines and repetitive behaviours

Before looking at how we might respond to obsessions, repetitive behaviours and routines it is important to ask ourselves a number of questions:

- Does the person appear distressed when engaging in the behaviour or does the person give signs that they are trying to resist the behaviour? (e.g. someone who flaps their hands may try to sit on their hands to prevent the behaviour).
- Can the individual stop the behaviour independently?
- Is the repetitive behaviour, obsession or routine impacting on the individual's learning?
- Is the behaviour limiting the individual's social opportunities?
- Is the behaviour causing significant disruption to other people in the individual's life?

It is important to consider whether it is really to the individual's advantage for limits to be set around a particular behaviour. If the answer is yes to any of the above questions, then it may be appropriate to look at ways of assisting the person to reduce obsessive and repetitive behaviours.

Reduction in repetitive behaviours is achieved by making small changes and moving slowly. The focus should therefore always be on the development of alternative skills to assist the individual to self-regulate stress levels and to better deal with their environment.

Repetitive behaviours, obsessions and routines generally become more resistant to change the longer they continue. For this reason, it is important to set limits around repetitive behaviours from an early age. A behaviour that may be quite acceptable in a two or three year-old child may not be appropriate as the child gets older and may, by this time, be very difficult to change.

Environmental structure

Increasing structure in the physical and social environments can assist an individual to feel more in control of their world and may reduce anxiety. Reduced anxiety levels may consequently minimise the need to engage in repetitive behaviours and reduce reliance on routines. Increased environmental structure may also reduce boredom thereby further limiting opportunities for participation in repetitive behaviours.

- Visual cues such as objects, photos, symbols or written lists can help reduce some of the anxiety related to difficulties in predicting what will happen next in a sequence of activities and can support an individual who has a strong preference for routines. Information regarding visual cues can be found at the Do 2 Learn



website, which also includes a number of picture symbols which can be downloaded for free: www.do2learn.com

- Minimising the impact of sensory input such as noises (e.g. school bells) or smells (e.g. perfumes or soaps) can also assist the person to better cope with their environment.
- Changes are an unavoidable and important part of life which can present significant difficulties for many people with an autistic spectrum disorder. While it may not always be possible to prepare for changes to routines or circumstances, it is important to provide the individual with as much warning and preparation as possible. Gradually exposing the new object, place, person or circumstance to the individual in small, manageable chunks can help the individual to cope with the change.

Set clear and consistent boundaries for the behaviour

Setting limits around repetitive behaviours, routines and obsessions is an important and often essential strategy to minimise the impact of these behaviours on the individual's life.

- Clearly identify the repetitive behaviour, obsession or routine of concern (e.g. Peter likes to talk about train engines during most social interactions. Peter currently starts talking about train engines after approximately ten seconds of conversation for up to 15 minutes).
- Think about reasonable and achievable limits that can be placed around the behaviour for instance Peter is allowed to talk about train engines initially after 20 seconds of conversation for five minutes only. Dependent on how Peter copes with this, the time restriction will gradually increase and limits will be introduced around the number of times per day that Peter is allowed to talk about train engines and then around who Peter is allowed to talk about train engines with. The eventual goal may be for Peter to speak about train engines to family members only for one minute two times per day).
- Limits can be set in a range of ways dependent on the behaviour of concern:-
- Can carry five pebbles only at a time in his pocket;
- Can watch Thomas the Tank engine video for 20 minutes at a time twice per day;
- Spinning only allowed inside own home.
- It is important that a consistent approach to limit setting be adopted across environments to assist the individual's learning.
- Limits need to be set using clear and transparent rules which state where, when, with whom or for how long the behaviour is allowed to occur. Present this information visually (with a focus on when the individual is able to engage in the behaviour as well as when the individual is not able to engage in the behaviour) to assist the individual's understanding and to help them to cope with anxiety that restricted access to the obsession or activity may create.

Obsessions can be positively channeled to increase skills and areas of interest, promote self-esteem, and expand an individual's social group.

- An obsession with computers could be developed into a vocation in IT.
- A person with a special interest in historical dates could join a history group and meet people with similar interests.
- A person with knowledge of sport or music would be a valuable member on a quiz team.
- An interest in particular sounds could be channeled into learning a musical instrument.
- An obsession of tearing paper could be used to develop skills in making recycled paper.
- A strong preference for ordering or lining up objects could be developed into housework skills.

Obsessions can also be used to motivate and reward by following a less desired activity (such as homework) by a period of access to an obsession (such as extra time on the computer). "THEORY OF MIND AND "MINDBLINDNESS"



- Theory of Mind can be explained as one's ability to be able to consider and understand other people's thoughts and feelings, as this skill plays a major role in our interaction with others.

Mindblindness

- For the person with ASD this skill is severely impeded, resulting in the following difficulties:-
- Extreme difficulty in predicting possible behaviours of others, which can lead to the person with ASD developing a sense of insecurity and a resultant avoidance of people;
- Not being able to understand the intentions of those around him, nor understanding the motivations of their actions;
- A lack of understanding concerning their own emotions or the emotions of others. This can manifest as a lack of empathy, which is often not accepted or understood by the people within their social circle;
- Poor comprehension of how one's behaviour affects how others feel and think about you. This can lead to a lack of motivation to please and a lack of conscience;
- Minimal understanding/concern regarding what people know or want to know and a defective ability to detect or react to their audience's level of interest This can result in either, the person with ASD speaking endlessly on a subject.
- Minimal understanding as to why their focus of attention must change, whether it be in a conversation, or in a classroom setting etc.
- Due to a lot of inabilities in the area of social interaction, there is often a lack of understanding as regards the need to "take turns" in conversation and allowing others to talk without interruption, or the need to take takes turns in the playground etc;
- All of the above adversely affect the person's ability to establish and maintain friendships, benefit from daily life, learning and teaching.

PLACING A CHILD WITH ASD IN A SCHOOL SETTING

When considering a school there are varying issues that must be considered:-

1. Bear in mind that it is not only the child's education that is important, but how that school's environment will affect the child emotionally on a day to day basis;
2. The teaching staff at the school must have a broad and sound knowledge of ASD;
3. The ethos and curriculum of the school must be able to accommodate and be sympathetic to a child with ASD;
4. Be wary of schools that have too many children in each class. A good ratio for a child with ASD is 6-8.
5. Ensure that there are open channels of communication between the parents and teachers and that the staff are willing to listen to the parent's thoughts;
6. Be sure that the school can and will modify your child's educational plan to accommodate the problems that can occur as a result of the Triad of Impairments;
7. Study the school policy as regards discipline for inappropriate behaviour;
8. Establish whether the classrooms are open plan, as this can cause great distraction for the child. It is preferable for children with ASD to have independent work stations with all their belongings close by;
9. Establish the availability of computer assisted learning and symbolic communication methods, should the need arise;
10. Be wary of a school where they have an overriding concern of treating all the children in the same way; this will not facilitate flexibility for your child's needs;
11. Establish whether there will be the availability for your child to work with different age groups for different subjects;
12. If you struggle to find a school that can respond positively to the many questions as regards your child's education, then establish how "open" they are to constructive guidance from teaching staff from the schools specifically for learners with ASD.

Please feel free to contact Autism South Africa for assistance and further information.

