

SASSG Sunraysia Autism Spectrum Support Group

Welcome to Autism

A guide for individuals and families living with an Autism

diagnosis in Sunraysia.









Mildura Country Women's Association



The Lions Club of Mildura & Red Cliffs



The Nexus Service Club of Red Cliffs



WELCOME ABOARD THE AUTISM JOURNEY!!!!

Congratulations!!!! You have successfully managed to navigate the long pathway of referrals, assessments and appointments and you have FINALLY reached a diagnosis within the Autism Spectrum.

"So, what next?" you might ask.

The first thing to remember is that you are NOT ALONE. There are many people and services available to support you.

This pack was designed by people whose lives have been touched by Autism. They all know someone who has been diagnosed with an Autism Spectrum Disorder and they understand how confusing and overwhelming it can be once you receive your diagnosis.

By following the simple steps contained within this information pack, you will be guided along the Autism journey and will hopefully alleviate some of those feelings you have at the moment.





THE AUTISM JOURNEY

- STATION 1: FIND OUT MORE ABOUT AUTISM SPECTRUM DISORDERS Information about Autism and Asperger's Disorder.
- STATION 2: **KNOW THAT YOU ARE NOT ALONE** Hear from those people who have already travelled the Autism journey.
- STATION 3: **GET SOME HELP** A guide to accessing local services.
- STATION 4: **FIND OUT ABOUT RESOURCES AVAILABLE** A guide to finding resources and information about Autism, including recommended resources and Autism 'experts'.
- STATION 5: **BE AWARE OF FUNDING OPTIONS** The what, where and how of different funding options available.
- STATION 6: **MAKE AN INFORMED DECISION ABOUT TREATMENTS** Taking a closer look at treatment options...
- STATION 7: **TELLING YOUR CHILD AND SIBLINGS ABOUT THE DIAGNOSIS** The Dos and Don'ts of telling your child about Autism.
- STATION 8: **STRATEGIES** Here are some practical strategies you may find useful
- STATION 9: **LOOKING AFTER YOURSELF** Looking after yourself is just as important....



STATION 1:

LEARNING MORE ABOUT AUTISM SPECTRUM DISORDERS

So, your child has been diagnosed with an Autism Spectrum Disorder.

"What does that mean?" "What is the difference between Autism and Asperger's Disorder?" "What kinds of treatments are there?" "Is there a cure?" "What is the cause?"

These are just a few of the questions you probably have swimming around in your head at the moment.

This chapter is designed to provide you with information that will assist you in understanding your child's diagnosis.

- PART A What is Autism?
- PART B What is Asperger's Disorder?
- PART C What causes Autism?
- PART D How common is Autism?
- PART E What is the difference between Autism and Asperger's disorder?
- PART F Is there a cure?



PART A – WHAT IS AUTISM?

The following information is obtained from the ACT-NOW website by Professor Bruce Tonge & Dr Avril Brereton.

Autism is a syndrome consisting of a set of developmental and behavioural features. The core features of Autism include impairments in three main areas of functioning;

- 1. Social Interaction
- 2. Communication
- 3. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities.

How does Autism affect children?

1. Social interaction

One of the key features of Autism is abnormal interpersonal relationships. Children with Autism often show a reduced responsiveness to or interest in people, an appearance of aloofness and a limited or impaired ability to relate to others. Children with Autism usually show very little variation in facial expression, have abnormal eye contact and tend not to engage in social imitation, such as waving bye-bye and pat-a-cake games. They rarely develop age-appropriate empathy or the ability to understand that people have feelings. Although children with Autism do develop some social relating skills, these skills are usually restricted or abnormal. Their ability to make friends is absent or distorted and they are usually unable to play reciprocally with other children.



2. Communication

Children with Autism usually have quite delayed and unusual speech. Approximately 50% of children with Autism will eventually have useful speech. Children with Autism also have an impaired ability to use gesture.

In those children who do develop language, the tone, pitch and modulation of speech is often odd and the voice may sound mechanical or flat in quality. Some children speak in whispers or too loudly and some speak in an unusual accent. Echolalia, the immediate repetition of what has just been said or the delayed repetition of phrases, is common. Some children repeat advertising jingles or large pieces of dialogue from videos, perhaps days later, for no apparent reason. Their understanding of spoken language is often literal and they do not understand metaphors such as 'shake a leg'.

Some children with Autism develop a wide vocabulary and expressive verbal skills, however, even they have difficulty with the pragmatic or social use of language. They have impaired ability to initiate conversation and maintain the 'to and fro' of a conversation.

3. Ritualistic and Stereotyped Interests or Behaviours

Ritualistic and compulsive behaviours are common, such as lining up toys and having rigid routines for daily activities. There is often a resistance to change in routine or the environment so that the child may become extremely distressed if a new route is taken to school, furniture in the house is rearranged or the child is asked to wear new clothes.

Hand and finger mannerisms and repetitive body movements, such as hand flapping or tip-toe walking, are common. There is often a fascination with movement of objects, such as spinning wheels. Children may look closely at the fine details of an object such as the edge of a table or spokes on a wheel, or collect objects such as buttons or twigs. Many children with Autism, especially in middle to late childhood, have unusual pre-occupations that they follow to the exclusion of other activities. These may involve a fascination with bus routes or train timetables in association with repeatedly asking questions to which specific answers must be given.

4. Play and Imagination

Children with Autism usually have rigid and limited play, with a noticeable lack of imagination and creativity. They may repetitively line up toys, sort by colour, or collect various objects such as pieces of string or objects of a certain colour or shape. Intense attachment to these objects can occur with the child showing great distress if these objects are taken away or the patterns are disrupted.

Older children may develop play that superficially appears to be creative, such as reenacting the day at school with dolls or acting out scenes from favourite videos. Observation of this type of play over time often reveals a highly repetitive scenario that does not change and cannot be interrupted.



5. Associated Features

Many other abnormalities are associated with Autism, such as unusual dietary habits, sleep disturbance, abnormalities of mood and self-injurious behaviour. Perceptual abnormalities such as lack of response to pain, heightened sensitivity to sound and preoccupation with tactile stimulation are also common. These features are not specific to individuals with Autism and may occur in other children with intellectual disability.

6. Intellectual Ability

The majority of children with Autism have intellectual disability. A recent review of the literature found that in most samples approximately 50% of cases exhibit severe intellectual disability, 30% mild to moderate disability and the remaining 20% have IQ's in the normal range.





PART B – WHAT IS ASPERGER'S SYNDROME?

(The following information is obtained from the Autism Victoria fact sheet).

Asperger's disorder is.....

A developmental disorder which falls within the Autism Spectrum. The main features of this disorder become obvious during early childhood and remain constant throughout life, although the common features and degree of actual impairment can vary. Rarely recognised before the age of three, it is more common in boys than girls. Core features of the syndrome are lack of social skills, limited ability to have a two way conversation and an intense interest in a particular subject. Most of these children attend normal primary schools.

Individuals with Asperger's syndrome experience difficulties in the following areas:

- 1. Communication
- 2. Social Interaction
- 3. Social Behaviour

Communication

Although these children are often highly articulate, content of speech may be abnormal, tending to be pedantic and is often centred on one or two favourite topics. Sometimes a word or phrase is repeated over and over in stereotyped fashion. Usually, there is a comprehension deficit despite apparent superior verbal skills. Non-verbal communication, both expressive and receptive is often impaired.



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Social Interaction

There tends to be impairment in two way social interaction due to an inability to understand the rules governing social behaviour. A lack of empathy with others and little or no eye contact may be evident. They can appear stuck at the egocentric stage of social and emotional development. They tend to perceive the world exclusively from their own point of view. Although interested in social relationships often social contact is made inappropriately.

Social Behaviour

Social behaviour is often naïve and peculiar. They can tend to become intensely attached to particular possessions often engaging in repetitive activities. They are often resistant to change and cope best when life is predictable. They prefer structure and may concentrate exclusively on matters in which they are interested. They are often 'loners' who never quite fit in because of eccentric behaviour, peculiar ways of speaking and a lack of social skills.

Common Features

Other features of Asperger's syndrome can include:

- Excellent rote memory, absorbs facts easily.
- Generally performs well with maths, science and reading.
- May be anxious and unable to cope with criticism or imperfection.
- Often victims of teasing and bullying leading to withdrawal into isolated activities.
- Can appear clumsy and have an unusual gait or stance.
- Often seen as odd or eccentric.
- Language often appears good but may have limited content and poor social understanding.
- Self-interested and lacks empathy.

Age of Onset

Asperger's disorder tends to be diagnosed later than autism in young children. Parents of young children with autism often recognise problems with behaviour and in particular, language development by about 18 months to two years of age. Because children with Asperger's disorder do not have delayed early language, or problems with cognitive development, there are few early signs that all is not well. It is more usual for parents to become concerned about their child's emerging unusual or odd behaviour and social development but these tend to be identified later, usually from about 3 to 4 years of age. Diagnosis of Asperger's disorder may not occur until the child has attended preschool or some other early childhood setting such as crèche. This is probably because the child's social and behavioural problems become more noticeable when the child is seen with peers in a more structured social setting where there are more demands for social interaction.



Some examples of how Asperger's disorder affects children

Acquisition of language follows a normal or even accelerated pattern, but content of speech is abnormal - pedantic, and may centre on one or two favoured topics.

Little facial expression, vocal intonation may be monotonous and tone may be inappropriate.

Impairment in two-way social interaction including an inability to understand the rules governing social behaviour. May be easily led.

Problems with social comprehension despite superior verbal skills.

Very rigid, prefer structure.

Well developed verbal memory skills, absorb facts easily, generally good level of performance at maths and science.

Highly anxious with a dislike of any form of criticism or imperfection.

Most attend mainstream schools and are often victims of teasing which causes withdrawal into isolated activities.

Are seen to be "odd" or "eccentric".

Please note that the diagnosis of Asperger's disorder/syndrome is likely to be removed in the new Diagnostic and Statistical Manual – Fifth Edition (DSM-V) to be released in 2013. It is proposed that Asperger's will then be diagnosed as Autism (with modifiers/features).





PART C – WHAT CAUSES AUTISM?

(This information is obtained from the ACT-NOW website by Professor Bruce Tonge and Dr Avril Brereton).

The exact causes of Autism are unknown. We do know that it is a biological condition that children are born with.

Genetic factors play an important role in the causation of Autism, although which genes are involved has not been determined. People with Autism probably share features of abnormal brain function, but the nature of these remains elusive and controversial.





PART E – HOW COMMON IS AUTISM?

(This information is obtained from the ACT-NOW website by Professor Bruce Tonge and Dr Avril Brereton).

Recent international research (Chakrabarti and Fombonne, 2005) now suggests that the best estimate for the prevalence of all Autism Spectrum disorders is 60 per 10,000 population.

A three-year study commissioned by the Australian Advisory Board on Autism Spectrum Disorders into the prevalence of Autism, concluded that there is a prevalence of 62.5 per 10,000 or one in 160 Australian children aged between 6 and 12 years have an Autism Spectrum Disorder (ASD) (Wray and Williams, 2007).





PART D – WHAT IS THE DIFFERENCE BETWEEN AUTISM AND ASPERGER'S DISORDER?

(The following information is obtained from the ACT-NOW website by Dr Avril Brereton).

For the past decade or so there has been a continuing debate as to whether or not Asperger's disorder is a type of autism or whether it constitutes a separate disorder. Many publications have tried to delineate the boundaries, if any, between autism and Asperger's disorder. Despite the differences that can be seen when looking at the original cases described by both Kanner and Asperger, there is continuing confusion over the diagnostic criteria for Asperger's disorder, particularly as subsequent accounts and case studies have not necessarily adhered to the criteria suggested by Asperger himself. The principal areas of inconsistency relate to early development in the areas of cognition, motor skills and language.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and the Classification of mental and behavioural disorders (ICD-10) have attempted to introduce a consistent international approach to diagnosis and specify that the key differentiation is that **persons with Asperger's disorder do not have delayed language development which is a characteristic of Autistic disorder**. **Persons with Asperger's disorder have overall normal intellectual ability**. Approximately 20% of persons with Autistic disorder also have IQ in the normal range and are referred to as high functioning.

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PART F - IS THERE A CURE?

You may come across treatments that offer a 'cure' for Autism. At this stage, there is not enough known about the cause of Autism to be able to offer a cure.

Be wary of any treatments that offer a 'cure' for Autism. There are many treatments that may assist with improving some of the symptoms of Autism. It is important to make informed decisions about any treatments your child engages in.

You will find more information relating to treatments at Station 6.





STORIES FROM OTHER PARENTS AND CARERS

Build a Bridge

Like most first time expectant fathers, the thought of an impending new arrival brought with it the normal excitement and fears associated with such an important and special occasion. My wife, Shauna, and I spent countless hours preparing by attending birthing classes, renovating our new nursery and even arranging for her best friend to share with us the experience of the birth. At the time, these seemed important issues but in retrospect, they paled into insignificance compared with what was to come.

The great day arrived and the nursing staff regarded the birth as pretty regulation. Our doctor performed the post birth examination and declared our son fit and well. As a proud new father, my thoughts quickly raced forward to the day when my son would wear the baggy green cap, or the famous number five Essendon guernsey. So excited was I, that I even suggested to Shauna that our son should have the same initials as my father, and she readily agreed. I am not sure whether this was because she shared my view on peerage or because she was still under the influence of large doses of pethidine. We took our new son home, and all seemed well.

For the first few months, things moved steadily between mother and son, but occasionally, Shauna noticed things that did not seem quite right. As Rhys was our first child we had no way of comparing him with other children. Shauna had the normal banter with other mums, relatives and health professionals who all assured her that Rhys' inattentiveness and avoidance of eye contact would soon change and not to worry. Despite all this well-meaning encouragement, Shauna's intuition told her that all was not right.

Sure enough, at the age of about four Rhys was diagnosed with Pervasive Development Disorder - 'not otherwise specified' (work that out if you can!). As big a shock as it was, it was slightly softened by the fact that we had suspected for some time that all was not well with Rhys.

Notwithstanding our suspicions, the reality of a formal diagnosis immediately turned our world upside down. Our initial feelings were the normal 'why us' and 'could we have done something to prevent this?'. Our paediatrician explained that these things just happen and nothing could have been done to prevent it. It was nobody's fault. On learning of Rhys' condition, many of our friends and acquaintances attempted to console us by saying 'only special parents have children with special needs' a phrase which we have grown tired of from that day to this.

As reality set in, it was up to us to work through the maze of health professionals, government departments, child care and school facility issues that all had to be addressed. However, before we could take that step, we had to get over what I consider to be the biggest hurdle, and that was one of acceptance.



Shauna has on many occasions castigated me for moping around and sulking over the most trivial of issues. Her blunt and terse reply is to 'build a bridge and get over it'. As simple as this sounds, nothing else can be achieved until this first step is overcome. Acceptance of such a major issue can take different forms and vary from person to person. Whatever method is used, progression cannot continue until you have acceptance. When I speak to parents who are still waiting for a miracle cure, I know that they have not yet accepted their situation.

Fortunately, our acceptance did not take long and we were able to make some good decision in relation to Rhys.

Not least of all was our choice of school. At preschool Rhys displayed anti-social behaviour which placed an enormous strain on Rhys, his teachers, classmates and in particular, Shauna. Every time Shauna picked up Rhys from preschool, she was told of his antics during the day and often when I came home from work she was upset.

As with all parents, we endeavoured to give Rhys the best education we could. We decided to send Rhys to a specialist school and avoided the temptation of integration. After looking at a number of different schools, we made our choice and tried to get him enrolled. We assumed that with his diagnosis, and aggressive and anti-social behaviour, enrolling Rhys at the school of our choice would be a formality. This was not to be.

Rhys had to sit for an IQ test to assess his eligibility, and his IQ was one point over the threshold. Once again we were on the treadmill, chasing politicians, paediatricians and school principals in an effort to get him enrolled. Eventually, he was accepted; not on his diagnosis, but because of his anti-social behaviour and severe language disorder. We found this to be a good test for us. If you feel strongly about an issue, don't just accept the decisions of the bureaucrats, take it as far as you can because if you don't, no one else will.

Rhys is now ten years old, and has done extremely well at school. He is computer literate and loves spending hours at a time surfing the Internet. (Yet we are still dismayed by his compulsive behaviour and his need to delete icons and shortcuts from the desktop.) He also loves his football, but when he has had enough rather that put his football away, he kicks it over the fence next door to show he is finished.

For the past two years, Rhys and I have been able to share our love of football. These days he copes a little better with the big crowds, noise, flashing lights and the excitement of an AFL match at Colonial Stadium. We still have a few hiccups on match days, but in the main we both look forward to our 'boy's days'.

He loves his younger sister but when things don't go his way he takes his frustration out on her, despite the knowledge of having to spend hours in his room as punishment. He takes medication to curb his compulsive behaviour but he still struggles at times to cope with his condition. We also struggle, but with the support of a great network of friends and service providers that we have built over the years, life seems a little easier.

We have had to overcome many challenges over the past ten years but we often take a reality check, knowing that other families are worse off than we are. As a father with a son who has a disability, I have found my role is continually changing. Initially, I saw myself trying to support Shauna in getting the best results for Rhys, but now I am able to



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We have had to overcome many challenges over the past ten years but we often take a reality check, knowing that other families are worse off than we are. As a father with a son who has a disability, I have found my role is continually changing. Initially, I saw myself trying to support Shauna in getting the best results for Rhys, but now I am able to share in the many benefits he brings to our family. I now realise that my dream of him being a great sporting hero was just that and that we are lucky to have what we have.

While I would be lying if I said I would not want Rhys to be 'normal', we would not swap him for the world. We love him dearly, and although he has presented us with many challenges, he has helped us grow in many ways. We are generally more accepting of many issues both great and small, and as his life continues to move forward, hopefully ours will too. Thanks Rhys, we're enjoying the ride (most of the time).

Dad

'This personal account was obtained from the Association for Children with a Disability: <u>www.acd.org.au/information/dad_story_2.htm</u>'





A GUIDE TO ACCESSING LOCAL SERVICES

You probably don't know it yet, but there are loads of services in your local area that are waiting for you to contact them to provide support, information and advice. Here are some of them.....

Autism Specific Services

Name	Type of Service Provided
Lower Murray Medicare Local	Regional Care Co-ordinator- Autism Spectrum and Developmental Disorders Tanya Bott 220-228 Thirteenth St Mildura VIC 3500 Ph: (03) 5023 8633 Email: <u>tbott@lowermurrayml.com.au</u>
Sunraysia Autism Spectrum Support Group (SASSG)	Support for families of individuals with an Autism Spectrum Disorder. Opportunities for information seminars. Social outings for kids and parents. Community networking Newsletters Contact Details Phone: 0447 112 507 Office Location: 159 Langtree Avenue Mildura Postal Address: PO Box CP2084, Mildura VIC 3501 Email: <u>sunraysia.autism@gmail.com</u> Website: www.sassg.org.au Facebook: 'SASSG Discussions'
Loddon Mallee ASD Case Consultant Practitioner (Vic Autism State Plan)	Consultancy to professionals. Referrals / pathways for management. Practical info and resources. Promotion of ASD events. Mentorships to ASD Parent Support Groups. Contact Details Linke Smedts-Kreskas Phone: 03 5480 2388 www.clrsasd.org.au



Name	Type of Service Provided
Autism Spectrum Support & Evaluation Team (ASSET)	Autism assessment and diagnosis. Referral to support services. Contact Details By Pediatrician referral only. Contact the Child & Adolescent Mental Health Service (CAMHS)
Autism Victoria trading as AMAZE	Autism Victoria provides the following information services: The Spectrum is a print based magazine published quarterly and mailed to members. eSpectrum - is a periodic electronic bulletin emailed to all interested persons. Information Packages - Autism and Asperger's Syndrome - Our printed information packages are available on request from our office. Simply send us an email with your name and postal address, and whether you want the Autism or Asperger Syndrome package. Information packages are free of charge to families and service providers. Library - we have over 1700 books, videos and newsletters about Autism Spectrum Disorders. The Library is available to Autism Victoria members (and is available in Mildura via Postal Service) Guidance about Victorian service options and their contact details. At Autism Victoria you can talk to someone who knows about Autism Spectrum Disorders and can help you navigate the service maze. If we don't know the answer, we will try and find out. This service is free of charge Early Days Workshops-information sessions for newly diagnosed families from 0-6 years of age. Information can be found at the AMAZE website or at www.facebook.com.au/earlydaysworkshops Support - We have a Family Counsellor on staff. Our current counsellor is a psychologist experienced in Autism Spectrum Disorders. Our program of support services is free of charge to Autism Victoria members. Fees apply for non-members and for in-service presentations. Contact the Counsellor by phone - 96571606 or 1300 308 699 for non-metropolitan callers) and leave a message, or by email - counsellor@amaze.org.au Information Line (03) 9657 1605 or 1300 308 699 email: info@amaze.org.au Professional Advice Line 1300 598 272 Family Counsellor (03) 9657 1619
	Library and Membership (03) 9657 1601 Autism Advisors (Helping Children with Autism) (03) 9657 1608 or 1300 424 499



Name	Type of Service Provided
Mansfield Autism Statewide Service	Travelling Teacher Service is a service for families who have a child diagnosed with an Autism Spectrum Disorder / Asperger's Syndrome who resides within the family home.
Service	Assists families to develop the skill and confidence to work and live with their child/children who have an Autism Spectrum Disorder.
	Contact Details
	Phone : (03) 5775 2876 http://www.autismmansfield.org.au
Autism Spectrum Australia - ASPECT	Autism Spectrum Australia (Aspect) has been helping people with an autism spectrum disorder and their families since 1966. Aspect is the country's largest not-for-profit, autism specific service provider. We offer a range of services including diagnostic assessment, early intervention, schools and educational outreach, positive behaviour support, services for adults with autism, support and information for families.
	Contact Details
	Ph: 03 9377 6600 http://www.autismspectrum.o rg.au
RDI Consultants	
Donna Milne	Relationship Development Intervention Consultant (in training). Contact Details www.connectandrelateforautism.co m.au
Renee Dela Cruz	Contact: 0438 056 471 mailto:rdimildura@bigpond.com
	Visiting psychologist and Relationship Development Intervention (RDI) Consultant Contact Details
	www.connectandrelateforautism.com.au
	Contact on 0417 393 876 rdimelbourne@bigpond.com



Disability Services

Name	Type of Service Provided
Mildura Early Childhood Intervention Service	Transdisciplinary team of specialists providing family centred intervention support to families of children with a disability or developmental delay Contact Details Ph: (03) 5022 9038 for more information
Sunraysia Residential Service (SRS)	Lifelong support of individuals with disabilities. Educational programs, Respite, Recreation & social opportunities, Signposts program (to assist parents of individuals with a disability) Contact Details Ph: (03) 5022 1741 877 Fifteenth Street Mildura VIC 3500 <u>www.srsinc.com.au</u> <u>srs@srsinc.com.au</u>
Disability Client Services (Department of Human Services)	Can provide case management for individuals with a disability, particularly where behaviours are severe. Respite services. Contact Details Contact Statewide Disability Intake and Response service: 1800 783 783 or 1800 229 822
CRS Australia Commonwealth Rehabilitation Centre	Assistance to people aged 14-65 years with a disability to find and maintain employment Contact Details www.crsaustralia.gov.au
Mildura Specialist School	Vision: To provide students with intellectual disabilities the opportunities to realise their potential, and to gain utmost independence within the school, home and community. Contact Details Ph: 5021 3311 Principal: Marg Curran www.mildss.vic.edu.au



Name	Type of Service Provided
Mallee Accommodation & Support Program (MASP)	Support to young people and adults with a disability. Social groups. Family services Accommodation Contact Details Ph: 5021 6500 140 Langtree Avenue Mildura VIC 3500
Sunraysia Disability Resource Centre	"SDRC has been established to help and support you if you have just been diagnosed with a disability. SDRC supply information about services and support groups in our area. Our volunteers are here to assist you to source correct information on specialist aids and equipment." <i>"We're able to help!"</i> Office Hours at our Centre are Tuesday to Friday 10.00am – 3.00pm Contact Details Ph: 5023 2580 http://www.sdrc.org.au/ 159 Langtree Ave. Mildura VIC 3500
Education Contacts (Victoria)	
Department of Education Contact and Early Childhood	
Kim McCarty	Contact Details Ph: 03 5051 1324 mccarty.kim.m@edumail.vic.gov.au
Carol Brown – Disabilities Coordinator	Contact Details Ph: 03 5440 3126 brown.carol.a@edumail.vic.gov.au
Sharon Houlden Wellbeing and Engagement Program Coordinator	Contact Details Ph: 03 5400 3174 Houlden.sharon.l@edumail.vic.gov.au



Name	Type of Service Provided
Catholic Education	Contact Details
Teresa Cavallo	tcavallo@ceoballarat.catholic.edu.au
Tina Fersterer - Team Leader Student Services	Ph: 03 9267 0228 tfersterer@ceomelb.catholic.edu.au
Independent Schools Contact	Contact Details www.independentschools.vic.edu.au
Elspeth Adamson	Ph: 03 9825 7204 elspeth.adamson@independentschools.vic.edu.au
Home-schooling Contact Distance education Department Malcolm McIver	Local Services Guide, MILDURA (Parents and Carers) Page 6 of 16 Contact Details Ph: 1800 133 511
Catholic Education	www.distance.vic.edu.au Contact Details
Office Wilcannia Forbes	Ph: 02 6853 9300 Ask for a primary or secondary consultant
Independent Schools Contact	Contact Details
Robyn Yates	Ph (02) 9299 2845 ryates@aisnsw.edu.au
Home-schooling Contact	Contact Details
Home Education Network	Ph: 03 9517 7107 <u>Error!</u> <u>Hyperlink reference not</u> <u>valid.</u>
School Support Schools Welfare Officer	Your child's school may be able to access additional support for your child in the classroom.
	Contact Details Contact the School Welfare Coordinator.



Name	Type of Service Provided
Kristen Veltmeyer	Provides online tutoring and education programs for ASD children who are home schooled
	88 Vice Road Buderim QLD 4556 Ph(07) 5445 4124 <u>Email: info@positivecentre.com.au</u>
Department of Education and Early Childhood Development (DEECD)	Support workers (including: psychologists, social workers, occupational therapists and speech pathologists) may be able to assist your child at school and/or work with school staff to provide support to your child.
	Contact Details Ph: 5540 3111

Counselling / Mental Health

Name	Type of Service Provided
Centacare – Family	Individual, family and marriage counselling.
Services	
	Contact Details
	136 Lime Avenue Mildura VIC 3500
	Ph: 5021 2475
Sunraysia Community	Individual counselling.
Health Services	
	Contact Details
	Ph: 5022 5444
Malloo Family Caro	Holping familias improve parenting skills, and easks to
Mallee Family Care	Helping families improve parenting skills, and seeks to enhance family strengths and skills.
	Out of home Care is a home based placement
	service which arranges care for children 12 years
	and under who cannot live at home for a variety of
	reasons.
	The Family Preservation Program is home-based,
	offering intensive support for a three month period;
	working towards educating families.
	Contact Details
	Ph: 5023 5966



Name	Type of Service Provided
Private Practitioners	Supportive counselling in relation to management of
	difficult behaviours, social skills training, anxiety, etc.
	Contact Details
	The following list is not exhaustive:
	Dowdy's Wellbeing Centre Ph: 5021 4192
	233 Deakin Ave, Mildura
	reception@dowdyswellbeing.com.au
	Namalia Olinia
	Magnolia Clinic Ph: 5023 0075
	Lime Avenue, Mildura
	magclin@bigpond.net.au
	Mildura Kids Clinic
	Ph: 5021 5569
	www.mildurakidsclinic.com.au
	Sunraysia Psychological Services Ph: 5021 5171
	Gerald Purchase, Psychologist Ph: 5021 1697
	Kate French, Psychologist
	Ph: 5021 5569
	kfrench@iprimus.com.au (includes anxiety groups for children with Autism
	Spectrum Disorders)
	Additional listings in Yellow Pages.
ADHD Support Group	Support for families who have a child diagnosed with ADHD
	Contact Details
	Leeann Rothwell
	Ph: 0409 423 176



Name	Type of Service Provided
National Carer Counselling Program	Short term counseling for people caring for a family member with a disability or challenging behaviours.
	Contact Details Ph: 1800 242 636
	www.carersaustralia.com.au
Child & Adolescent Mental Health	Assessment and case management for individuals
Services (CYMHS)	with significant mental health issues.
	Contact Details
	Contact the CYMHS Triage worker on Ph: 5022 3500.
	Mildura Base Hospital
	Ontario Avenue
	Mildura VIC 3500
Primary Mental Health Service	Counselling support for individuals with anxiety and depression.
	Contact Details
	GP referral required.
	Ph: 5018 7900 107 Pine Avenue Mildura VIC 3500
Relationships Australia	Telephone Counseling
Australia	Contact Details
	Ph: 1800 817 869
Men's Line	Telephone Counseling for men
	Contact Details Ph: 1300 789 978
Sunraysia Rural Counselling Service	Financial Counseling
	Contact Details Ph: 5022 0799
Dad's in Distress	24 hr counseling service
	Contact Details Ph: 1300 853 437



Name	Type of Service Provided
Life Line	24 hr counseling service
	Contact Details Ph: 13 11 14
Suicide Helpline	24 hr counseling service
	Contact Details Ph: 13 00 651 251
Parent Line	Counseling service
	Contact Details Ph: 13 22 89
Kids Helpline	Free Online counseling service specifically for young people aged 5 – 25 years.
	Contact Details Ph: 1800 551 800 www.kidshelp.com.au
Carers Victoria	Information regarding local services and support for carers.
	Counselling, support and respite connections.
	Contact Details Ph: 1800 242 636
	http://www.carersvictoria.org.au
Beyond Blue	Depression – You're not alone. 24 hr counseling service
	Contact Details Phone: 13 22 890 1300 224 636
	Infoline@beyondblue.org.au



<u>Advocacy</u>

Name	Type of Service Provided
Regional Information & Advocacy Council Inc	The Regional Information and Advocacy Council (RIAC) provides Individual Advocacy and Systemic Advocacy services for people with a disability, their families and carers. This is a free service. Contact Details
	http://www.riac.org.au Ph: 03 5021 0265
	Freecall: 1800 993 263 148 Lime Ave, Mildura, Vic 3500
Australian Human	Contact Details
Rights Commission	www.hreoc.gov.au
Family Advocacy	Family Advocacy is an independent, disability advocacy organisation which works across New South Wales.
	The organisation works with families in which there is a child or an adult with a developmental disability.
	Contact Details
	www.family-advocacy.com Email: familyadvocacy@family-advocacy.com Ph: 9869 0866
Victorian Equal Opportunity and Human Rights	The Advice line can be contacted by phone or emailing: adviceline@veohrc.vic.gov.au
Commission	
	Provides information about their rights or responsibilities under anti-discrimination law. Weekdays 9am-5pm
	Contact Details www.humanrightscommission.vic.gov.au Ph: 1300 292 153
Association for	Run by parents, ACD undertake a range of systemic
Children with a Disability	advocacy and community education activities. Free telephone information and advice on any issues concerning children with a disability.
	Contact Details Ph: 1800 654 013 www.acd.org.au



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Family Support Services

Name	Type of Service Provided
Centacare – Family Services	Individual, family and marriage counselling.
	Contact Details
	Ph: 5021 2475
Suprovoio Community	136 Lime Avenue Mildura VIC 3500
Sunraysia Community Health Services	Individual Counseling service
	Contact Details Ph: 5022 5444
Mallee Family Care	Helping families improve parenting skills, and seeks to enhance family strengths and skills. Out of home Care is a home based placement service which arranges care for children 12 years and under who cannot live at home for a variety of reasons. The Family Preservation Program is home-based,
	offering intensive support for a three month period; working towards educating families. Contact Details Ph: 5023 5966
Child First	Child and family information Referral and support team Aiming to support the safety, wellbeing and health of young children and their families.
	Contact Details Ph: 1300 625 533
Chances for Children Mallee Family Care	Financial assistance and mentoring of young people to assist them to achieve their goals, regardless of financial position.
	Contact Details 122 Ninth Street Mildura VIC 3500 Ph: 5023 5966 www.malleefamilycare.com.au
Centrelink	Information on financial assistance available to families.
	Contact Details 112-124 Deakin Avenue Mildura VIC 3500 Ph: 131 021 www.centrelink.gov.au



Name	Type of Service Provided
Family Relationship Centre	Information and referral to help strengthen family relationships. Advice and dispute resolution (mediation).
	Contact Details
	105 Lemon Avenue Mildura VIC 3500 Phone: 1800 667 382
Man & Family	www.malleefamilycare.com.au
Men & Family Relationships	Assisting men to balance work and family life issues.
Program - MFC	Contact Details
	105 Lemon Avenue Mildura VIC 3500 Ph: 5021 7400
Mildura Rural City	Maternal and childcare
Council – Family Services	Playgroups Playcentres
	Toy libraries
	Positive Parenting Program
	Contact Details
	108-116 Madden Avenue Mildura VIC 3500 Phone: 5018 8271
Mallee	Support to young people and adults with a disability.
Accommodation &	Social groups.
Support Program (MASP)	Family services Accommodation
	Contact Details
	Ph: 5021 6500
Avalan Family	140 Langtree Avenue Mildura VIC 3500
Avalon Family Connexions	Family counselling
	Contact Details
	536 Ontario Avenue Mildura VIC 3500
Signacoto	Ph: 5023 7260
Signposts	Parenting program designed to assist in designing a personalised program for children 3 – 16 years to
	assist in managing difficult behaviours.
	www.signposts.net.au/
	Contact Details
	Julie Riley Organisation: Private Practitioner
	Phone: 0412 293 700
	Win Moser
	Organisation: Mallee Family Care
	Phone: 03 5023 5966



Occupational Therapy

Name	Type of Service Provided
Megan Dalla Santa	Occupational Therapy assessment and treatment, including sensory processing difficulties, Autism, handwriting, motor co-ordination, visual perception and auditory processing. Contact Details Mildura Kids Clinic 181 Walnut Avenue
	Mildura VIC 3500
	Ph: 5021 5569 Mobile: 0412 026 336
Sunraysia Community Health	Occupational therapy assessment and intervention
Service	Contact Details
	Contact Belinda Dixon
	Sunraysia Community Health Service, Mildura Ph: 5022 5444

Speech & Language Therapy

Name	Type of Service Provided
Linda Phillips	Speech and language treatment for children and adults, specialising in learning difficulties, Autism, stuttering, voice disorders and dyslexia.
	Contact Details Mildura Kids Clinic 181 Walnut Avenue Mildura VIC 3500 Ph: 5021 5569 Fax: 5023 4743
Brooke Gibbons	Speech and language therapy and assessment Contact Details Ph: 0419 346 315



Name	Type of Service Provided
Sunraysia Community Health	Speech and language therapy and assessment
Service	Contact Details Contact Mel Bauer Sunraysia Community Health Service, Mildura Ph: 5022 5444
Mildura Base Hospital	Speech and language therapy for pre-school aged children.
	Contact Details Mildura Base Hospital Allied Health Department Ph: 5022 3250

<u>Dieticians</u>

Name	Type of Service Provided
Karen Bulman	Assistance with dietary advice. Areas of interest include: healthy eating, eating disorders, obesity, insulin resistance, diabetes, heart disease, irritable bowel syndrome and sports nutrition. Contact Details Mildura Kids Clinic 181 Walnut Avenue Mildura VIC 3500 Ph: 5021 5569
Sunraysia Community Health Service	Dietitian services Contact Details Contact Candice Sunraysia Community Health Service, Mildura Ph: 5022 5444



<u>Psychology</u>

Name	Type of Service Provided
Wendy Leane	 Psychological assessment and counselling for children and adults. Areas of interest include: assessment for learning difficulties and developmental disorders, counselling for grief and loss, school problems, anxiety and depression. Contact Details Mildura Kids Clinic 181 Walnut Avenue Mildura VIC 3500
	Ph: 50215 569
Kate French	Psychological assessments, including Autism assessments. Counselling and group programs. Special interest in working with children with Autism Spectrum disorders.
	Contact Details Kate French Mildura Kids Clinic 181 Walnut Avenue Mildura VIC 3500
	Ph: 5021 5569
Lienne Wenzel	Psychologist. Anxiety, stress and anger management, relationships, depression and support for families.
	Contact Details Tristar Medical Group 239-241 Thirteenth St Mildura, VIC 3500 Ph: (03) 5022 9247
Headstart Intervention Service	78 Goodwood Rd Wayville SA 5034 Ph (08) 83734531 Consults at Medicare Local Mildura Ph (03) 5023 8633



Name	Type of Service Provided
Gerald Purchase	Psychologist
	Contact Details 133-137 Flora Avenue Mildura VIC 3500 Ph: 5021 1697
Dowdy's Wellbeing	Psychology and counseling services
Centre	Contact Details 233 Deakin Avenue Mildura VIC 3500 <i>Ph: 5021 4192</i>
Carmen Jewell	Psychologist
	Contact Details
	Mildura
	Ph: 0488 241 638
The ASD Clinic	Pyschologists specializing in ASD including assessments
Richard Eisenmajer Kate Fidler	Consults at Lower Murray Medicare Local Mildura Ph: (03) 5023 8633
Geoff Martin Sally Rigley	Contact Details Ph: 0408 231 038 Suite 2, 830 High Street Kew East VIC 3102 Ph: 03) 8851 3600
The Australian Psychological Society	The Australian Psychological Association Ltd web site provides a data base of psychologists in private practice throughout Australia.
	Contact Details www.psychology.org.au Ph:1800 333 497



Refer to Counselling/Mental Health for additional services.

Respite Options

Name	Type of Service Provided
Bendigo Health	http://www.bendigohealth.org.au/
	Contact Details
	PO BOX 10267
	Mildura 3502
	Ph: 5018 7301
Interchange	Contact Details
_	Mallee Office (Kerang to Mildura)
	Ph: 5033 1775 or 1300 799 421
Sunraysia Residential	Provides respite services for individuals with an
Services	disability or challenging behaviours (and their siblings)
	, , , , , , , , , , , , , , , , , , , ,
	Contact Details
	Ph: 03 5022 1741
	877 Fifteenth Street
	Mildura VIC 3500
	www.srsinc.com.au srs@srsinc.com.au
National Carer	Short term counseling for people caring for a family
Counselling Program	member with a disability or challenging behaviours.
	Contact Details Ph: 1800 242 636
	www.carersaustralia.com.au
	www.carcroadstrana.com.au
Life Without Barriers	Respite & Holiday programs
	Contact Details
	Ph: 03 50 517000
	http://www.lwb.org.au
Mildura Rural City Council	Disability Services
	Contact Details
	Ph: 03 5018 8100
	http://www.mildura.vic.gov.au



Name	Type of Service Provided
Trio Support Services	Home care & Respite.
	Contact Details Ph: 03 5022 7778
Mallee	Contact Details
Accommodation &	Ph: 03 5021 6500
Support Program (MASP)	http://www.masp.org.au/index.php/links/disability
Commonwealth Respite and Carelink Centre	Commonwealth Respite and Carelink Centres provide a single point of contact for the general public on community, aged and disability services and carer support. The Centres can also assist with information about costs for services, assessment processes and eligibility criteria. The Centres can also help arrange respite, when carers need to take a break from caring. Contact Details Ph: 1800 052 222 www.health.gov.au
Carer Support & Commonwealth Carer Respite Centre	Contact Details Ph: 5018 7313 http://www.bendigohealth.org.au

Other Services

Name	Type of Service Provided			
Paediatricians	Specialist support in relation to behaviour management, medications, medical illnesses. Contact Details Please note, no appointment can be made without a referral from your GP.			
Consultant Paediatrician	Mildura Consulting Suites Dr Suri Hariprakash Dr Chellam Kirubakaran Dr Lakshman Doddamani Ph: 5023 4377			



Name	Type of Service Provided			
Mildura City Council Library	Access to a range of books and resources relating to Autism, parenting, etc. Contact Details 180-190 Deakin Avenue, Mildura Ph: 5018 8350			
Psychiatrists	Mental health assessment, therapy and medication management. Contact Details Dr Alex Caracatsanis Ph: 5021 0788 Dr Jo Pollock Ph: 5022 2355			
My Time	MyTime is a national initiative funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). MyTime groups provide facilitated peer support for mums, dads, grandparents and anyone caring for children with a disability or chronic medical condition. Each group has a play helper who leads children and siblings in activities, so parents and carers can spend time focusing on catching up with others Contact Details www.mytime.net.au			
Alpha Employment Services	Assists job seekers on the Autism Spectrum or those with similar needs with employment preparation, job search, job placement and post placement support, in the open labour market. AES operates as part of the Disability Employment Network (DEN). Contact Details Ph: 9885 2777 <u>http://alpha-autism.org.au</u>			



Name	Type of Service Provided			
Post school Options National Disability Coordination Officer Program	The Australian Government's NDCO Program targets the barriers that people with disability face in successfully accessing and completing post-school education and training and subsequent employment. A national network of NDCOs works within 31 specific regions across Australia to improve the coordination and delivery of support services to help make it easier to enrol or participate in post-school education, training and employment. Contact Details www.deewr.gov.au/NDCO			
SRS Holiday	Contact Details			
Program & After School Care	Ph: 03 5022 1741 http://www.srsinc.com.au			
Recreational Rideability (previously called Riding for Disabled)	Rideability is a non-profit organisation which offers therapeutic riding programs for children and adults with disabilities. Programs are tailored to suit the ability of the rider. Contact Details			
	http://www.rdav.asn.au/			
Interchange Holiday Program	Interchange Loddon-Mallee Region Inc. is an incorporated, non- profit, non-government agency which provides respite, recreation and support to families of and people with disabilities. Contact Details <u>http://www.interchangelm.org.au/home.html</u>			
"Basketball 4 All"	Basketball4All is an all abilities basketball program in Mildura. Session times :			
	Juniors (5-14) Monday 4pm-5pm – No Cost!			
	15+ Wednesday 4pm – 5pm - No Cost! Contact Details			
	Phone Maria: 0409 235 680 <u>mpiscioneri@srsinc.com.au</u>			



Soccer – MilduraCasual Soccer Activities for children & families to get involved and learn some skills. Please phone "Ross" for more information. Currently available on Saturdays. Contact Details Phone Ross: 0410 557 485	Recreational (cont'd)	
	Soccer – Mildura	involved and learn some skills. Please phone "Ross" for more information. Currently available on Saturdays. Contact Details

STATION 4

PART A - FINDING OUT ABOUT AVAILABLE RESOURCES

Name	Type of Service Provided			
Autism Victoria trading as AMAZE	Information Advice Emotional support Assistance with accessing funding. Library and resource centre.			
	Contact Details Infoline 1300 308 699 Mon – Fri 9am – 5pm. <u>info@autismvictoria.org.au</u> Autism Advisors: 1300 424 499 Website: <u>www.autismvictoria.org.au</u> Email: <u>info@autismvictoria.org.au</u>			
Raising Children Website	Information relating to Autism A guide to accessing services. Detailed descriptions and evidence for a variety of therapies. Parent forums (enables you to have discussions with other parents). Contact Details www.raisingchildren.net.au/autism			
Autism Spectrum Australia (ASPECT)	Information Educational workshops information News / events Contact Details			
	www.autismspectrum.org.au			



Name	Type of Service Provided				
Signposts Statewide	A program designed to help parents of children aged 3-15 with a developmental delay or an intellectual disability to manage difficult behaviour before serious problems develop.				
	Contact Details				
	Contact the Signposts hotline on 03 8660 3562 to				
	find out about a program in your area.				
	www.vicparenting.com.au				
ACT-NOW Website	Information relating to Autism. Current research				
(Monash University)	Information relating to suggested interventions for				
	specific behaviours / concerns.				
	Contact Details				
	www.med.monash.edu.au/spppm/				
	research/devpsych/actnow/				
Correre Mistorie	factsheet.htm				
Carers Victoria	Information				
	Advice Counselling				
	Couriseining				
	Contact Details				
	www.carersvic.org.au				
Carer Support Services	Support, advice, respite and referral to services.				
Services	Contact Details				
	Ph: 1800 052 222				
	Ph: 5018 7301				
Positive Partnerships	Supporting School Aged Children on the Autism				
	Spectrum.				
	National program of workshops and info sessions				
	designed to help you work in partnership with your				
	child's school to improve their learning outcomes. Provides online training for parents/carers.				
	Contact Details				
	Info line: 1300 881 971				
	www.autismtraining.com.au				



Name	Type of Service Provided					
Scope	Scope offers a wide range of services from services for people with a disability.					
	Contact Details Ph: 03 9843 3000					
	http://www.scopevic.org.au/					
Olga Tennison Autism Research Centre	Focus on research but provides comprehensive newsletter, information about events and training opportunities.					
	Contact Details Ph : 03 9479 2497					
Yooralla	http://www.latrobe.edu.au/otarc/ Yooralla offers a wide range of services for people with a range of disabilities.					
	Contact Details Ph : 1300 9667 6600					
	http://www.yooralla.com.au/					
The Association of Occupational Therapy Australia	The Association of Occupational Therapy Australia provides an online database of its members throughout Australia. Enter your postcode to search for therapists in the private and public sector in your area.					
	Contact Details www.ausot.com.au					
Speech pathology Australia	Speech Pathology Australia provides an online database of its members throughout Australia. Enter your postcode to search for therapists in the private and public sector in your area.					
	Contact Details www.speechpathologyaustralia.org.au					
]						



Name	Type of Service Provided				
Autism Awareness Australia	A comprehensive website for up to date autism services and providers.				
	Hosts the annual Autism Awareness Expo.				
	Contact Details www.autismawareness.com.au				
JCP Blog	Keep up-to-date with the on-line blog written by the authors of the "Australian Autism Handbook". It contains useful entries ranging from government initiatives to the use of 'video modelling'.				
	Contact Details http://janecurrypublishing.com.au/blog/				

FOR CHILDREN

Care For Kids	On-line child care resource				
	Contact Details www.careforkids.com.au				
"What are you doing?"	A short film created by Autism Awareness which aims to teach school aged children about acceptance and understanding of their peers with ASD. Contact Details www.whatareyoudoingfilm.com				
	www.whatarcyoddollighin.com				
Sibling Support Sibling Australia	A national organization committed to enhancing the well-being of siblings of children and adults with				
	special needs.				
	Contact Details				
	www.siblingsaustralia.org.au				
Online forums / useful websites for siblings	Contact Details <u>http://www.siblingsaustralia.org.au/</u> <u>www.siblink.org.au</u> <u>www.sibs.org.au</u> <u>www.yourshout.org.au</u> <u>www.youngcarers.net.au</u> 				



PART B - LEARN FROM THE EXPERTS

Here are a few well-renowned speakers and authors advocating for Autism.

Name	Type of Service Provided
Tony Attwood	Provides seminars regarding Autism Spectrum Disorders. Author.
	Contact Details
	www.tonyattwood.com.au
Wendy	Wendy provides seminars and workshops about her
Lawson	experience of Autism. Author.
	Contact Details
	www.mugsy.org/wendy/
Dr Richard	Provides seminars and workshops regarding Autism.
Eisenmajer	Publisher.
	Contact Details
	http://www.theasdclinic.com.au/website/
	richardsdesk.htm
Sue Larkey	Website includes free tip sheets with practical strategies. Provides seminars and workshops regarding Autism. Publisher.
	Contact Details
	www.suelarkey.com.au
Karen	Play Based Therapy for children with Autism – "Learn to Play".
Stagnitti	http://www.karenstagnitti.com/
Dr Temple	An adult diagnosed with Autism. Author and
Grandin	presenter.
	Contact Details
	www.grandin.com ites, books or other resources please do not hesitate to contact t

If you have any websites, books or other resources please do not hesitate to contact the Sunraysia Autism Spectrum Support Group for inclusion in this document on ph: 0447112507, email: <u>sunraysia.autism@gmail.com</u>.



STATION 5

FUNDING OPTIONS

The following information was obtained primarily from fact sheets prepared by Autism Victoria. Ph: (03) 9657 1600. <u>www.autismvictoria.org.au</u>

FUNDING OPTIONS AT A GLANCE

Total no. of sessions	Enhanced Primary Care Plan 5 + Dental	Mental Health Care Plan 12 Individual + 12 Group	Helping children with Autism Treatment Plan 20	Helping Children with Autism Early Intervention (FaCSHIA) \$6000 per year over 2 years	Access to Allied Psychological Services (ATAPs) 12 sessions
Must be used by	Each calendar year	Each calendar year	Child's 15 th birthday	Child's 6 th birthday	Each calendar year
Referral needed from	Paediatrician or GP	Paediatrician or GP	Paediatrician only	Autism Advisor to approve confirm the diagnosis and refer to relevant services	GP (for low- income families, and referrals can only be made to ATAPs providers)
Speech therapy		×			×
Psychology		\checkmark	ν	ν	
Occupational Therapy	V		V		
Social Worker	\checkmark	\checkmark	×	×	\checkmark
Group Sessions	×	V	×	×	
Adult Eligibility	\checkmark	\checkmark	×	×	
Equipment / Travel expenses	×	×	×	√ N	×

(table obtained and adapted from Autism Victoria www.autismvictoria.org.au; Ph: (03) 9657 1600)



FUNDING OPTIONS - EXPLAINED

'Helping Children with Autism' Early Intervention Funding

Funded by FaCSHIA (Department of Family, Community Services, Housing and Indigenous Affairs). <u>www.facshia.gov.au</u>

Families of children under school age with a diagnosis of Autism Spectrum Disorder are eligible to apply for \$6000 per year, for two years before their child starts school to be used for approved Early Intervention Services. The family must apply for the funding before the child turns 6 and can be used until the child turns 7.

35% of the funding can be using on equipment prescribed by a therapist (the therapist must order the equipment for you).

Rural families are also able to access additional \$2000 over the two year period in recognition of the travel and other costs they incur by being away from professionals in major city centres.

Families need to speak to an 'Autism Advisor' by contacting the **Autism Advisor Line** (1300 424 499) to access the funds. This professional will confirm the child's diagnosis of ASD through citing the relevant paperwork, and then advise the family on services available.

Service providers need to be listed on FaCSHIA's approved provider panel (on FaHCSIA's website: <u>www.facshia.gov.au</u>

'Helping Children with Autism' Assessment / Diagnosis Funding

Medicare rebates available for Autism assessment / diagnosis by private practitioners. Rebates are provided for the child to be seen by a paediatrician or child psychiatrist, along with four sessions with Allied health Professionals to assist in multi-disciplinary assessment and diagnosis of Autism Spectrum Disorder for children up to 13 years of age.

The process is:

- (1) Obtain referral from GP to an appropriate medical specialist (Paediatrician or Child Psychiatrist)
- (2) Visit medical specialist and discuss developmental concerns. Obtain referral to other Allied Health professionals to assist with team diagnosis of ASD. Up to 4 sessions in total with OT, psychologist or speech pathologist (e.g. 2 sessions with psychologist, one session with speech therapist and one session with OT).
- (3) After all the assessments are completed, return to the medical specialist to discuss the outcome, and if ASD is diagnosed, to write 'intervention plan' to enable access to Medicare rebates for 20 sessions of Allied Health therapy services.



Rebate amounts are:

Allied Health Provider	Item Number	Medicare Scheduled Fee	Rebate	
Paediatrician	135	\$238.50	75% (or 85% if accessing the Medicare safety net)*	
Child Psychiatrist	289	\$238.50	75% (or 85% if accessing the Medicare Safety net)*	
Speech Pathologist	82020	\$79.40	\$67.50	
Occupational Therapist	82025	\$79.40	\$67.50	
Psychologist	82015	\$90.15	\$76.65	

Medicare Safety net enables families with 'out-of-pocket' expenses after using Medicare rebatable services to gain greater rebates when reaching a threshold per calendar year. The thresholds are \$1539 per family, or \$529.30 per family where one member has a healthcare card (including a child whose parents receive Carer Allowance). Register once at Medicare for the Safety Net, and Medicare automatically begins rebating at the higher rate.

Error! Hyperlink reference not valid. to www.facshia.gov.au/autism

Helping Children with Autism Treatment Plan

Families of children under 13 years of age with a diagnosis of Pervasive Developmental Disorder (Autism, Asperger Syndrome, PDD-NOS, Rett's Disorder, or Childhood Disintegrative Disorder) can access a total of 20 sessions of rebates for Allied Health Providers. The 20 sessions are a 'once off' for each child (not per calendar year, as per other Medicare schemes). The rebates per session are:

Allied Health Provider	Item No.	Medicare Schedule fee	Rebate
Speech Pathologist	82020	\$79.40	\$67.50
Occupational Therapist	82025	\$79.40	\$67.50
Psychologist	82015	\$90.15	\$76.65

In order to access the items, families must visit their Paediatrician or Psychiatrist (not GP) to develop a treatment plan. Once the paediatrician or psychiatrist charges a certain item number for developing the plan, this will activate the family's eligibility for the 20 Medicare session rebates.

The plan will include how many sessions with each type of allied health provider (20 sessions in total). The plan will be reviewed, and the number of sessions allocated for a certain professional can be modified if needed. The name of the practitioner / service provider must be specified in the plan.

Families have up until their child is 15 to use the sessions.

*These 20 sessions are **IN ADDITION** to those claimable through other Medicare schemes (e.g. Enhanced Primary Care Plan, Better Access to Mental Health items).

Refer to www.facshia.gov.au/autism



Mental Health Care Plan

Enables access to:

6 sessions of therapy with an additional four sessions may be available in exceptional circumstances.

The Mental Health Care Plan is an option available for anybody (individuals with an ASD, parents, siblings, carers, etc) who feels that their overall wellbeing and mental health is affected (including parents who may be experiencing sadness / anxiety / confusion / grief in relation to caring for a child with Autism. People who have Autism Spectrum Disorders can also have mental health difficulties. They may be anxious about the environments around them; they may be depressed because they are having difficulty forming relationships with people. In such circumstances, the individual can access appropriate support through the Mental Health Care Plan.

Group sessions can be used for Social skills groups, play therapy groups, anxiety groups; any group that is run by the above listed professions and is working towards building the confidence, self-esteem and ability of the person with an Autism Spectrum Disorder.

People are eligible for 6 sessions under the Mental Health Care Plan every calendar year. You can get a referral from your GP or Paediatrician. Make sure you book a long consultation with your doctor to allow you and your doctor enough time to prepare a GP Mental Health Care Plan and discuss your treatment options. After the initial plan has been written, you do not need a new plan each year, but the doctor may review the plan.

Refer to: http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-bbetter

Enhanced Primary Care Plan

Enables access to:

5 sessions per calendar year with an Allied Health Professional, including:

- Psychologists
- Occupational Therapists
- Speech Pathologists
- Social Workers
- Dieticians
- Asthma Educators
- Audiologists
- Orthotists or Prosthetics
- Dental Therapists
- Pharmacists
- Dentists
- Podiatrists
- Physiotherapists
- Diabetes Educators
- Exercise Physiologists
- Aboriginal Health Workers



• Optometrists

\$4250 worth of dental treatment if the doctor writing the referral feels that the chronic condition (Autism Spectrum Disorder) is causing the dental problems (e.g. teeth grinding, eating non-edible items, refusing to brush teeth, etc). The total payment is available across two consecutive years.

The Enhanced Primary Care Plan can be written by your GP or Paediatrician and people with Autism are eligible for 5 sessions every calendar year. Once the initial plan has been made, they will not need GPs to write new plans each year, but GPs may review the plan. Adults are also eligible to receive this.

Refer to: <u>http://www.health.gov.au?internet/main/publishing.nsf/Content/health-medicare-health pro-gp-pdf-allied-cnt.htm</u>

Better Outcomes / ATAPS (Access to Allied Psychological Services) Funding The

Better Outcomes in Mental Health Care (BOiMHC) program improves community access to quality primary mental health care. It includes the Access to Allied Psychological Services (ATAPS) funding which enables individuals with low incomes to access free sessions with an allied health professional.

A referral can be obtained by anyone from a low-income background who is seeking counselling support from an allied health professional. A referral needs to be obtained from your GP and only includes professionals who provide services under the ATAPs scheme in your local area.

* The following information was obtained from the Dept of Health and Ageing (Australian Government): <u>http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-boimhc-atapsATAPS</u>

ATAPs enables GPs under the Better Outcomes in Mental Health Care (BOiMHC) program to refer consumers to allied health professionals who deliver focussed psychological strategies.

Allied health professionals have been defined to include psychologists, social workers, mental health nurses, occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications.

Through ATAPS, patients are eligible for a **maximum of 12 sessions per calendar year** – (six time-limited sessions with an option for a further six sessions following a mental health review by the referring GP). Sessions can be individual and/or group therapy sessions. ATAPS provides patients with assistance for short-term intervention. If further sessions are required it may mean that the patient needs a longer term program to meet his/her needs.

In exceptional circumstances the patient may require an additional six individual focussed psychological strategies above those already provided (up to a maximum total of 18 individual services per patient per calendar year).



Through ATAPS, patients are **also eligible for up to 12 separate group therapy services**, within a calendar year, involving 6-10 patients. These group services are separate from the individual services and do not count towards the 12 individual allied mental health services in a calendar year. Patients are not to be referred for treatment through Better Access to Psychiatrists, Psychologists and General Practitioners through the Medical Benefits Schedule (Better Access) Program and ATAPS at the same time. Treatment through both Better Access and ATAPS may occur within one calendar year, provided the total number of individual or group services provided under both programs does not exceed the maximum allowable in a calendar year.

ADDITIONAL INFORMATION REGARDING FUNDING CAN BE ACCESSED:

- Autism Victoria <u>www.autismvictoria.org.au</u>
- <u>www.raisingchildren.net.au/autism</u>
- <u>www.facsia.gov.au</u>
- Dept of Health & Ageing website (Australian Government)

OTHER FUNDING OPTIONS (including non-profit / charitable organisations)

Adam Scott Foundation Autism Grants Program

Available to young people, aged 6-16 with an Autism diagnosis across Australia. <u>www.autismqld.com.au</u> <u>http://www.autismqld.com.au/userfiles/Autism%20Applications.pdf</u>

Carer's Allowance

Carer Allowance is an income supplement available to people who provide daily care and attention in a private home to a person with disability or a severe medical condition.

Carer Allowance is not taxable or income and assets tested. It can be paid in addition to a social security income support payment.

To be eligible for Carer Allowance, a person must be providing daily care and attention to a person with disability or a severe medical condition who is either:

- aged 16 years or over and whose disability or severe medical condition is permanent or for an extended period (as assessed under the Adult Disability Assessment Tool), or
- a dependent child aged under 16 years:
 - whose disability appears on the <u>List of Recognised Disabilities</u>, or where a child's medical condition or disability is not on the List, the disability causes the child to function below the standard for their age as assessed under the Disability Care Load Assessment (Child), or
 - a carer who qualifies for Carer Payment (child) receives Carer Allowance automatically for that child.



To find out more about Carer Allowance and your eligibility for this payment:

- visit your nearest Centrelink office
- telephone 132 717, or
- visit the Benefits and Payments page or visit <u>Centrelink's website</u>.

The GP or Paediatrician can then complete the forms (notify them you may need a longer appointment) detailing the diagnosis and impact of this on the overall functioning and well-being of the child. This form is then re-submitted to Centrelink and evaluation for eligibility for a Carer's allowance.

Carer Payment

Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment. Carer Payment is income and assets tested and paid at the same rate as other social security pensions.

To be eligible for Carer Payment a claimant must:

- be providing constant care in the home of the person(s) being cared for,
- and the person being cared for must be an Australian resident and either;
 - o a person who has a physical, intellectual or psychiatric disability, or
 - an adult who has a dependent child in their care. If the dependent child is aged six years or over, a person must qualify for and receive Carer Allowance for that child, or
 - o a child with a severe disability, or a severe medical condition, or
 - o two or more children with disability, or medical condition, or
 - o a disabled adult and one or more children each with a disability or medical condition, or
 - a child with severe disability or severe medical condition on a short-term or episodic basis, or
 - o a profoundly disabled child or a disabled child.

Parents exchanging care of two or more children each with severe disability or severe medical condition or disability or medical condition, under a parenting plan.

A person who receives Carer Payment for a child may automatically be entitled to Carer Allowance.

To find out more about Carer Payment and your eligibility for this payment:

- visit your nearest Centrelink office
- telephone 132 717, or
- visit the Benefits and Payments page or visit Centrelink's website.

Carer Support Services / Commonwealth Respite and Carelink Centre

Madden Avenue, Ph: 5018 7314 or 1800 052 222

Can assist individuals to access funding to access specific services.



Chances for Children

Chances for Children is a fund that aims to remove financial barriers for children and young people in the Mallee to achieve their potential. Chances for Children provide scholarships and funding to young people. There are two funding rounds per year, usually in March/April and again in September/October. Visit

<u>www.chancesforchildren.com.au</u> or contacting 5021 7480. Fiona Harley (Manager of Chances for Children).

Department of Education

Department of Education has programs for families (workshops) as well as programs for teachers and schools. Look at DEEWR website.

There has been a move away from providing funding for children with Autism Spectrum Disorder in the school setting.

Disability Services

Disability Services can provide assistance to families to access services and/or funding for services. Case management via Behaviour & Intervention Support Team (BIST) and outreach services can also be arranged if there are significant behavioural difficulties. Enquiries and/or registration with Disability services can be made by contacting the Disability intake worker on 1800 229 822.

Early Childhood Intervention Service (Flexible Support Packages)

State funded intervention. The Early Intervention Service is allocated funding for children up to 6 years of age who have a disability or developmental delay – no formal diagnosis required.

A Family Service & Support Plan can be arranged by the Family Service Co-ordinator at Early Intervention Service and needs to be signed off by the Family Support Service Co-ordinator. Applications are approved by a regional panel of individuals who work in early childhood (can vary from region to region).

The funding can be used to fund supports, including: respite, access to transport, therapy, equipment, support for children to participate in play groups, and additional support to parents and family (including siblings). These services are provided by the Early Intervention Service until the child reaches school age.

Early Days (Promoting development of young children on the Autism Spectrum)

Early Days provides free workshops for mothers, fathers and other family carers of children 6 years and under who have an Autism Spectrum Disorder (ASD) or are going through the assessment and diagnosis process. Early Days is a national program funded by the Federal Government under the Helping Children with Autism Strategy(HCWA). Register either online: www.earlydays.net.au or freecall 1800 334 155



Noah's Ark

Noah's Ark is a not-for-profit state-wide organisation assisting children with additional needs and their families. Noah's Ark is Victoria's largest Early Childhood Intervention and Inclusion Support Agency and also provides training and support to a range of children service providers within Victoria and interstate.

Noah's Ark offers several programs to families through HCWA. Programs can vary in different parts of the State, so contact 8823 8600 to enquire about services in your local area. Services offered under HCWA can include information programs and individual sessions with a Noah's Ark Early Childhood Intervention worker.

For Further Information about HCWA at Noah's Ark, click here to download the HCWA information pack in word format, contact **03 8823 8600** or email <u>autism@noahsarkinc.org.au</u>.

Teacher aide (inclusion) support can also be obtained by your child's child care service if a paediatrician has identified there are concerns regarding your child. A copy of a paediatrician's referral letter or a letter from the paediatrician detailing those concerns can be sufficient to access teacher aide support for a period of 6 months. Accessing teacher aide support at kinder can be more difficult.

Noah's Ark Mildura Contact: Nedi Adams 0447 552 463 84 Lemon Avenue, MILDURA VIC 3500

Sunraysia Community Health Service

Appointments with Allied Health professionals (speech therapy, occupational therapy, etc) at Sunraysia Community Health Service are \$8.80 for concession card holders.

Victorian Government Carer Card

Carers of an individual with a disability are eligible to receive a 'Carer card' which provides discounts and benefits from businesses, local government and community organisations. For application information, refer to: <u>https://carercard.vic.gov.au</u> or phone 1800 901 958.

Victorian Government Companion Card

Companion card promotes the right of people with a disability, who require a companion, to fair ticketing at Victorian events and venues (get in for free if you are a companion of a person with a disability). Entry includes a variety of transport and venue options. Refer to: <u>http://www.vic.companioncard.org.au</u> or phone: 1800 650 611



Wings for Kids Inc. Sunraysia Mallee

Wings for Kids Inc. Sunraysia Mallee is a non-profit Incorporated Organisation comprising of local community members who volunteer their time and expertise to raise money to assist in the purchase (wholly or gap funding) of specialised medical equipment, aids and supports for 'special needs' children and their families in the vast geographical area of Sunraysia Mallee, after Government and other funding sources have been exhausted or are not available. Examples of equipment includes: wheelchairs, gait trainers, car seats, communication boards, sensor mats, etc.

'Wings' receive formal referrals from allied health professionals (physiotherapists, speech pathologists, occupational therapists etc), medical practitioners, Mildura Early Intervention Services, Community Care Options and the Department of Education & Training Visitng Teacher Services. A Family Liaison Officer acts as a link between the referee, the family and 'Wings' members.

Further information available by visiting <u>www.wings4kids.net</u> or contacting Di Pearson, 5023 6192.





STATION 6

TREATMENTS

With so many treatment programs to choose from, the decision regarding treatment options can sometimes be overwhelming.

The following information may assist you in finding out information about available treatments and in choosing suitable treatments for your child.

The following information was obtained from the Better Health Channel. (www.betterhealth.vic.gov.au)

Choosing a management program

Suggestions include:

• Seek advice from your doctor, autism professionals and autism organisations. It may be worth collecting information on an intervention program you're considering and discussing it with the medical or paramedical team (or both) involved in your child's care

• Only choose management programs that are based on sound, scientific principles (evidence-based practice).

• Carefully consider the validity, value and risk of experimental programs. Consult with your doctor or autism professionals for guidance.

• Make sure the people offering the program are properly qualified. You may wish to ask questions about staff qualifications, their participation in ongoing professional development and their experience in working with people with autism.

• Make sure the program deals with all aspects of autism.

• Find out about the time, effort and cost involved – for example, you may not have the time or resources to devote to an intensive program because of other children or work commitments.

• The program may be for children with particular abilities or who are a particular age, so check that it is appropriate for your child.

• Be wary of programs that claim to work for everyone with autism – their approach may be too broad to be useful.



The following information was obtained from the Raising Children Network. Additional information regarding treatments is available from the Raising Children Network: <u>www.raisingchildren.net.au/autism</u>

There are currently over 400 interventions that claim to help children with Autism Spectrum Disorders. Generally, there is little reliable research evidence to support the use of these interventions.

The Raising Children Network has rated treatments, based on the research evidence available to support each treatment. The ratings are based on a 2006 report to the federal government, prepared by two Australian experts in autism, Dr Jacqueline Roberts and Professor Margot Prior. The report identified common therapies and practices used in Australia.

The 'research rating' offered for each therapy describes how much scientific evidence supports that therapy. This information comes mostly from the National Standards Project (National Autism Center, 2009). For this project, experts carefully looked at ASD treatments to see which have been shown to be effective for people with ASD – a 'systematic review'. To develop research ratings for therapies not yet reviewed by the National Standards Project, we used similar reviews by the Cochrane Collaboration.

But it's important to bear in mind that there are many different treatments or interventions for autism, and this information is updated all the time.

Each therapy review offers a research rating of the therapy. The ratings are:

Established – research shows positive effects.

Promising – some research shows positive effects, but more research is needed.

Yet to be determined – not enough research is available.

Ineffective/harmful – research shows this approach is ineffective or can be harmful.

Unrateable – not yet reviewed by our research sources.

We have only listed here those therapies that are shown to be 'Established' or 'Promising' as per the Raising Children Network website in May 2011, however this information is updated frequently. Further information regarding these treatments and other treatments can be obtained by visiting the Raising Children Network website.



ESTABLISHED EVIDENCE

(1) Applied Behaviour Analysis (ABA)

Applied Behaviour Analysis (ABA) is **not a therapy in itself**, but a theory, a set of principles upon which some therapies are based. The theory identifies various teaching techniques which generally involve breaking down complex skills (or behaviours) in to smaller steps and teaching them through the use of clear instructions, rewards and repetition.

(2) Functional Communication Training (FCT)

Functional Communication Training (FCT) is a therapy that focuses on replacing difficult behaviour with more appropriate communication that serves the same purpose. For example, some children might have tantrums when they want a toy. In FCT, these children would be taught how to ask for the toy in a more appropriate way.

(3) Social Stories[™]

Other common name: social scripts

Social Stories[™] is a highly structured intervention that uses stories to explain social situations to children with autism. They also help children learn socially appropriate behaviours and responses.

(4) Discrete Trial Training (DTT)

Discrete Trial Training (DTT) is **not a therapy in itself**, but a teaching technique used in some autism spectrum disorder (ASD) therapies. Derived from Applied Behaviour Analysis (ABA) theory, DTT involves breaking skills down to their most basic parts and teaching those skills to the child, step by step. All achievements are rewarded, which encourages the child to learn. Sometimes called discrete trial teaching, DTT is often used as part of a more broadly ABA-based approach.

(5) Incidental teaching

Incidental teaching is **not a therapy in itself**, but a **naturalistic teaching** technique used in some therapies. No specific teaching method is applied. Rather, naturally occurring opportunities for learning are maximised and the child's attempts to behave in a desired way are increasingly reinforced the closer they get to the desired behaviour. Incidental teaching is based on Applied Behaviour Analysis (ABA) theory.

(6) Pivotal Response Training (PRT)

Other common names: Natural Language Paradigm, NLP, Pivotal Response Intervention

Pivotal Response Training (PRT) is not a therapy in itself. Rather, it is a set of teaching techniques used in a child's everyday environment. Some therapies for autism spectrum disorder (ASD) include PRT techniques as part of their approach. PRT is based on the principles of Applied Behaviour Analysis (ABA). It focuses on four key or 'pivotal' areas of a child's development, which helps the child develop more complex skills and behaviours (such as social and communication skills).



(7) Positive Behavioural Support (PBS)

Positive Behavioural Support (PBS) involves the development of an individualised and comprehensive plan that parents and carers use to teach and encourage appropriate behaviour (to replace difficult behaviour). Psychologists usually develop PBS support plans along with parents, teachers and others involved in the daily life of the child.



PROMISING EVIDENCE

(1) Early Start Denver Model

Other common names: Denver Model

The Early Start Denver Model is a play-based approach to teaching that focuses on helping children with ASD develop social communication skills (such as showing interest and responding to others). The approach is used in three different settings – one-to-one intensive teaching or therapy sessions, time in a typical preschool setting and teaching at home. The Early Start Denver Model emphasises the development of play skills, relationships and language.

(2) Treatment and Education of Autistic and related Communicationshandicapped Children (TEACCH)

Treatment and Education of Autistic and related Communications-handicapped Children (TEACCH). The program is not offered in Australia. The approach looks at the skills and strengths a person already has, and aims to build on these skills to promote development. For children with autism, TEACCH offers an intensive intervention



program that supports children by creating a very structured learning environment. The environment includes physical boundaries between different tasks and clear schedules of daily activities. This helps children understand how daily life works so that they can become more independent.

(3) Developmental social-pragmatic model

The DSP model is not a therapy in itself. Rather, it is an approach to intervention that uses everyday interactions between caregivers and children to promote communication. The model uses techniques derived from Applied Behaviour Analysis (ABA), such as **incidental teaching**. Other interventions that use a DSP perspective include the More Than Words® program and the DIR®/Floortime[™] model.

(4) DIR®/Floortime[™] Model

Other common names: Developmental, Individual Difference Relationship-Based, Floortime, Greenspan

The DIR®/Floortime[™] Model is also known as the Developmental, Individual Difference, Relationship-Based Model. It focuses on promoting development by encouraging children to interact with parents and others through play. It's thought that this interaction will help children reach milestones in their emotional development.

(5) Relationship Development Intervention®(RDI®)

Relationship Development Intervention[®] (RDI[®]) is a parent-led approach that focuses on teaching children how to develop social skills. Children learn how to engage and form close relationships with others. Through the RDI[®] program, parents are trained in techniques and strategies that make use of everyday activities to support the child's social development. Parents work with a consultant trained in the approach.

(6) Atypical antipsychotics

Other common names: risperidone, aripiprazole, clozapine, ziprasidone

Atypical antipsychotics are a group of drugs that are traditionally prescribed to people for schizophrenia and other psychoses. For people with autism, atypical antipsychotics have been prescribed to improve behavioural problems, such as repetitive behaviour, hyperactivity, irritability and aggression.

(7) Music therapy

Music therapy uses music and the interaction between teacher and child to teach specific skills. For people with autism spectrum disorder (ASD), music therapy uses interactive musical activities to improve social and communication skills. There are many different types of music therapy.



(8) Manual signing

Other common names: Augmentative and alternative communication (AAC), Sign language, Auslan, Makaton

Manual signing is a way of using hand signs to communicate. For people with speech or hearing problems, manual signing can be used to support speech skills, or as the main way of communicating.

(9) Picture Exchange Communication System(PECS)

Based on the principles of ABA (Applied Behaviour Analysis), Picture Exchange Communication System (PECS) is a way for people with autism to communicate without relying on speech. Instead, they use cards that feature pictures, symbols, words or photographs which represent tasks, actions or objects.



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STATION 7

TALKING TO YOUR CHILDREN ABOUT AN ASD DIAGNOSIS

How do you tell your child that they have an Autism Spectrum Disorder? When is the best time to tell your child about their diagnosis? It can be difficult, you don't know how they'll react - and you keep putting off the inevitable.

Remember how you felt as a parent when you were told? You may have had mixed feelings. In one way you were relieved, because now you knew what 'IT' was, and in another, you felt a lump in your heart. Why us? Why our child? If your child is mature enough to understand, they may also go through the same grieving and confusion as we, the parents did. Although the diagnosis can have a higher impact on the child because they are living it!

It's all a matter of how you present a disability to any child. Asperger's or Autism, both can have many of the same issues and it's a parental choice as to how they tell a child. Some parents will never have to deal with the question but for others, my opinion is if a child asks, the parent should be as honest as they can, not only about a disability but anything in life, as a child knows better than we what his/her limitations are.

Options worth considering are:

Videos obtained through your local support group or the Autistic Association of your State.

Useful publications, including:

Pictures of Me by *Carol Gray.* This social story book introduces a child with Asperger's Syndrome to their individuality.

Special People, Special Ways by Arlene Maguire.

What I Like About Me by *Allia Zabel-Nolan*. This book talks about differences in all people/ pop up book

The Autism Acceptance Book by *Ellen Sabin* with exercises to help demonstrate differences, can be read to a child.

"All cats have asperger syndrome" by *Kathy Hoopmann* (Jessica Kingsley Publishers, ISBN 1843104814)

The booklet "A Special Book About Me" offers a fun and accessible introduction for a child diagnosed with Asperger Syndrome and is a reading tool for children in the initial period after a diagnosis of AS and addresses questions and concerns the child might have.

If your child is a capable verbal learner, then you may decide just to sit them down and have a face-to-face discussion about the diagnosis. You may like to do this on your own, with your partner, as a family, or with outside support, e.g. paediatrician, support group, or an older child with Asperger's Syndrome.



For invaluable web information, Google:

- Sue Larkey, or
- Wendy Lawson



The Support tool

There are various ways in which you can support your child after informing them. Various reactions have been denial, indifference, and depression. Here are some easy strategies you can put into place to support your child.

- Talk openly with them and other family members about Autism Spectrum Disorder, to show them that it isn't a taboo subject.
- Provide them with more information as a follow up to your first discussion.
- Help build their confidence with self-esteem activities.
- They may feel ready to share the diagnosis with their peers/classmates, discuss this with your child and if so, follow up with the class teacher on how and when to do this.
- Ensure your child understands that they can come to you anytime with questions.
- Have their pediatrician/psychologist/doctor confirm the diagnosis with the child.
- Encourage your child to keep a diary/journal of their thoughts and feelings.

The Learning tool

- Join the local Autism Spectrum Disorder support group. This will help the child (and parents!) feel less alone.
- Attend social skills classes.



• Explain the importance of timetables, charts, and diaries. They will become essential tools for your child as they grow into adulthood. (Let's be honest, how many of us can get by without timetables, charts and diaries!)

Note: Italicised quotes are taken from a conference paper first published at the autism99 conference on the worldwide web, November 1999 by **Josie Santomauro**. Reproduced with the author's kind permission from her site at: <u>www.booksbyjosie.com.au</u>

Josie Santomauro is an international author and presenter on the topic of Asperger Syndrome. She 'fell' into this role many years ago when her son was diagnosed. She now specializes in resources on how to explain the diagnosis to not only the child but the whole team i.e.: mother, father, carer, grandparent, sibling, friend and peer.





STATION 8

STRATEGIES

The following information was obtained from the Better Health Channel. <u>www.betterhealth.vic.gov.au</u>

Around the home

Parents are used to childproofing their homes, but children with autism may need extra precautions. However, it is important to find a balance between keeping your child secure and making sure your home is still safe and easy to get out of in an emergency (like a fire). Talk to a locksmith and other parents who face similar issues.

Suggestions include:

- Some children with autism are experts at escaping the most secure homes. Talk to a locksmith about installing lockable security doors on all exterior doors and window locks but make sure you can still get out quickly in an emergency.
- Use key-lock door knobs (or bolts or chains installed high on interior doors) to keep your child in their room at night, or to block access to certain rooms.
- Fences and gates are a good idea for both your front and back yards. Some are more easily scaled, or opened than others, so consider this when choosing or installing them.
- Window blind cords can be dangerous to children who put their head inside the loop. Perhaps cut through the loop, shorten the cords, install a hook on which to wind the cord, or remove it all together.
- If your child likes listening to the sound of breaking glass, you may want to try
 using acrylic plastic in place of glass, use shatterproof glass or in extreme cases
 reinforce, protect or board up your windows. In some cases, you can install foam.
 Use picture frames with plastic instead of glass.
- Try to keep these safety precautions low-profile so that you or other family members do not feel confined in your own home.

Personal hygiene

Suggestions include:

 Contrary to popular belief, it's not necessary to bathe children daily unless there are special medical or sanitary reasons to do so. If your child resists bathing, aim for one or two baths per week – at other times, clean them as best you can with a damp cloth. A flexible shower hose can be very useful for washing the hair of children who are afraid of the big shower.



- The fear of water may be overcome by the novelty of swimming pools, showers, jumping over lawn sprinklers, or appealing bath toys.
- Some children with autism dislike getting their fingernails and toenails cut. You could try teaching the child to do it themselves (with nail clippers rather than scissors), but ensure age is considered and appropriate safety precautions are taken. Curved toenail clippers are larger and easier to operate than smaller fingernail clippers, and can do both jobs passably. Another option is to perform the task while the child is asleep.
- If your child is sensitive to getting their hair cut at the hairdressers, try hugging them in your lap. Regularly brushing your child's hair, reading them a social story, or roleplaying with your child the procedure of having a haircut may assist to 'desensitise' them to getting their hair cut. Perhaps try cutting their hair yourself. If this is too difficult, cut their hair as best you can while they are asleep.

Clothes

Some children with autism do not like wearing particular kinds of clothes or fabrics. To help manage this, you could:

- Ask your child **why** they want to take their clothes off. They may be able to tell you what's irritating them.
- Your child may be overly sensitive to the feeling of clothes against skin. Consult with your occupational therapist for help to develop a 'desensitisation' program.
- Choose soft fabrics, preferably cotton.
- Avoid clothing with tight waistbands, collars or cuffs.
- Remove clothing tags that may rub against their skin.
- If a child frequently takes off their own clothes, you could try dressing them in clothes that are difficult to remove, such as overalls or jumpsuits.
- Choose shirts, dresses and pants that button at the back.
- Replace zippers, velcro, buttons and other easily opened fasteners with more complicated options.
- If your child constantly removes their nappy, check that it's comfortable. Try switching from cloth to disposable (or the other way around) or try a different brand.
- You may need to wash clothing several times before your child starts wearing them.
- This may help to remove any unfamiliar smells, soften the fabric and reduce possible irritation.



Going out

Suggestions include:

- Plan the outing or trip. Prepare your child before leaving home for example, verbal reminders, visual cue cards or the use of a timetable outlining 'today's activities'.
- Try to have another adult with you to help out if needed.
- Choose 'family friendly restaurants' or chain restaurants that don't expect perfect behaviour from young patrons.
- Take books, pens and toys for your child to play with.
- When eating out or shopping, try to choose times when it will not be busy.
- Reinforce good behaviour with plenty of praise.
- Try to avoid delays. For example, book the first appointment when visiting the doctor or dentist so that your child doesn't have to sit for too long in the waiting room.
- Remember to reward your child for good behaviour, such as praise, encouragement, tangible rewards.
- Alert cards may also be useful. These small cards are designed to tell other people about autism and ask them to show respect and tolerance. They can be easily carried in a wallet or purse and handed out as appropriate. Alert cards are available from Autism Victoria.



The following information was obtained from the Raising Children Network (www.raisingchildren.net.au/autism)

Strategies for difficult behaviours

The difficult behaviours of children with ASD are one of the things that cause parents and families the most stress. It helps to pay particular attention to the specific situations that seem to trigger your child's behaviour, and to how or why this causes you stress. When you know about situations that cause stress, you can either avoid or change them.

It's also very important to try to stick with the behaviour strategies that have been designed for your child. If you find it difficult to put the behaviour strategies into action, try to work out what's causing the difficulty. For example, do you feel your child isn't responding to the strategies? Or are you having trouble understanding what you're supposed to do? Whatever it is, you can ask your early intervention provider for help.





STATION 9

LOOKING AFTER YOURSELF

The following information was obtained from the Better Health Channel. <u>www.betterhealth.vic.gov.au</u>

Being a parent is a difficult job, but parenting a child who has an Autism Spectrum Disorder poses extra challenges. The following suggestions may help.

See your doctor, autism professionals or autism associations for more information and advice.

Remember that other parents of children with autism can be a goldmine of tips and suggestions, so raise any issues you have with your support group.

After the diagnosis

An initial period of panic, which could include a fruitless search for the 'cure', is completely normal.

This reaction settles down once the shock of the diagnosis has passed. You may like to consider the following ideas:

• Counselling to help manage your own feelings about your child's diagnosis.

• There are many different approaches to the management of autism. You may like to research them yourself to find the best approach for your child and family. Good starting points also include your doctor or paediatrician.

• Other parents who have children with autism can be excellent sources of information. Contact an autism support group for further information, support and guidance. Autism Victoria has a service directory with contact details for support groups in your area.

• When searching the Internet for information on autism management programs, be aware that not all information on the Internet is reliable. Check with your doctor or autism professionals, and be wary of any website that claims a 'cure' for autism.

• You could try using the online (Internet) Raising Children Network's 'Guide to Therapies'. This trustworthy guide can help you find reliable information about a wide range of therapies and interventions for children with autism. Each parent guide sets out what the research says about the therapy, and the approximate time and costs involved. For more, visit: <u>www.raisingchildren.net.au</u>

Additional information regarding treatments is also available at Station 6 of this booklet.



The following information was obtained from the Raising Children Network (www.raisingchildren.net.au/autism).

Autism spectrum disorder and family relationships

Taking care of your family relationships is as important as taking care of any other aspect of your family life. You can strengthen your family relationships and quality of life by:

- focusing on your family strengths
- building your family's resilience
- focusing on relationships within your family.

The more you focus on these things, the more they become part of your thinking and behaviour. Building them into your everyday routines helps as well.

Focusing on your family strengths

When times are tough, you can improve your family relationships by shifting the focus to your family's strengths. This is instead of focusing on the negatives of family life with a child with ASD.

Here are some ideas for identifying and promoting your family strengths:



Think about your family's interests and the things you do that are fun for everyone.

Identify as many as possible and write them down. It can be useful to have a few activities on the list that don't take up much time. This will ensure that you can still do something together as a family, even if you're pressed for time. Try to do one thing from your list together every week. It might be as simple as a trip to the park or enjoying a meal together.



Get everyone in the family to **write down one good thing about every other person** in the family (for example, a skill or an interest). Include your child with ASD. Do this each night for a week. At the end of the week, share your ideas.

Choose one family member's strength – it could be time-keeping or being good at getting organised to go out. Think and talk about new ways the family can make the most of this strength during daily routines. Try these ideas out for one week, and then talk about the experience.

Good family relationships are very important in families with children with ASD. Positive relationships help you support each other, deal with challenges, and fully appreciate the contributions that everyone makes to your family.

All families raising a child with ASD have tough times. But some families also say positive things can come out of the experience. For example, some find it helps them learn humility, patience, compassion, acceptance and respect for others.

Building your family's resilience

Resilience is the ability to come through hard times feeling that you're stronger than before. Here are some ideas for promoting your family's resilience:

Identify family members' strengths and resources. These can help when you have to face difficulties associated with your child with ASD. For example, your partner might be particularly good at calming your child with ASD. One of your other children might play well with your child with ASD. Be aware of situations when these strengths might come in handy.

Focus on staying connected and committed to each other. This gives everyone in your family a sense of belonging and loyalty to each other. For example, when one of your children explains something about ASD to someone else, this child is showing family loyalty.

Acknowledge your child's contributions to the family. This means identifying and acknowledging the contributions your child has made to your family. For example, you might notice that your children are more compassionate towards others because of their experience with their sibling with ASD.

Encourage your family to **work together as a group** when roles and responsibilities change because of your child's ASD.

Work on **communicating and problem-solving** as a family. When a problem arises, talk it out and find a solution together.



Focusing on relationships within your family

All the members of your family have different relationships with each other. And these relationships are all equally important in building a family that works well.

If you and your family members can maintain healthy and positive relationships with each other, it will really help to make your family strong in times of crisis and in the long term.

To foster the key relationships in your family, you can **identify how having a child with ASD affects your relationship** with your partner. This is a positive step in dealing constructively with any possible relationship strains caused by your child's disability.

It's also important to **work on fostering positive interactions** between you as parents and all of your children, including your child with ASD. You are a role model for how your children interact with each other.

Finally, try to **understand the feelings of the siblings** of your child with ASD. When you make time to listen and share feelings with your other children, it can help siblings of children with disabilities cope.

How ASD-related stress affects the family

Family members experience and respond to stress in different ways.

There's no one right way of feeling or responding to your child with ASD.

But it does help to be understanding of each other's feelings, and the things that cause different people stress.

For example, mothers often report feeling stressed more than fathers -

possibly because mothers tend to be the primary caregivers in the majority of families. Particular sources of stress for mothers include their children's unpredictable sleeping patterns, limited ability to express emotion, and fussy eating. For fathers, children's difficult behaviour is often reported as a cause of stress.

Siblings of children with ASD also report sometimes being bothered by

their sibling's behaviour difficulties – often because their sibling's behaviour embarrasses them or stops them from bringing friends home to play. And relatives often report stress as they see how the family is responding to the child with ASD.



Family stress and ASD: common causes

Research tells us that families with children with ASD often experience more stress than other families.

Families report several reasons for this, including:

- feelings of being overwhelmed by the things they don't yet know or understand about ASD and what it means for their child
- uncertainty or the feeling of having little control over the future for their child with ASD
- difficult behaviours of the child with ASD, including how the child interacts with others
- difficulty navigating the ASD service system, which is quite complex
- challenges of daily life with a child with ASD doing things with a child with ASD can simply
- take longer and can often be quite frustrating.

Coping with stress

Although stress is part of family life, you can learn to cope with it more positively.





The following information was obtained from the Raising Children Network (<u>www.raisingchildren.net.au/autism</u>).

AUTISM SPECTRUM DISORDER AND FAMILY STRESS



Families of children with autism spectrum disorder (ASD) often report high levels of stress. This is a normal part of a family's journey with ASD, and *you can develop effective ways to manage those stressful times.*

Positive thinking and positive self-talk are effective ways of dealing with stress. They increase your positive feelings and therefore your ability to cope with stressful situations. For example, you might have a negative thought such as 'People probably think I'm a bad parent'. You can challenge it by asking yourself, 'How do I know that people will think this?' You might also use more positive thoughts, such as 'Who cares what other people think?', 'I can do this', or 'I will stay calm'.

The more you practise positive self-talk, the more automatic it will become in your life. Start practising in one situation that causes you stress, and then move on to another one.

Relaxation and breathing strategies

Practise some breathing exercises and muscle relaxation techniques. If you practise and use relaxation exercises as soon as you feel signs of stress, or when you know you're going into a situation that makes you stressed, it can calm things down.

You could even consider setting aside a little bit of time each day for relaxation or meditation. Even 10 minutes at the beginning or end of the day could be enough. This might help you sleep better and feel more positive during the day.

Support groups and friends

Actively seek support from friends and family members who understand you and your child with ASD. It can really help to feel that other people know you're going through tough times. It can also help to share feelings, ideas and information. Other people might be able to suggest ways you can manage your stress, or change the things that cause you stress.

For online support and sharing, check out our forum for parents of children with ASD.



Tips from other parents

Make sure you prepare yourself for situations that cause you stress. This includes practising healthy coping responses to these situations. The more you know about how your child's individual ASD characteristics affect your child's learning and development, the better equipped you'll be to minimise and prevent your

Be aware that your partner and other children will respond differently to your child with ASD. Their experiences of stress will also be different. They might need different kinds of support from you. Connect with service providers and other parents in similar situations so your family feels competent and supported. Accept that there will be ups and downs in your family as a result of living with ASD.

Avoiding stress:

As well as managing stress, there are some things you can do to avoid getting too stressed in the first place.

Getting organised

Stress is often related to the feeling that things are out of your control. Getting organised is a very effective way to get things – including your stress levels – under control.

In your daily life, for example, focus on getting one thing done at a time. Try to put some family routines into action. You can adjust routines for children with disabilities such as ASD.

Looking after yourself

When you have a child with autism, it's easy to forget to make time for yourself. But you can reduce the stress levels in your family by making sure that everyone in the family – including parents – has time to themselves to do things that make them feel good.

Getting help

If you need help to cope with stress, you have several options:

counselling – although you don't need a referral, you can ask your GP to suggest someone appropriate

- respite care contact your state or territory autism association, or a Commonwealth Respite and Carelink Centre
- financial assistance contact your state or territory autism association or autism adviser to
- get started with accessing financial support groups.





- 1. Note the level of tension you're feeling. Then place one hand on your abdomen right beneath your rib cage.
- 2. Inhale slowly and deeply through your nose into the 'bottom' of your lungs send the air as low down as you can. If you're breathing from your abdomen, your hand should actually *rise.* Your chest should move only slightly while your abdomen expands.
- 3. When you've taken in a full breath, pause for a moment and then exhale slowly through your nose or mouth, depending on your preference. Be sure to exhale fully. *As you exhale, allow your whole body to just let go* (you might visualize your arms and legs going loose and limp like a rag doll).
- 4. Do ten slow, full abdominal breaths. Try to keep your breathing smooth and regular, without gulping in a big breath or letting your breath out all at once. It will help to slow down your breathing if you slowly count to four on the inhale (1-2-3-4) and then slowly count to four on the exhale. Remember to pause briefly at the end of each inhalation. Count from ten down to one counting backwards one number with each exhalation. The process should go like this: Slow inhale....Pause....Slow exhale (count "ten") Slow

inhale....Pause....Slow exhale (count "nine") Slow

inhale....Pause....Slow exhale (count "eight").....

*If you start to feel light-headed, stop for 15-20 seconds, and then start again.

5. Extend the exercise if you wish by doing two or three "sets" of abdominal breaths, remembering to count backwards from ten to one for each set (each exhalation counts as one number). *Five full minutes* of abdominal breathing will have a pronounced effect in reducing anxiety or early symptoms of panic.



REFERENCES

ACT Now Website: www.med.monash.edu.au/spppm/research/devpsych/actnow/factsheet.htm

American Psychiatric Association. (1994). Diagnostic and Statistical Manual of Mental Disorders. (4th ed.). Washington, DC: American Psychiatric Association Press.

Association for children with a disability website: www.acd.org.au/information/dad story 2.htm

Autism Victoria website: www.autismvictoria.org.au

Better Health Channel website: http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Autism

Department of Health & Ageing (Australian Government) website: <u>http://www.health.gov.au/internet/main/publishing.nsf/Content/autism-children</u>

FACSHIA website: www.facshia.gov.au/autism

Raising Children Network website: <u>http://raisingchildren.net.au/children with autism/children with autism landing.html</u>

Sabtomauro, Josie (1999). Information obtained from website: <u>www.booksbyjosie.com.au</u>

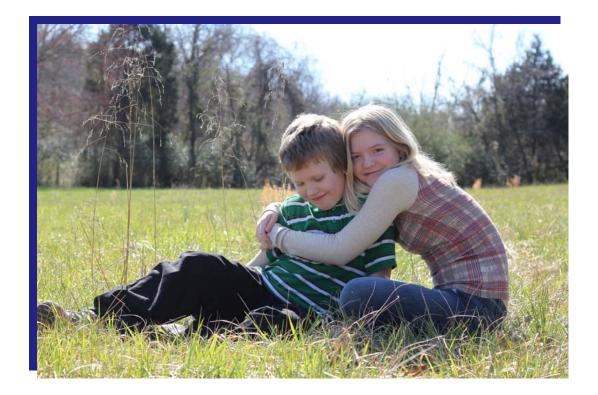
Wray, J., Williams, K. (2007) The Prevalence of Autism in Australia. Report commissioned by the Advisory Board on Autism Spectrum Disorders.

Shutterstock pictures obtained from website: http://www.shutterstock.com/pic











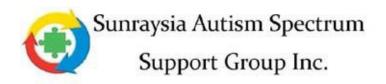


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