

What do we do now?



An Information Pack for Families

This pack has been compiled and supplied by



**AUTISM
ASPERGER ACT**

Proudly supported by Bendigo Bank



**AUTISM
ASPERGER ACT**

Autism Asperger ACT Inc. has donated this Information Pack to parents who have recently had a child diagnosed with an Autism Spectrum Disorder.

It is hoped that the information in this pack will help parents understand more about their child's diagnosis and how the family can help the child with an Autism Spectrum Disorder.

This pack has been printed using funds supplied by FaHCSIA. Autism Asperger ACT Inc thanks them for their support.

DISCLAIMER

Autism Asperger ACT Inc does not provide medical or legal advice or services. Rather, Autism Asperger ACT Inc provides general information about autism as a service to the community.

The information provided in this kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. This kit is not intended as a tool for verifying the credentials, qualifications, or abilities of any organization, product or professional.

Autism Asperger ACT Inc has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.

Autism Spectrum Disorder is a pervasive, Neuro-biological disability that occurs before children have their 3rd birthdays. There is no known cause for autism and at present, no cure. All children who have an Autism Spectrum Disorder have significant difficulties with communication and with social and emotional understanding. Their lack of flexibility in thinking and behaviour impacts on their understanding of the world. The effects of autism on learning and daily functioning range from mild to severe. From being an extremely rare disability in the 1940s, when autism was first described, it is now the most commonly occurring childhood disability. It occurs in approximately 1 in every 160 children in Australia.



AUTISM
ASPERGER ACT

TEN THINGS EVERY CHILD WITH AUTISM WISHES YOU KNEW

©2005 Ellen Notbohm.

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute -- the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look "normal" but his behaviour can be perplexing and downright difficult.

Autism was once thought an "incurable" disorder, but that notion is crumbling in the face of knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism's most challenging characteristics. Equipping those around our children with simple understanding of autism's most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly -- every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am first and foremost a child. I have autism. I am not primarily "autistic." My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don't think I "can do it," my natural response will be: Why try?

3 | Autism Asperger ACT Revised September 2009

2. My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It his means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a "simple" trip to the grocery store may be hell for me:

My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today's special. Musak whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia ??â€™™??. I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented (see more on this below), this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

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

Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "*&^%\$#@, Billy. #\$\$%^&^%\$&* ??â€™™"? ??â€™™"? ??â€™™"?" Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

4. I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is "this will be easy for you to do." When you say "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me "It's raining very hard."

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

5. Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, I am very visually oriented. Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations. Here's a great website for learning more about visual schedules: www.cesa7.k12.wi.us/sped/autism/structure/str11.htm .

I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

7. Please focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

8. Please help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

9. Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge.

Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment.

Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.

10. If you are a family member, please love me unconditionally. Banish thoughts like, "If he would just...." and "Why can't she...." You did not fulfill every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you -- I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattletale on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh. They had autism too.

The answer to Alzheimer's, the enigma of extraterrestrial life -- what future achievements from today's children with autism, children like me, lie ahead?

All that I might become won't happen without you as my foundation. Think through some of those societal 'rules' and if they don't make sense for me, let them go. Be my advocate, be my friend and we'll see just how far I can go.

Reprinted with permission of the author.

MYTHS AND FACTS ABOUT AUTISM SPECTRUM DISORDERS

There are many different myths surrounding ASD's in the world. Here are some of the facts about ASD's.

Myth: Autism Spectrum Disorders are rare.

Fact: Autism Spectrum Disorders are NOT rare; they affect 1 in every 160 children in Australia.

Myth: Autism Spectrum Disorders are an emotional disturbance.

Fact: Autism is a Neuro-developmental disorder.

Myth: Poor parenting causes Autism Spectrum Disorders.

Fact: Parents do NOT cause Autism Spectrum Disorders. Parents DO need support to manage difficult behaviours with structure and consistency.

Myth: There is a cure for Autism Spectrum Disorders, or people will grow out of the disorder.

Fact: People do not "grow out" of Autism Spectrum Disorders. With early intervention and good educational programs progress may be significantly better.

Myth: Everyone with an Autism Spectrum Disorder behaves in the same way.

Fact: People with Autism Spectrum Disorders are individuals with strengths and needs unique to each individual.

Myth: All people with an Autism Spectrum Disorder have special savant or genius like skills

Fact: All children with an Autism Spectrum Disorder do NOT possess special genius-like abilities and memorization abilities.

Myth: All children with an Autism Spectrum Disorder should be taught the same way.

Fact: There is NOT one single treatment that is appropriate for all children with an Autism Spectrum Disorder at all times. Individually tailored programs using a range of teaching strategies are necessary to assist children in reaching their full potential.

Myth: People with Autism Spectrum Disorders have to be in special programs "for the autistic".

Fact: Individually designed programs best meet the needs of a person affected by an Autism Spectrum Disorder. They need to be learning, living and working in settings where there is ample opportunity to communicate and interact with others who have the skills they need.

USING VISUAL SUPPORTS

As most people who have an Autism Spectrum Disorder are highly visual it makes sense that we support communication and other interactions with visual supports.

Visual supports should be used with all young children with an ASD whether they are talking or not. This is important and people with an ASD usually have difficulty understanding and gaining meaning from the spoken word. We constantly need to remind ourselves that just because a child uses speech, it does not actually mean that they understand what we are saying or that they are using their speech in a meaningful way.

Visuals are useful as they are:

- Static while words and signs are fleeting
- Consistent and when the picture is labelled with a word everyone using the visual will use the same word
- More portable than actual objects

Hierarchy of visual supports:

- Objects
- Remnants
- Photos of the actual object
- Photos of a similar object
- Boardmaker or other symbol system
- Line drawings
- Written words

Using Visuals

Initially the visual should be coupled with the object. As the child grasps the connection the visual can be used rather than the object itself.

Always write the word on the visual as soon as you are able to move beyond remnants. This ensures that everyone calls the object the same thing and sometimes the child actually cracks the visual code and reads.

Just providing visual supports does not mean that your child will automatically use them. You will need to demonstrate their use to your child. Model each step, prompting your child as needed.

Visuals are very important in reducing anxiety and stress for many children.

Making Visuals

Although making visuals is time consuming it is well worth the effort. However, if you do not have time to find pictures take photos of the actual object, or if your child understands, draw pictures on paper.

Visuals do not need to be beautifully made – pen and paper or a small whiteboard or magna doodle are useful additions to your bag. Visuals can also be made small enough to attach to your key-ring.

Information needs to be:

- Relevant to the purpose of the visual
- Clear
- Concise

Visuals can be used:

- On schedules
- To share information
- As a checklist list (things to put in school bag)
- As an organizer (getting dressed)
- To support behaviour (how do I feel, social stories)
- To support learning

Gay von Ess
Autism Consultant and Special Educator
June 2008

CHILD SAFETY

Most young children with Autism Spectrum Disorder (ASD) have little awareness of the need to stay in the garden or near the adult when out at the shops etc. Some children with ASD are 'runners' – they do not just stray away from the adult, if they get a chance they run and keep on running.

There are a number of different ID bracelets on the market and if necessary a Child Personal Safety Alarm is a good investment to ensure your peace of mind as well as your child's safety.

Kids Kontakt (www.kidskontakt.com.au) have a variety of ID bracelets as well as temporary tattoos. In addition they stock Child Personal Safety Alarms.

You can have a MediAlert bracelet made for your child which has the advantage of being instantly recognisable as an information bracelet. Visit www.medicalert.com.au for further information.

CareTrak Systems Australia specialise in wrist transmitters with a perimeter system or mobile locator. All wrist transmitters are water proof. Please visit www.caretrak.com.au.

Children with ASD will usually initially resist wearing a bracelet. It is however important to persevere – use plenty of distractions for the first twenty four hours or so; after that most children accept them.

Please remember that identification bracelets and Child Alarms etc do not replace adult supervision.

MEDIFAB AUSTRALIA, Kiddiequip Products for Children, phone: 1300 543 343 have a range of safety harnesses that prevent even the most determined children undoing car or stroller seat belts.

WELCOME TO HOLLAND

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome To Holland".

"Holland?!?" you say, "What do you mean "Holland"??? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

© 1987, by Emily Perl Kingsley.

HELPING CHILDREN WITH AUTISM

The Australian Government has committed \$190 million until June 2012 to the *Helping Children with Autism* (HCWA) initiative. The package will help address the need for support and services for children with Autism Spectrum Disorders (ASDs). The HCWA initiative will be implemented by three government departments - the Department of Health and Ageing (DoHA); the Department of Education, Employment and Workplace Relations (DEEWR) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The Autism Advisory Service ACT is a component of the HCWA initiative, funded by FaHCSIA and hosted by Autism Asperger ACT. The role of the Autism Advisory Service is to provide information on the HCWA initiative; to help families access the HCWA early intervention funding; and to provide information on Autism resources and services in the ACT.

The Department of Health and Ageing:

- Medicare benefits are available for services provided by consultant physicians, eligible psychologists, speech pathologists and occupational therapists, to diagnose children under 13 years, and provide treatment services for children under 15 years. Conditions apply so please call Medicare on 132 011 or visit www.health.gov.au/autism.

The Department of Education, Employment and Workplace Relations:

- Professional development for teachers and other school staff to support children with Autism. For more information, visit www.dest.gov.au/schools/autism.
- The *Positive Partnerships* workshops are available to parents with a school aged child with an ASD. Visit: www.autismtraining.com.au or phone 1300 881 971 for more information and to register.

The Department of Families, Housing, Community Services and Indigenous Affairs: (www.fahcsia.gov.au):

- Early Intervention Payments: Currently, children with an ASD diagnosis, aged 0-7 years (up to their seventh birthday) are eligible for up to \$12,000 (a maximum of \$6000 per financial year) of early intervention funding. The funding can be used to access early intervention services through an approved service provider.

HELPING CHILDREN WITH AUTISM

NEW MEDICARE ITEMS

Adapted from information provided by the Department of Health and Ageing
www.health.gov.au

Items for Pervasive Developmental Disorders (PDD)

From 1 July 2008, new items are available on the Medicare Benefits Schedule (MBS) as part of the Australian Government's \$190 million *Helping Children with Autism* package.

The new items are available for:

- Consultant physicians (paediatricians and psychiatrists) to diagnose and develop a treatment plan for children aged under 13 years on referral from a GP;
- Psychologists, speech pathologists and occupational therapists to provide up to four services in total per child to collaborate with the psychiatrist or paediatrician on the assessment where required; and
- Psychologists, speech pathologists and occupational therapists to provide early intervention treatment following diagnosis (providing up to 20 services in total per child).

Medicare item numbers for the diagnosis and contribution to a practitioner's PDD treatment and management plan:

- Psychology: MBS item 82000
- Speech Pathology: MBS item 82005
- Occupational Therapy: MBS item 82010.

Referral requirements for the diagnosis and contribution to a practitioner's PDD treatment and management plan:

An eligible allied health professional can provide PDD assessment items (82000-82010) to a child where:

- The child has previously been provided with any MBS service covering items 110 through 131 (inclusive), as provided by an eligible consultant paediatrician; or
- The child has previously been provided with any MBS service covering items 296 through 370 (excluding item 359), as provided by an eligible consultant psychiatrist.

Description:

Professional attendance provided to a child aged under 13 years where:

- The child is referred by an eligible practitioner for the purpose of collaborating with the practitioner for the diagnosis of the child; and/or
- The child is referred by an eligible practitioner for the purpose of contributing to the child's pervasive developmental disorder (PDD) treatment plan, developed by the practitioner;
- The eligible practitioner is a consultant physician in the practice of his or her field of psychiatry or paediatrics;
- The allied health provider attending the child is registered with Medicare Australia as meeting the credentialing requirements for the provision of these services;
- The child is not an admitted patient of a hospital;
- The service is provided to the child individually and in person;
- The service lasts at least 50 minutes in duration.

These items are limited to a maximum of four services in total per child consisting of any combination of 82000, 82005 and 82010, provided by any combination of allied health professionals.

Allied Health Items for early intervention treatment of pervasive developmental disorders (PDD):

- Psychology: MBS item 82015
- Speech Pathology: MBS item 82020
- Occupational Therapy: MBS item 82025

Referral requirements for the PDD treatment items:

An eligible allied health professional can provide PDD treatment items (82015-82025) to a child where:

- The child has previously been provided with a PDD treatment and management plan (MBS item 135) by an eligible consultant paediatrician; or
- The child has previously been provided with a PDD treatment and management plan (MBS item 289) by an eligible consultant psychiatrist.

(NB – these items have only been available since 1 July 2008)

An allied health professional wanting to provide any of the items 82000-82025 must be in receipt of a current referral provided by a consultant paediatrician or a consultant psychiatrist.

Description:

Professional attendance provided for treatment of autism and any other pervasive developmental disorder (PDD) for a child aged under 15 years where:

A PDD treatment plan has been prepared for the child by an eligible practitioner (under item 135 or 289);

- The child has been referred by an eligible practitioner for services that are consistent with the PDD treatment plan;
- The eligible practitioner is a consultant physician in the practice of his or her field of psychiatry or paediatrics;
- The allied health provider attending the child is registered with Medicare Australia as meeting credentialing requirements for the provision of these services;
- The child is not an admitted patient of a hospital;
- The service is provided to the child individually and in person;
- The service lasts at least 30 minutes in duration.

These items are limited to a maximum of twenty services, in total (in a life time), per child consisting of any combination of 82015, 82020 and 82025, provided by any combination of allied health professionals. Within the 20 services provided, a course of treatment will consist of the number of services stated on the child's referral (up to a maximum of 10).

Who can access these services?

Children with autism or any other PDD can access these services:

- If their condition is being managed by an eligible psychiatrist or paediatrician under a PDD treatment and management plan and that PDD treatment plan is complete prior to the child's 13th birthday; and
- If they are under 15 years of age for treatment.

What is considered autism or PDD for the purposes of the items?

- The conditions classified as PDD for the purposes of these services are informed by the "American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorder", Fourth Edition (DSM-IV-TR) and the World Health Organisations International Classification of Diseases (ICD-10).

ENHANCED PRIMARY CARE PROGRAM (EPC)

The Enhanced Primary Care (EPC) program was introduced to provide more preventive care for older Australians and improve coordination of care for people with chronic conditions and complex care needs. The program provides a framework for a multidisciplinary approach to health.

Children who need clinical help to participate in the community either now or in the future, should be able to get clinical help through the health system. If you have a child with an Autism Spectrum Disorder who needs help in any of the allied health areas including speech pathology, psychology, and occupational therapy this scheme is worth trying.

How to get an Enhanced Primary Care Program (EPC):

Start by making an appointment with your child, making sure that when you make the appointment you specifically say that you want to talk to the GP about an Enhanced Primary Care program for your child.

Prepare for your visit by writing a list of your most serious concerns. Put these in order of priority. This will help your GP to develop an EPC for your child that provides the individual intervention for your child's highest needs.

It is crucial that your GP understands the difficulties that you and your child experience. Even if you are unable to complete the plan on your first visit it is important that you persevere – hopefully the experience will convince your GP that you do need some additional professional help.

CENTRELINK

Carer Allowance (caring for a child under 16):

Carer Allowance (child) is a supplementary payment for parents/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.

Who can get Carer Allowance (caring for a child under 16)?

A person may get Carer Allowance (child) if they look after a child with a disability or severe medical condition who requires a lot of additional care or attention in their own home. You must live in the same home as the child you are caring for. Both the carer and the child with a disability must also meet residence requirements.

A person can get either:

- A fortnightly payment plus the Health Care Card, or
- A Health Care Card.

What a person gets will depend on the severity of the child's disability. A single rate of Carer Allowance (child) may be payable where the combined level of disability of two children in the family meets the qualifying threshold.

The Child Disability Assessment Tool (**CDAT**) is a tool used by Centrelink to assess medical eligibility for Carer Allowance (child) when the person cared for is under 16 years. This tool measures the functional ability of the person receiving care. A list of severe disabilities and chronic medical conditions allows fast-track entry to Carer Allowance (child) for children with more severe conditions.

If your child has an Autism Spectrum Disorder, including Asperger Syndrome, you are entitled to the Carer Allowance.

The Carer Allowance is not means tested.

Changes to Carer Payment:

There is a new assessment process commencing July 2009 that will provide improved support for carers. The changes include greater access to Carer Payment and assess the total care load of the carer. For more information please contact Centrelink on 13 27 17 or visit www.centrelink.gov.au.

RESPIRE AND OTHER SUPPORT SERVICES

There are a number of services that offer limited respite care for families who have a child with an Autism Spectrum Disorder.

DISABILITY ACT

Ph: 6207 1086 Web: www.dhcs.act.gov.au/disability_act

Email: DisabilityACT@act.gov.au

Disability ACT plan and develop strategic policy, allocate funding and provide and monitor services for people with disability & their families in the ACT

OTHER SUPPORT SERVICE

BOOKS FOR SIBLINGS

Band, Eve. (2001). *Autism Through a Sister's Eyes*. Future Horizons. Texas.

Bleach, Fiona. (2001). *Everybody is Different. A Book for Young People who Have Brothers and Sisters with Autism*. Autism Asperger Publishing Company. Kansas.

Edwards, Becky and Armitage, Davis. (1999). *My Brother Sammy*. Bloomsbury Publishing. London.

Gorrod, Louise. (2001). *My Brother is Different*. National Autistic Society. London.

Harris, Sandra and Glasberg, Beth. *Siblings of Children with Autism*. Woodbine Press. USA.

Hames, Annette and McCaffrey, Monica. (ed.) (2005). *Special Brothers and Sisters*. Jessica Kingsley Publishers. London and New York.

Healy, Angie. (2005). *Sometimes My Brother. Helping Kids Understand Autism Through a Sibling's Eyes*. Future Horizons. Texas.

Lowell, James and Tuchel, Tara. (2005). *My Best Friend Will*. Autism Asperger Publishing Company. Kansas.

Peralta, Sarah. (2002). *All About My Brother*. Autism Asperger Publishing Company. Kansas.

These books are available in the Autism Asperger ACT library. Autism Asperger ACT also has several Sibling Boxes (which comprise a selection of materials for siblings and families) that are also available for loan.

AUTISM INFORMATION LINE

Autism Spectrum Australia (Aspect) runs an Autism Information Line to help answer the many questions individuals who have an Autism Spectrum Disorder, their families, carers, support staff and professionals may have.

The role of the Autism Information Line is to assist in answering specific enquiries, to provide a referral point for services within Aspect and also to services available in the wider community. The service is staffed by Aspect professionals from a range of disciplines. Sometimes the questions asked are very specific, such as "What is an Autism Spectrum Disorder?"; "Where can I go to get an assessment for my child?" or "What services does Aspect provide?".

The Autism Information Line can also provide brief practical advice to assist families and carers with their day-to-day management of children with ASDs. The information line has a wide range of information regarding services and resources.

To access the Autism Information Line, please call (02) 8977 8377 between 9.00am and 4.00pm on weekdays. If staff are busy, please leave a voice mail message and your call will be returned at the first opportunity.

Alternatively, please email your queries to infoline@aspect.org.au

Aspect is based in Sydney.

ADVOCACY FOR INCLUSION

The mission of Advocacy for Inclusion is to provide information, education and representation to effectively advocate for positive and inclusive outcomes for people who have a disability.

What does Advocacy for Inclusion do?

Advocacy for Inclusion acts with and on behalf of individuals in a supportive manner or assist individuals to act on their own behalf, free of conflicts of interest and motivated only by a desire to obtain a fair and just outcome for the individual concerned.

They act to influence systemic change (e.g. to government policies, agency practices and societal structures), which enable people who have a disability to be included as valued members of society.

Advocacy for Inclusion informs, educates, represents, encourages, lobbies, refers, networks, analyzes, facilitates questions and challenges.

Who can use Advocacy for Inclusion?

Advocacy for Inclusion can be used by:

- People who have a disability
- Family members and friends of people who have a disability
- People who speak on behalf of people who have a disability (including members of peak bodies, service organisations, workers, bureaucracy and government)

Advocacy can be provided for people who live in or use services in the ACT region.

How does Advocacy for Inclusion protect your privacy?

Confidentiality is maintained at all times and any information gathered or shared is always with the person's knowledge and consent. www.advocacyforinclusion.org

AUTISM ASPERGERS ADVOCACY AUSTRALIA A4

Autism Aspergers Advocacy Australia was formed in 2002 in response to the growing demand from people with autism spectrum condition and their families who wished to have a more direct involvement in raising the profile of autism-related issues with the decision-makers, to government and the media.

The aim of the advocacy organisation is to provide a voice on a national and a state and territory level for individuals and groups across Australia.

A4 is:

- *A National Grassroots Organisation.*
- *An e-mail based information network.*
- Focussed on the development and promotion of national Autism Spectrum Disorder policy and priorities.
- Concerned with the 'big picture' issues.
- Activities targeting the Federal Government.
- A small step in a long long process.

A4 is not:

- *An Autism support group.*
- *A protest group.*
- *Advocacy at the State or Territory level.*
- *An e-mail chat forum.*
- *A cure for Autism.*

There is no membership charge for A4. To join and /or for further information go to www.a4.org.au

WHERE TO FIND RESOURCES

Bookinhand

Bookinhand stocks a wide range of resources on Autism Spectrum Disorder
Ph: 07 3283 8214; www.bookinhand.com.au; bookinhand@optusnet.com

Footprint Books

Footprint books is the distributor of Jessica Kingsley books, one of the two main publishers of books on ASD; www.footprint.com.au

Co-Ordinates Therapy Services

Books and equipment are available from Co-Ordinates Therapy Services
www.therapybookshop.com/coordinates

Photos, Cards, Visual Supports and General Resource Links

Chelsea's Challenges 03 9758 2473

www.spectronicsinoz.com

Boardmaker and PICS for PECS (Autism Asperger ACT Inc. has a loan copy of Boardmaker).

www.dltk-cards.com

www.dotolearn.com

www.inekards.com

www.mayer-johnson.com

www.prompteducation.com

www.seeandspeak.com.au

www.slatersoftware.com

www.theracrew.com

www.usevisualstrategies.com

www.visualaidsforlearning.com

www.winningconnection.com.au

General Education Resources

www.cindysautisticsupport.com

www.fastforword.com.au

www.icommunicatetherapy.com

www.theracrew.com

www.tiptoeep.com.au

Google Images – go to www.google.com and select the images button.

Story Builder

www.autism.org.uk/storybuilder

Provides information on the computer-based tool called *Story builder* which can be used by parents, carers and teachers to create individualised stories for children with Autism and Asperger syndrome.

Social Stories

www.autism-help.org

Sensory Toys

www.focustoys.com

www.therapybookshop.com/coordinates

Books and equipment are available from Co-Ordinates Therapy Services.

The Early Learning Centre (Belconnen Mall), \$2 shops, National Geographic and Socrates also stock sensory toys from time to time.

Bullying

"Being Bullied: Strategies and Solutions for People with Asperger's Syndrome" (Nick Dubin) is a DVD available through the Autism Asperger ACT library.

Other Products

www.nanasweightedblankets.com

Weighted blankets that help children with Autism settle.

www.brightsky.com.au

Provides health care products including personal care, wound care products, supplements, vitamins, skin care, bowel care, pressure management, bedding, support and mobility aids.

SUGGESTED READING

Attwood, Tony. (2006). *A Complete Guide to Asperger's Syndrome*. Jessica Kingsley Publishers. New York and London.

Attwood, Tony; Grandin, Temple et al (2006) *Asperger's and Girls*. Future Horizons, Arlington. Texas

Dodd, Susan. (2005). *Understanding Autism*. Elsevier. Marrickville. Australia.

Ernsperger, Lori and Wendel, Danielle. (2007). *Girls under the Umbrella of Autism Spectrum Disorders. Practical Solutions for Addressing Everyday Challenges*. Autism Asperger Publishing Company. Kansas.

Grandin, Temple. (1996). *Thinking in Pictures*. Vintage Books. New York.

Gray, Carol and White, Abbie Leigh. (ed.) (2002). *My Social Stories Book*. Jessica Kingsley Publishers. New York and London.

Hall, Kenneth. (2001). *Asperger Syndrome, the Universe and Everything*. Jessica Kingsley Publishers. New York and London.

Jackson, Luke. (2002). *Freaks, Geeks and Aspergers Syndrome*. Jessica Kingsley Publishers. New York and London.

Larkey, Sue and von Ess, Gay. (2006). *The Early Years. The Foundations of ALL Learning*. Go to www.suelarkey.com

Larkey, Sue. (2007). *Practical Sensory Programmes*. Go to www.suelarkey.com

Larkey, Sue. (2005). *Making it a Success*. Go to www.suelarkey.com

Hodgdon, Linda. (1996) *Visual Strategies for Improving Communication*. Quirk Roberts Publishing. Michigan.

Holliday Willey, Liane (2001). *Asperger Syndrome in the Family. Redefining Normal*. Jessica Kingsley Publishers. New York and London.

McAfee, Jeanette. (2002). *Navigating the Social World*. Future Horizons, Arlington. Texas.

Notbohm, Ellen. (2005). *Ten Things Every Child with Autism Wishes You Knew*. Future Horizons, Arlington. Texas.

Notbohm, Ellen. (2006). *Ten Things Every Student with Autism Wishes You Knew*. Future Horizons, Arlington. Texas.

Notbohm, Ellen and Zusk, Veronica. (2004). *1001 Great Ideas for Teaching and Raising Children with Autism*. Future Horizons, Arlington. Texas.

O'Reilly, Bension and Smith, Seana. (2008). *Australian Autism Handbook*. Jane Curry Publishing. Sydney.

Positive Partnership Manual: Discusses behavior support, completing work, transitions, sexuality, making friends, siblings, bullying, and positive behavior. Available at the Autism Asperger ACT library.

Smith, Myles, Brenda and others. (2004). *The Hidden Curriculum. Practical Solutions for Understanding Unstated Rules in Social Situations*. Autism Publishing Company. Kansas.

Tullemans, Anna. (2004). *Talking to Family and Friends about the Diagnosis*. DJ Publishers. Redcliffe. Queensland.

Winter, Matt. (2003). *Asperger's Syndrome – What Teachers Need to Know*. Jessica Kingsley Publishers. New York and London.

Yapko, Diane. (2003). *Understanding Autism Spectrum Disorders. Frequently Asked Questions*. Jessica Kingsley Publishers. New York and London.

SUGGESTED WEB SITES

www.autismaspergeract.com.au

Home of Autism Asperger ACT

www.autismtraining.com.au

Website for the Positive Partnerships workshops for parents with school aged children with an ASD. It assists parents and schools to work together to improve the educational outcomes of children with ASD. It offers on-line training modules providing interactive learning modules and useful learning resources for parents and school staff including information modules on specific topics like bullying, homework and sexuality.

www.autismawareness.com.au

Includes family entitlements

www.asaonline.org

Up to date information on treatments and research evidence

www.autismtoday.com

Lots of current literature and includes an area where you can "Ask the Expert" a question. This includes people with ASD you can ask questions.

www.aspect.org.au

Useful Australian site

www.cyh.com

The South Australian website for children and youth health

www.bullyingnoway.com.au

Useful tips on dealing with bullying

www.dhcs.act.gov.au/therapyact

Information on the services offered by Therapy ACT

www.det.act.gov.au

Information on the ACT Education Department

www.handscantalk.com.au

Information on sign language.

www.health.gov.au

Information on the Helping Children with Autism Medicare items and provides access to published guides such as 'Early intervention for children with autism spectrum disorders: Guidelines for best practice'.

www.lifeskills4kids.com.au

List resources to help your child develop critical life skills

www.med.monash.edu.au/spppm/research/devpsych/actnow/factsheet.html

Useful Facts Sheets

www.nellefrances.com

AspergerChild.com aims to provide parents, carers, families, educators and professionals with reliable information and support in their journey with ASD's.

www.raisingchildren.net.au/autism

An Australian Parenting site with an ASD-specific section.

www.rdiconnect.com

Provides information on Relationship Development Intervention

www.siblingsaustralia.org.au

A website to help children and adults who have a sibling with special needs.

www.teacch.com

Information on the TEEACH (Treatment and Education of Autistic and related Communication- handicapped cHildren) program.

www.tonyattwood.com

Website of Tony Attwood- A Psychologist who specializes in ASD's.

www.suelarkey.com

Useful strategies and resources

www.thewatsoninstitute.org

Information on the Watson Institute today- an educational organization, specializing in educating children with special needs.

www.wrongplanet.net

Has a very interesting online forum.

For the kids:

www.abc.net.au

Home of the ABC- provides games and activities for young children.

www.askkids.com

Features interactive "edu-tainment"

www.comiclife.com

Create amazing comics and photo books.

www.do2learn.com

A goldmine of activities and resources.

www.dltk-kids.com

Features children's crafts and colouring pages.

www.learningtreasures.com

Provides education resources including games, spelling sheets, science experiments, maps, maths sheets and more.

www.symbolworld.org

Visuals galore!

www.pbskids.org/lions/games/blending.html

Interactive games for the early years.

www.polyxo.com

Teaching children with Autism

www.lego.com

The Lego website

www.watchmelearn.com

Uses multisensory products to engage children in learning.

GLOSSARY

Aphasia: The complete or partial loss of ability to use or understand language.

Apraxia: A disorder of voluntary movement, consisting of partial or total incapacity to execute purposeful movements, without impairment of muscular power, sensibility and coordination. The person has difficulty sequencing movements in the service of a goal. May be specific to speech.

Applied Behaviour Analysis (ABA): A style of teaching which uses a series of trials to shape a desired behaviour or response. Skills are broken down into their simplest components and then taught to the child through a system of reinforcement.

Asperger's Syndrome (AS): A developmental disorder on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviours. Unlike typical autism, individuals with Asperger's Syndrome have no significant delay in language and cognitive development.

Assistive Technology: Technology used to assist a person with a disability (for example alpha smarts or computer programs) particularly within the Government school system.

Attention Deficit Hyperactivity Disorder (ADHD): A particular symptom complex with core symptoms including developmentally inappropriate degrees of attention, cognitive disorganization, distractibility, impulsivity and hyperactivity, all of which vary in different situations and at different times. Common secondary symptoms include perceptual and emotional immaturity, poor social skills, disruptive behaviours and academic problems.

Atypical Autism: A general term for conditions that are close to but do not quite fit the set of conditions for autism or other specific conditions.

Auditory Integration Training (AIT): A technique used to relieve hearing dysfunctions by "retraining" the ear to hear in a more balanced fashion.

Augmentative Communication: The use of aids to help an autistic child communicate his/her wants and needs. For example, photographs and picture exchange communication.

Autistic Savant: An autistic individual who displays incredible aptitude for one or two skills (e.g. amazing musical or artistic ability).

Autistic Spectrum Disorders: A term that encompasses autism and similar disorders. More specifically, the following five disorders listed in the DSM-IV: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified, Childhood Disintegrative Disorder, and Retts Disorder.

Co-morbid Condition: Having more than one concurrent diagnosis. Another term for this would be "dual diagnosis". Many people with autism have one or more additional diagnoses, such as ADHD, Tourette's Syndrome or Epilepsy.

Discrete Trials: A short, instructional train which has three distinct parts: e.g. a direction - a behaviour - a consequence. Many discrete trial programs rely heavily on directions or commands as the signal to begin the discrete trial.

Diagnostic and Statistical Manual (DSM-III, DSM-III-R, DSM-IV): The official system for classification of psychological and psychiatric disorders prepared by and published by the American Psychiatric Association.

Dyspraxia: A disorder of motor planning.

Echolalia: Repeating words or phrases heard previously. The echoing may occur immediately after hearing the word or phrase, or much later. Delayed echolalia can occur days or weeks after hearing the word or phrase.

Electroencephalogram (EEG): A test that uses electrodes placed on the scalp to record electrical brain activity. It is often used to diagnose seizure disorders or to look for abnormal brain wave patterns.

Epilepsy: A brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behaviour or sometimes convulsions, muscle spasms, and loss of consciousness. Having a seizure does not necessarily mean that a person has epilepsy. A diagnosis of epilepsy needs to be confirmed using an EEG or brain scan.

Expressive Language: The use of spoken language.

Fragile X Syndrome: A genetic disorder that shares many of the characteristics of autism. Individuals can be tested for "Fragile X" by having a special test ordered by a doctor.

High Functioning Autism: Individuals with autism who are not cognitively impaired are called 'high functioning'.

Hyperlexia: The ability to read at an early age. To be hyperlexic, a child does not need to understand what he or she is reading.

Hypotonia: Low muscle tone.

International Classification of Diseases of the World Health Organization (ICD-10 currently): A numerical system used to classify diseases and disorders, including autism. Sometimes used in conjunction with DSM criteria.

Individualized Learning Plan (ILP): A plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services. It also identifies the methods by which the student's progress will be reviewed.

Intelligence: A broad concept made up of a large number of widely different yet specific skills. Its measurement through the use of intelligence tests attempts to assess these skills in order to provide a global score representative of an individual's level of functioning. Scores on intelligence tests relate a child's performance on the test to that of other children of the same chronological age.

Intelligence Quotient (IQ): A standard score derived from intelligence tests. It represents the intellectual age of the child (that is the age at which the average child would perform at a given standard) divided by the child's chronological age at the time of testing. The scores are organised such that 100 is an average score (i.e. when the intellectual age and chronological age are the same) but any score between 90 and 110 is considered average.

Joint Attention: The ability to follow someone else's gaze and share the experience of looking together at an object or activity

Magnetic Resonance Imaging (MRI): A diagnostic technique that uses the magnetic qualities of body chemicals to produce an image of the brain.

Meltdown: A meltdown is when a person with an ASD has received so much sensory information (sounds, lights, smells etc) that they lose control of their behaviour and appear to have a tantrum.

Neurotypical: A term used for neurologically normal individuals.

Obsessive-Compulsive Disorder (OCD): Having a tendency to perform certain repetitive acts or ritualistic behaviour to relieve anxiety.

Occupational Therapist (OT): Individuals who specialize in the analysis of purposeful activity and tasks to minimize the impact of disability on independence in daily living. The therapist then helps the family to better cope with the disorder, by adapting the environment and teaching sub-skills of the missing developmental components.

Perseveration: Repetitive movement or speech, or sticking to one idea or task that has a compulsive quality to it.

Pervasive Developmental Disorder (PDD): A term that encompasses autism and related disorders. It specifically refers to the following five disorders listed in the DSM-IV: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified, Childhood Disintegrative Disorder, and Retts Disorder.

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS): A diagnostic category that is used when there is a severe and pervasive impairment in the developmental of reciprocal social interaction or verbal and non-verbal communication skills or when stereotyped behaviours, interests and activities are **present, but the criteria are not met for a specific Pervasive Developmental Disorder.**

Picture Exchange Communication System (PECS): An augmentative communication system. PECS teaches people with language difficulties to exchange a picture of a desired item with a teacher/parent, who immediately honours the request. Allows people with language difficulties to initiate communication.

Pragmatics: The use of language in social contexts (for example, knowing what to say, how to say it and when to say it).

Proprioception: The ability to sense the position, location, orientation and movement of the body and its parts.

Rett's Disorder: A disintegrative disorder where after a period of normal development, between the ages of 5 and 48 months, head growth decelerates and there is a loss of previously acquired skills. Other symptoms include stereotyped hand movements, uncoordinated movement and language difficulties. Only reported in females.

Receptive Language: The ability to understand language of others.

Risperdal (generic name: Risperidone): Risperdal, like other new antipsychotic drugs currently under development, is designed as a serotonin/dopamine antagonist. While its exact mechanism of action is not yet understood, Risperdal seems to block the action of serotonin and dopamine, two neurotransmitter chemicals in the brain. Conventional antipsychotics seem to primarily affect only dopamine.

Selective Serotonin Reuptake Inhibitor (SSRI): A class of drugs used as antidepressants. Functionally, they increase the levels of serotonin in the body. These drugs can be dangerous if mixed with other drugs such as other antidepressants, illicit drugs, some antihistamines, antibiotics and calcium-channel blockers. Some examples of SSRIs are Prozac, Zoloft, Paxil.

Sensory Integration (SI): This is a term applied to the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

Serotonin: A neurotransmitter implicated in the behavioural- physiological processes of sleep, pain and sensory perception, motor function, appetite, learning and memory.

Speech Pathologist: Individuals who specialize in the area of human communication. The focus is on communication, not speech, to increase the child's ability to interact and to understand their environment.

Stim: Short for 'self-stimulation', a term for behaviours whose sole purpose appears to be to stimulate one's senses. Many people with autism report that some 'self-stims' may serve a regulatory function for them (i.e. calming, increasing concentration, or shutting out an overwhelming sound).

T.E.A.C.C.H. (Treatment and Education of Autism and Related Communication Handicapped Children): This is a therapeutic approach broadly based on the idea that individuals with autism more effectively use and understand visual cues. It focuses on promoting independence by using items such as picture schedules to break down tasks step-by-step. This enables an individual to better comprehend and perform the task independently. This approach often aids receptive communication and sequential memory.

Theory of Mind: The ability to understand that others have beliefs, desires and intentions that are different from one's own.

Tourette's Syndrome: Both multiple motor and one or more vocal tics present with tics occurring many times a day, nearly daily, over a period of more than one year. The onset is before age 18 and the disturbance is not due to direct physiological effects of a substance or a general medical condition. The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning.

Vestibular Sense: The “movement sense.” This sense is involved in balance and position in space as well as muscle tone.

Visual Supports: The presentation of information is a visually structured way to make it easier to understand; e.g. daily schedule may be shown using photographs or Boardmaker.