

FIRST OPTIONS



First Options: A guide for Families with a new ASD Diagnosis

This document has been created to provide parents with some guidance for first steps to take or options available when your child has just been diagnosed with an Autism Spectrum Disorder.

It has been created by other parents with children on the spectrum who have been navigating the world of autism support and services themselves for some time.

This information is provided to offer parents new to the diagnosis with some options. We recommend you look further into any of these or discuss them with your appropriate advisors before proceeding.

FIRST THINGS TO DO

- Contact ASPECT to ask about:
 - a) The **Autism Advisor Service** regarding FAHCSIA funding if your child is under 6yrs old: 1300 978 611 (for funding of \$12,000 until the age of 7yrs).
 - b) The various ASPECT **Schools, workshops, information days** and/or other services available in your area. There is a long waiting list to get into an Aspect school; speak to them about whether you should be getting on their waiting list.
- Meet with your child's teacher to ask whether you can arrange for an Individualised Education Program (**IEP**). Whether your child is in public or private school this can be a valuable way to identify how the school can best support your child's educational needs. A free downloadable handbook, '*Who's going to teach my child?*' from the Dept of Education is an invaluable guide: www.det.nsw.edu.au enquiries ph: 9561 8999
- Contact a **Diagnostic Centre** to book for relevant tests (developmental reports, cognitive assessments, etc) and enquire about services in your local area. Note there are waiting lists but such tests are very useful/necessary for school applications, etc.
- If your child is at a daycare or preschool enquire about funding for an extra staff member who could assist in the classroom (note this might not necessarily be specialized one-on-one care).
- Make an appointment with your **GP** to discuss ongoing management, also find out about Medicare items (sessions with speech therapists, occupational therapists, etc.)
- Contact **Centrelink** regarding the Carers Allowance and/or Carer Payment
- Contact ADHC (Department of Ageing, Disabilities and Home Care) to
 - a. See whether you qualify for a case worker to help you
 - b. Ask about what funding options are available to you
 - c. see whether you qualify for a Companion Card – this can be difficult to get but helps carers gain free access to venues where you take your child.
- Contact **Learning Links** regarding courses or services you / your child could attend (eg Transition To School, Preschool, Carer courses)
- Become a member of **Carers NSW** (free) to receive regular information on changes and options available www.carersnsw.org.au/

- Find a local **support group**. These often run week days, week nights and weekends (see www.autismcommunity.org.au)
- Make enquiries regarding **respite services** if you feel you may need such support. See ACN website for member recommended options.
- Remember to be patient and do not overload your child or yourself with too much therapy at a time. (Your child will not require all the therapies or programs listed here). This is a list of some of what is available; some of it would be of benefit to your child, but certainly not all of it.
- **Have some time out**. Do things you enjoy, either alone or with others whose company you enjoy, or ring someone, even if it is only for 5-30 minutes.
- Look into a **My Time** group in your area. These are designed to help carers find some time for themselves. <http://www.mytime.net.au/>

THERAPIES – OPTIONS

Some of the therapies you may wish to consider are listed below. Discuss with your medical advisor for what may be best suited to your needs, and remember that early intervention is encouraged but also plan for the future as well.

- **Speech Therapy**
- **Occupational Therapy**
- **Cognitive / Behavioural Therapy**
- **Socialising / Communication Courses**
- Physiotherapy
- Hydrotherapy
- Art Therapy
- Alternative therapy (ie Homeopathy, Massage therapy, Osteopathy, Chiro)
- Pet Therapy or Animal assisted therapy (AAT)

PROGRAMS

These are some of the most commonly used programs out there. They may be great for you or not your best option. Please look into each to determine what is best suited to your needs (i.e. check your service provider and seek feedback before choosing one).

- **Positive Partnerships** program provided by ASPECT. These are free 1-2 day courses. Alternatively, the individual modules can be completed online.
<http://www.autismtraining.com.au/public/index.cfm>
- **More Than Words** Course—Hanen program for speech
- **Building Blocks** Early Intervention Program for pre-schoolers
- **Family Advocacy** provide free courses regarding integrated education in a mainstream school setting – for both public and private education
- **Cool Kids Program** - for management of anxiety. Make enquiries with your child's psychologist or contact Macquarie University for a therapist in your area.

- Applied Behavioural Analysis (**ABA**). This is usually a home-based program with therapist visiting throughout the week. Available from various service providers.
- Autism Behavioural Intervention (**ABI**)-NSW. A home based program of 20hrs over 40wks for children under 6yrs who haven't commenced school. Note you will not be able to access ABI-NSW if you already have an ABA program in place.
- **DIR/Floortime**. A program where the parent, therapist and child spend much of the time interacting on the floor, encourages interaction through a play-based approach.
- Relationship Development Intervention (**RDI**). This is a long term program that trains the parents/carers to be the child's primary therapists.
- Some ideas to **complement** the above programs include: Toy/Resources Libraries, PECS books/images, Social Stories, Visual Schedules, Sensory items, etc
- Also note some **other opportunities** to develop various skills such as: social skills through playgroups, specific interests such as hobbies, computer skills with electronic tablets (i-pad).

FUNDING OPTIONS

Funding options are always changing but we have listed some here to start with. For a more comprehensive list please go to the Funding page on the ACN website.

- **Autism Advisor Program:** Speak with an advisor at Autism Spectrum Australia about funding for children under 6 year old 1300 978 611
- **Helping Children With Autism Package / FAHCSIA FUNDING**
<http://www.fahcsia.gov.au/sa/disability/progserv/people/HelpingChildrenWithAutism>
- **Medicare:** Chronic Disease Allied Health Services – GP Management Plans (GPMP). You need a referral from your GP to receive five services per calendar year for any of the following – physiotherapy, occupational therapy, speech pathology, psychology.
- **Mental Health Care Plan:** You need a referral from your GP or Paediatrician to access up to 12 visits to a psychologist, clinical psychologist, social worker or occupational therapist within a calendar year.
For more information call Medicare on 132 150 or at www.medicareaustralia.gov.au
- **Centrelink Payments:** Carer Allowance (child) is a supplementary payment for parents or carers who provide daily care and attention for children with a disability or severe medical condition at home. Carer Allowance (child) may be paid on top of [Carer Payment \(child\)](#) or other payments, such as [Age Pension](#). For more information about this payment go to www.centrelink.gov.au and search for carer allowance.
- **Carer Adjustment Payment:** May be eligible for up to \$10,000 from Centrelink but must apply within first two years of diagnosis
- **Carer's Allowance:** This is administered by Centrelink and assists Carers looking after a child or an adult with a severe disability and/or medical condition which requires much additional attention – Autism included.
Web: <http://www.centrelink.gov.au> (Search for carer's allowance)
- **Carer's Payment:** Carer's Payment is income and assets tested, similar to a full pension and difficult to qualify for. Web: <http://www.centrelink.gov.au> (Search for carer's payment)
- **Health Care Card:** The Health Care Card may entitle the holder to significant discounts on visits to the doctor (bulk billing) / filling scripts at the pharmacy and entertainment venues

(e.g. Easter Show, Sea World).

<http://www.centrelink.gov.au> (Search for health care card)

- **ADHC NSW - Family Assistance Fund**

The Family Assistance Fund aims to increase family wellbeing and strengthen the capacity of families to provide ongoing care for a child or young person with a disability in their home. Small amounts of discretionary funding are provided to families to help them address needs that cannot be met through the standard range of services, are not available from other funding sources, or would otherwise be unaffordable. Unlike the recent Commonwealth Government's annual Child Disability Payment, Family Assistance Funding is not a grant or entitlement.

<http://www.dadhc.nsw.gov.au/DADHC.htm>

WHERE TO FIND THERAPISTS / RESPITE

- ACN www.autismcommunity.org.au
- ASPECT www.aspect.org.au
- Childcare listings www.localchildcare.com.au
- Learning Links www.learninglinks.org.au
- Carers NSW www.carersnsw.asn.au
- Diagnostic and Assessment Centre at major hospitals eg Kogarah D & A, at St George Hospital, Royal North Shore Hospital
- Association for Children with a Disability NSW ([ACD NSW](#)) offers:
 - [‘Through the Maze’](#) handbook, listing a wide variety of resources and services
 - [‘Helping You and Your Family’](#) handbook, with information and support information
- ASPECT helpline phone 8977 8335 (Someone to Turn to program)

RECOMMENDED READING

Below are some of the titles which could prove helpful for you, depending on your situation.

This list has been compiled based on recommendations by parents in the Autism Community Network.

Autism books can be expensive. Check your local library first. They may have it or order it in for you.

1. ***A Friend Like Henry*** – Nuala Gardner
2. ***Asperger's and Girls*** - Tony Attwood
3. ***Australian Autism Handbook*** – Benison O'Reilly and Seana Smith
4. ***Autism Answer Book*** - William Stillman
5. ***Can I tell you about Asperger Syndrome*** – Jude Welton
6. ***Complete Guide to Asperger's Syndrome*** – Tony Attwood
7. ***Curious Incident of the Dog in the Night-time*** - Mark Haddon
8. ***Emergence: Labelled Autistic*** - Temple Grandin & Margaret M. Scariano
9. ***Freaks, Geeks & Asperger's Syndrome*** – Luke Jackson
10. ***The Hidden Curriculum*** – Brenda Smyth Miles
11. ***Life Behind Glass***: Wendy Lawson
12. ***Look Me In The Eye*** - John Elder Robinson

13. *New Social Stories Book* – Carol Gray
14. *Out-Of-Sync Child: Recognizing and Coping with Sensory Processing Disorder* – Carol Stock Kranowitz
15. *Siblings of Children with Autism. A Guide for Families* – Sandra L Harris & Beth A Glasberg
16. *Smiling at Shadows* - Junee Waites and Helen Swinbourne
17. *Social Skills Picture Book* - By Jed Baker
18. *Special Boys Business* – Fay Angelo, Heather Pritchard & Rose Stewart (also available, *Special Girls Business*)
19. *Thinking In Pictures* - Temple Grandin
20. *What did you say? What do you mean* – Jude Welton

Documentaries / Movies Worth Watching

<i>Adam</i>	<i>Intricate Minds II</i>	<i>My Name is Khan</i>	<i>Snow Cake</i>
<i>Autism: The Musical</i>	<i>Mary and Max</i>	<i>Temple Grandin</i>	

OTHER OPTIONS TO CONSIDER

- Support for siblings who are not coping ie they are stressed/depressed etc
- Consider dietary changes eg Organic products, Casein &/or Gluten Free products, preservative free products, colour free products.
- Talk to your child's GP or The Allergy Clinic at Sydney's RPA Hospital.
- Toy/resource libraries. See www.autismcommunity.org.au
- Social Stories. To help your child learn how to respond appropriately
- Purchase of toys/games/aides that assist the child eg. Pencil grips, communication games, things to aide gross/fine motor skills, time timers
- Membership of organizations that email news of coming events eg St George and Sutherland Multipurpose Centre, Aspect, Learning Links, Family Advocacy
- Join mailing lists for free newsletters eg www.autismcommunity.org.au , Warringah Disability Newsletter
- Biomedical testing. Discuss with your child's paediatrician
- Download iTunes apps for iPhone, iPod or iPad to help your child communicate & learn eg ABA apps - see www.autismcommunity.org.au for list of recommended apps.
- Use of natural care products free of petro-chemicals. These can be purchased from chemists, health food stores and supermarkets.
- Medication: Can be used to treat behavioural problems such as ADD, anxiety and depression, and increase the effectiveness of other interventions. Speak with your medical advisors.
- Vitamins and minerals. Seek advice from your paediatrician or a Nutritionist. Supplementing with appropriate levels of vitamins and minerals has been known to bring about improvements.

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Incorporation No. INC9896017 | ABN : 64 103 662 535 | CFA No: CFN/2282