AUTISM SPECTRUM DISORDERS – A PARENT’S GUIDE

ABOUT THIS BOOKLET

This booklet has been assembled especially for parents and carers of children or adults with autism spectrum disorders (ASD). It will also be helpful for other professionals working with someone with ASD.

Everyone with an autism spectrum disorder is different, with their own particular strengths and challenges, so this booklet can only give you a general guide. It answers some of the questions you will have about how best to help your child and will give you pointers as to where to go for more help.

Throughout the booklet, the term “child” is used to mean anyone with an autism spectrum disorder, whom you are parenting or caring for.

IN THIS BOOKLET YOU WILL LEARN:

• The difference between Autism and High Functioning Autism.
• How to recognise the signs and get the right diagnosis.
• How to get help for yourself and your child.
• How to teach your child through play.
• Useful tips for coping with difficult behaviour.
• Some terms you will hear and what they mean.
• Where to go for additional information

OUR MISSION

“AUTISM NEW ZEALAND IS THE NATIONAL PRE-EMINENT PROVIDER OF SERVICES AND SUPPORT FOR PEOPLE ON THE AUTISM SPECTRUM AND THOSE WHO SUPPORT THEM.”
Up until recently the diagnostic criteria used terminology such as Autism and Asperger’s Syndrome. With the new DSM-V in 2013 the terminology will be Autism (LFA) and High Functioning Autism (HFA) and a third possible diagnosis of Social Communication Disorder (SCD).

How common is ASD?
Autism is much more common than most people realise, with approximately 1 person in every 88 having an Autism Spectrum Disorder.

WHAT ARE THE TRAITS?

AUTISM
If a person has significant problems in their development or abilities then it is useful to determine the areas where the problems occur.

Some people with autism find these things difficult:
• Telling people what they need, and how they feel.
• Meeting other people and to make new friends.
• Understanding what other people think, and how they feel.

Not everyone with autism will find these things difficult. This is because everyone with autism is different.

Some people with autism behave in the following ways:
• They may not speak. But they may use things like pictures or sign language to communicate.
• They may not understand what other people say.
• They may copy what other people say.
• They may only talk about their favourite subject.
• They may only take part in games or activities with other people.
• They may participate in repetitive activities with toys.
• They may like to play the same game or do the same thing every day.
• They may be very interested in one thing and know a lot about it.
• They may be good at remembering information.

WHAT CAUSES ASD?
The exact cause isn’t known, but research shows that genetic factors play an important part. More males are affected than females (four times as many), and as yet no one knows why. There is also much debate about environmental issues.

“Long ago I grieved for the child I didn’t have and along the way I fell in love with child I do have” – parent.

WHAT IS THE DIFFERENCE BETWEEN AUTISM AND HIGH FUNCTIONING AUTISM?
While all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities. However people with high functioning autism are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.
Other possible special characteristics of those with autism:

- They may find co-ordination difficult. This means that they may find it difficult to do things like use scissors, use knives and forks, or ride a bike.
- They may be very good at something, e.g. they may be very good at maths, art or music.
- They can be good at learning how to do something when they see someone else doing it.
- They may be good at concentrating on one activity.
- They may have learning disabilities, and other difficulties.

HIGH FUNCTIONING AUTISM (HFA)

Just like a person with autism, a person who is high functioning will have challenges. They will find it difficult to:

- Tell people what they need, and how they feel.
- Meet other people and to make new friends.
- Understand what other people think, and how they feel.

They may have fewer problems with speaking and are often of average, or above average, intelligence. They may have specific learning difficulties. These may include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD).

People with High Functioning Autism may:

- Be unable to play imaginatively with objects or toys or with other children or adults.
- Tend to focus on the detail of things rather than the ‘big picture’, for example, an earring rather than the person wearing it, or a wheel instead of the whole toy car.
- Have a limited range of imaginative activities, perhaps copied from others and followed rigidly and repetitively.
- Miss the point of activities that involves words, such as social conversation or books, especially fiction, and subtle spoken humour.
- Try hard to be sociable and can enjoy human contact.
- Find it hard to understand body language, including facial expressions.
- Have difficulty understanding gestures, facial expressions or tone of voice.
- Have difficulty knowing when to start or end a conversation and choosing topics to talk about.
- Use complex words and phrases but may not fully understand what they mean.
- Be very literal in what they say and can have difficulty understanding jokes, metaphor and sarcasm. For example, a person with High Functioning Autism may be confused by the phrase ‘That’s cool’ when people use it to say something is good.

In order to help a person with Autism understand you, keep your sentences short - be clear and concise.

CHALLENGING BEHAVIOUR

People with ASD may show challenging behaviours, such as running away, screaming, biting or kicking other people, socially unacceptable habits, or making negative and embarrassing remarks. Some children will have difficulties with learning to speak, toilet training, restricted diets, clothing that feels uncomfortable, being in large warehouse stores and supermarkets.

It is important to bear in mind that behaviour has a function and that there could be a number of reasons for it. These may include difficulty in processing information, unstructured time, over-sensitivity (hyper) or under-sensitivity (hypo) to something, a change in routine or physical reasons like feeling unwell, tired or hungry. Not being able to communicate these difficulties can lead to anxiety, anger and frustration, and then to an outburst of challenging behaviour.

Coping with a child who has an autism spectrum disorder (ASD) can be very difficult; particularly when they display challenging behaviour. It can be even more difficult to cope if your child is non-verbal. Challenging behaviour includes what would typically be considered physically aggressive behaviour.

The reason for this challenging behaviour may be:

- Frustration at not being able to communicate.
- Difficulty waiting for something, because of difficulty with concept of time and abstract thinking.
- An unfamiliar person.
- A change in routine.
- Over-sensitivity to noise, crowds, smells, touch, sight.
- Under-sensitivity – seeking out sensory input from pinching or slapping.
- Feeling unwell, tired, hungry, thirsty or uncomfortable.
- Not wanting to do something.

Behavioural Strategies:

- Speak clearly and concisely.
- Use visual supports.
- Identify emotions.
- Write a story for understanding.
- Give praise where praise is due.
- Modify the environment.
- Learn to relax as a parent and carer.
**THE IMPORTANCE OF EARLY DIAGNOSIS AND TREATMENT**

The earlier autism spectrum disorder is recognised in a child’s life, the better. Early diagnosis gives both you and your child access to the right services for effective intervention, treatment and management of the condition, as well as professional support for you and your family.

**SHARING INFORMATION WITH OTHERS**

Not everyone understands how to react around people with disabilities and one of the best ways to help people is to encourage and guide them to be flexible around the way they interact with your child.

**WHAT NEXT?**

**Getting The Right Help**

Autism Spectrum Disorder is not a disease and cannot be “cured”. People with ASD will always have ASD, however by learning to understand a person’s ASD, a lot can be done to make their life easier and also the lives of those who live with and care for them.

Because every individual is unique there is no treatment/therapy that works for everyone. At Autism New Zealand we encourage you to seek the help of professionals/carers who are able to positively help enhance the skill base, both physical and social, of your child in order for them to maximise their potential and independence as best they can. Autism New Zealand can give you information about the variety of management strategies and therapies available for you.

**What About School?**

Again because each child is unique the choice of setting in the school environment will need research and reasonable time to make the best possible choice available, including meeting eligibility criteria.

**The Right Help for Yourself – Getting Support**

The first step in coping with any disorder is to understand it. This isn’t always easy with Autism Spectrum Disorders. You may find it useful to follow these steps:

- Contact Autism New Zealand for services in your area.
- Get your extended family and/or friends involved. Teach them about your child’s Autism Spectrum Disorder. Ask them for help. All children enjoy and benefit from being part of a community.
- Seek counselling for yourself and your family if required.
The power of play

Some ideas for toys and other fun things to do:

Children with ASD tend to prefer toys that use visual and spatial skills, such as shapes and colour matching, jigsaw puzzles or building toys (like Lego).

What your child chooses will depend on their social and emotional maturity. What is really important is the value of play in a child’s daily life.

However, just remember that while it’s important for you to keep the age and sex of your child and the situation in mind, these activities may still be the most helpful thing you can do.

Physical Play

It is useful to encourage physical activities that don’t need imagination or the understanding and use of language. Exercise can reduce anxiety and will often reduce unnecessary behaviour. It also improves motor skills and coordination.

Try some of these:

- Swings
- Slides
- Climbing frames
- Paddling pools
- Trampolines
- Football
- Sand pits
- Rocking Horses
- Ride-on toys bikes
- Basketball
- Swimming

Games to play with others

Try to involve your child in play to help improve the quality of life for your child. At Autism New Zealand we have developed a specific programme called Way to Play which offers some simple, easy to use strategies to begin playing joyously together with your child.

Helping someone with ASD to cope in the world can be very demanding for the family, but the rewards are great. Remember that you are trying to improve the quality of life for your child and all those around them. You are also trying to help them develop language skills and behave in a more socially acceptable way so that others respond to them more appropriately, thus the children are happier.
Try to encourage your child to play simple games with others. Board games are an opportunity for them to learn about the idea of winning and losing, as well as developing turn taking skills.

Try some of these, most are available from Early Learning Centre shops and Toy shops
- Bubbles (bubble blowers)
- Colour torch (available from Early Learning Centres)
- Shape and colour matching, or sorting toys
- Jigsaws
- Jack-in-the-box or Tommy’s ‘Pop up Pirate’
- Duplo, Lego and other construction toys
- Marble Run toys
- Train toys from push’n’go versions to full train sets
- Drawing, colouring and painting, this includes toys such as Magnasketcher
- Picture or word lotto

Indoors
- Tapes of music including singing and dancing games
- Picture lotto games
- Guess Who?
- Snakes & ladders
- Chess
- Snap
- Skittles
- Connect 4
- Ludo

Outdoors
- Running and chasing
- Eating out
- Walking in the park
- Sand
- Travel
- Swimming and water play
- Sports
- Fairs, rides
- Animals
- Swinging

Computers
Computers and computer games are particularly fascinating. Set clear limits for the use of the computer. A timer can be used to enable children with ASD to judge the time that has been allocated for an activity. This is particularly useful as a tool in relieving stress and anxiety created by the child’s need for structure in their day and the need for clear communication of your expectations.

Also some of these may be useful:
- Character software, such as Pingu, Dr Seuss Living Books or Disney Magic Artist etc.  
  www.disney.com
- Software to develop vocabulary
- Software for young children
- Factual software, such as Microsoft Magic School bus, or the online encyclopaedia Encarta
- Software written with children with developmental delay in mind:
  Max and Friends: quality programmes on DVD that both entertain and educate children, developed as home based parent coaching programmes that replicate ABA therapy
  www.launchintolearning.org
- Ultimate Learning Software: The software supports both auditory and visual data processing while encouraging critical thinking and problem solving www.diigisoftdirect.com

MAKING THINGS EASIER FOR YOUR CHILD

Questions to ask yourself:
- What does your child like and dislike? What do they want and need?
- What do they respond to? What can they do? Who gets the best from them? What are they good at?
- Make some notes for yourself as you notice things as they occur to you.
  It might be helpful to keep a diary.
- Tell others what to expect.
- Protect your child from teasing from siblings, or from being bullied by others.
  You will need to help those around them to understand their different ways.
- Encourage other people to be gentle with them – patient and firm and also considerate.
- Establish routine and build in flexibility. Make your child’s day as predictable as possible. Establish regular and meaningful routines using pictures initially, so that they can understand their day and know what is going to happen next.
- When sudden changes occur, prepare your child and help them to manage the changes.
- Consistency is important as it will help your child understand what is happening and what is expected of them.
- Use of visuals, schedules and timetables
- Stories for understanding
- FANZ and Way To Play Programmes
COPING WITH DIFFICULT BEHAVIOUR

Some of the following strategies may be useful when you are facing particular challenges.

<table>
<thead>
<tr>
<th>THE BEHAVIOUR</th>
<th>THE STRATEGY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very bad language</td>
<td>Ignore. Teach safer phrases, such as ‘go away,’ or something else appropriate.</td>
</tr>
<tr>
<td>Very abusive remarks to strangers</td>
<td>Discuss their favourite topic when around strangers to distract them.</td>
</tr>
<tr>
<td>Obsessive possessiveness toward a person</td>
<td>Usually caused by high anxiety. Provide a schedule of activity.</td>
</tr>
<tr>
<td>Unprovoked aggression toward younger siblings</td>
<td>Set up a programme on emotions, concentrating on anger. Discuss their emotions and explain how it affects themselves and others. Use consequences to discourage unacceptable behaviour.</td>
</tr>
<tr>
<td>Physical violence and aggression</td>
<td>Check if there is an underlying medical cause, such as epilepsy. Allow them free time during each day. Have regular routines. Prepare a picture and word daily timetable. Constantly tell them about their routine and what is happening.</td>
</tr>
<tr>
<td>Obsession with collecting large amounts of items</td>
<td>Help them organise their collection. Encourage them to keep their collection in perspective.</td>
</tr>
<tr>
<td>Reluctance to accept change</td>
<td>Introduce new things very gradually. Use visual supports</td>
</tr>
<tr>
<td>Difficulty coping with others</td>
<td>Set up a quiet space somewhere in the home.</td>
</tr>
<tr>
<td>Expanding interests and ideas</td>
<td>Encourage new activities.</td>
</tr>
<tr>
<td>Light sensitivity</td>
<td>Investigate the use of tinted lenses, sun glasses or blue blockers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THE BEHAVIOUR</th>
<th>THE STRATEGY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sound sensitivity</td>
<td>Explain what may be causing the noises and what they are if the sounds are unavoidable; forewarn the child, use ear muffs.</td>
</tr>
<tr>
<td>Refusing to do activities with others that they don’t want to</td>
<td>Encourage short participation. Allow them to stay on the fringes, close enough to hear what is going on but at a comfortable distance from others.</td>
</tr>
<tr>
<td>Stress/anxiety</td>
<td>Create visual routines such as pictures in a daily diary. Plan regular ‘time out’ breaks to minimize stress.</td>
</tr>
<tr>
<td>Doesn’t understand emotions</td>
<td>Use a notebook for your child or teenager to record emotions. Encourage the child to draw faces and ask them to draw faces showing emotions. Show facial expressions in front of a mirror and get them to try making them. Use material suitable for their age. Get a scrapbook with photos of people they like, food, places, activities, etc. Children may feel overwhelmed by intense feelings. One simple way to begin to understand feelings is to label them. Talk about what people do to make you happy. Ask them what they can do to make people happy. Work on one emotion at a time, such as: happy 2 weeks; sad 2 weeks. Draw a thermometer showing from angry to happy.</td>
</tr>
<tr>
<td>Sleeping Problems</td>
<td>Make sure the cause is not a medical one. Establish a night-time routine. Reward your child for sleeping through the night. Do this gradually if anxiety is a problem.</td>
</tr>
</tbody>
</table>
WHAT ABOUT THE FUTURE

After School
From a university student with Asperger’s Syndrome

“It takes time for any student to settle into university life, but if you are autistic you need to be very patient with both yourself and others. Then, with the right support and understanding, you can do more than survive the process of gaining a degree; you can actually enjoy it too”.

The expectations you and your child have for their future will depend on their ability and needs, but also, and most importantly, on their dreams. It’s important that their path through life is their own choosing.

It’s a good idea to plan your child’s transition from secondary school to adult life early. A good time to begin this is after their first year of secondary school, so that their educational programme can be planned to fit their needs.

For example, some students with ASD may plan to go onto further education. In that case, there will be greater emphasis on academic preparations as well as work experience. For others, the educational programme may focus on work experience, community-based training and self care.

Here are some things that may be good to think about.

• When will your child be ready to leave school?
• What are their employment choices?
• What further training and education will they need?
• Where will they live?
• What transport needs will they have?
• What medical needs will they have?

What recreation and leisure opportunities will they have?

• How will they maintain relationships with family and friends?
• What income support/insurance might they need?
• Will they need advocacy/guardianship?
• What about Trusts, Wills and long term planning?

ABOUT AUTISM NEW ZEALAND

Autism New Zealand is a national registered not-for-profit organisation with 14 branches around New Zealand. It’s main purpose is to provide support resources and educational training and information on autism spectrum disorder (ASD) to people with these conditions, their family/whanau, carers and professionals working with them.

What we do:
At Autism New Zealand our goal is clear: to be the pre-eminent provider of training and support for people on the autism spectrum and those who support them.

Autism New Zealand makes a positive difference in the community by providing the following services and programmes.

• NAS EarlyBird ®
• Disability Information & Advisory Services
• Advocacy and liaison with other agencies on behalf of families
• National Conference (Bi-annually)
• Social Groups for those on the Autism Spectrum
• Holiday Programmes
• Way To Play
• Out Reach Programmes
• Seminars
• Newsletter
• New Parent Information
• Parents & partner Support Groups
• Social Skills Programmes
• Framework for Autism New Zealand (FANZ)
• 0800 Helpline 0800 288 476
HOW AUTISM NEW ZEALAND CAN HELP YOU

Books
Each Autism New Zealand branch has an extensive list of resources on Autism Spectrum Disorders. Books and DVD’s are available for hire, including communication aids. Please contact your local branch to discuss suitable materials you may need.

Knowledge
Autism New Zealand organises conferences, workshops and seminars for parents, teachers and other professionals. We also provide telephone support, make submissions to government departments on behalf of the autism community and continue to source current information and research.

Autism New Zealand Branches
Our branch network provides a range of services based on supporting the community needs. These services include resources and information for parents/carers. Parent and other support groups are managed. In some areas we provide Holiday Programmes. Our Outreach Coordinators make home visits and work alongside schools and professionals and families ensuring the optimum outcome for all involved.

Please refer to our website for details of your local branch. www.autismnz.org.nz

Contact with other organisations
Autism New Zealand works alongside other agencies and is able to provide recommendations should further help and support for families be required.

MEMBERSHIP

Autism New Zealand is a membership organisation and has over 10,000 general memberships. Financial membership fees enable Autism New Zealand to continue to provide much needed services in our community.

Please check our website to see how you can join today.

Autism New Zealand National Office
Level 1
Master Builders Building
271-277 Willis Street
Te Aro
Wellington 6011
Phone: 04 803 3501
Fax: 04 803 3502

Tips for talking to obtain support
- Take a support person with you
- Take notes
- Get a second opinion if you want one
- Write down questions before you go and insist on answers
- Use email to send questions in advance
- Go to the appointment prepared for a long wait in the waiting room
- Remember you may need to be a ‘squeaky wheel’ if you are struggling to get what you need
- Profile your child’s condition, and take relevant information with you
WHERE TO GO IF YOU NEED MORE HELP

Financial help
There are different types of financial help available, depending on your situation. Talk to Work and Income (or Senior Services if you are over 65). To find out what types of support you may be able to receive contact 0800 559 009, www.workandincome.govt.nz.

You may be entitled to receive:
- Child Disability Allowance (under 18)
- Disability Allowance
- Supported Living Allowance (over 16)

You or your child may also qualify for:
- Community Services Card
- Accommodation Supplement
- Subsidies for childcare
- Training Incentive Allowance
- Family Support
- Child Support
- Extra income support

Contact your local Work and Income New Zealand office for more information about the financial help mentioned in this booklet.

NEEDS ASSESSMENT AND SERVICE CO-ORDINATION AGENCIES
The Ministry of Health contracts with Needs Assessment and Service Coordination (NASC) agencies throughout New Zealand. Their role is to assess all the needs for your child, identify service options and arrange access to support services. For more information contact the Ministry of Health www.moh.govt.nz or your local branch of Autism New Zealand www.autismnz.org.nz.

EDUCATIONAL HELP
If your child has education needs related to their disability, help may be available. All services are free of charge if your child is eligible to receive them. Ministry of Education, Special Education staff or service providers work with children with moderate to severe special education needs at home or in kindergartens, early childhood education and care centres, and Kohanga Reo.

If your child is at school:
Most children with special education needs receive support and services from the school. If eligible, schools can arrange for specialist teachers to provide services or make a referral to the Ministry of Education, Special Education. An assessment of your child may be needed to determine whether they have mild, moderate or high special education needs.

Contact the Ministry of Education’s Special Education Information line 0800 622 222

OTHER SOURCES OF INFORMATION
- ADHD Resources (New Zealand) www.adhd.org.nz
- Allergy New Zealand Inc. Information Support line and membership: Ph: 0800 340 800 www.allergy.org.nz
- New Zealand Association of Gifted Children: (NZAGG) exists to promote the needs of gifted kids. www.giftedchildren.org.nz
- IHC (New Zealand Society for the Intellectually Handicapped) Incorporated Society (see Idea Services Ltd) advocated for the rights, inclusion and welfare of all people with an intellectual disability and support them to live meaningful and satisfying lives in the community. Ph: 0800 442 442 www.ihc.org.nz
- Parent to Parent: Supporting families who have a child or family member with disabilities, health impairments or special needs. Ph: 0508 236236 www.parent2parent.org.nz
- CCS Disability Action: Providing support so people with disabilities are included in the life of the family and in their community. Ph: 0800 2272255 www.ccsdisabilityaction.org.nz
1. I am first and foremost a child. I have autism. I am not primarily ‘autistic’.

2. My sensory perceptions are disordered.

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

4. I am a concrete thinker. This means I interpret language very literally.

5. Please be patient with my limited vocabulary.

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

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

8. Help me with social interactions.

9. Try to identify what triggers my meltdowns.

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

Ellen Notbohm – Author of *Ten Things every Child with Autism wishes you knew.*
How to contact us:

Physical Address: Autism New Zealand, 271-277 Willis Street, Te Aro, Wellington 6141
Postal: PO Box 6455, Marion Square, Wellington 6011
T: 04) 803 3501 • F: 04) 803 3502 • Helpline: 0800 Autism (0800 288 476)
E: info@autismnz.org.nz • W: www.autismnz.org.nz