

Asperger Syndrome: After the Diagnosis

YOUR SPECIAL STUDENT

A Book for Educators of
Children Diagnosed with
Asperger Syndrome

JOSIE SANTOMAURO
MARGARET-ANNE CARTER

YOUR SPECIAL STUDENT

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A Book for Educators of Children
Diagnosed with Asperger Syndrome

JOSIE SANTOMAURO
AND MARGARET-ANNE
CARTER

Illustrated by Carla Marino



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Preface

Enjoy your student's successes
Accept their eccentricities, feel their failures
Unearth your humility, seek their special talents
Encourage their uniqueness
Welcome their questions with honesty
And build upon their self-worth
Allowing them to feel safe in who they truly are
...Travel the journey with them

Josie Santomauro 2001

Introduction

Your Special Student is a 'must read' for those professionals and paraprofessionals who strive to create teaching and learning programmes based on inclusive teaching practices. It offers practical assistance, direction and concrete strategies for professionals and paraprofessionals as they strive to establish class programmes inclusive of the diverse and often complex needs of individual students.

Professionals and paraprofessionals working in these communities are challenged to act as facilitators of learning. They are encouraged to be flexible in attitude and approach, supporting all students to develop as independent, responsible, interested, active and engaged lifelong learners. They endeavour to structure teaching and learning environments that foster a sense of belonging, acceptance, respect, competence, achievement, success and a genuine interest in learning. Professionals and paraprofessionals are continually challenged to work to collaborate, genuinely appreciate, nurture, embrace, respect and celebrate student diversity.

Your Special Student is an extremely useful resource to assist professionals and paraprofessionals in this exciting, often complicated, frequently demanding yet incredibly rewarding journey of inclusive education for students with ASD. It provides down-to-earth, hands on strategies and frameworks for professionals and paraprofessionals working in the field of education.

Dr Margaret-Anne Carter and Josie Santomauro

Key Terms

| | |
|--------------------------|--|
| AS | Asperger Syndrome |
| ASD | Autism spectrum disorder |
| DSM IV | <i>Diagnostic & Statistical Manual of Mental Disorders 4th edition</i> |
| Negotiated Learning Plan | A process for collaborative planning between school, home, student and other support services and agencies |
| NT | Neurotypical |
| Para-professionals | Players in the student's inclusion team, e.g. teaching aide, classroom volunteers |

What is Asperger Syndrome?

Throughout this book you will find Asperger Syndrome referred to as AS, and sometimes as an ASD. ASD is an abbreviation for autism spectrum disorder. Asperger Syndrome falls within the autistic spectrum.

Dr Hans Asperger, the head of the Department of Pediatrics at the University of Vienna, Austria, originally described Asperger's Syndrome in 1944. In more recent times the syndrome has been classified as an autistic spectrum disorder (ASD).

ASD is a neurological disorder affecting the way an individual processes information in four main areas: communication/language, socialization, behaviour and sensory stimulation (hyper-sensitive or hypo-sensitive to environmental factors). No two individuals on the autistic spectrum present with an identical profile of strengths, needs and weaknesses. The degree of intensity and frequency of their profile differs markedly.

Individuals with AS reside on the higher functioning end of the spectrum. Their intellectual capacity is within the normal range. They have no clinically significant delay in language, or in the development of age-appropriate self-help skills and adaptive behaviours.

They often have good expressive language, but have a different way of thinking about socialization, sensory experiences and perspective taking.

Individuals with AS may have difficulty with self-regulation – management and expression of emotions. They often speak their mind, are painstakingly honest and direct and seek social justice above all else.

Current statistics are one in every 150 births are children diagnosed with AS. It is four times more common in boys than in girls.

The cause of ASD remains a mystery. Research to date suggests there may be different subsets arising from several potential genetic origins, environmental influences or a combination of both. Children are being diagnosed as early as 15 months, and intensive early intervention is proving very effective. Regardless of the age of diagnosis, individuals with ASD are constantly learning, and growth and development can be made at any age or developmental stage provided the intervention/support is appropriate. This focus of the intervention is care not cure.

With relevant and sufficient intervention, children with ASD can become competent in adapting to the social world in which they live.

Why does the student have Asperger Syndrome?

We don't really know the exact answer to this question. It may be genetic, it may be due to their mother contracting a virus whilst pregnant, or it may be that the child contracted a virus in their first year.

With Josie's son, Damian, it could be any or all three:

1. They have observed family members with mild traits.
2. At 22 weeks pregnant, Josie contracted a virus and was hospitalized due to dehydration.

3. At 11 months, Damian contracted the measles virus (one month before he was due for the immunization). He was a very sick little boy, and it took him about two months to recover. When he did get better, he reverted to crawling.

Asperger Syndrome is not caught like a cold, that glass of wine does not cause it during pregnancy, and it's not because the child fell and hit their head. There have been many studies done and research is ongoing. Some say it's possibly due to immunizations, some say there's a possible dietary factor. Until the day the experts discover the cause, I believe we should move on and deal with the symptoms.

Looking at the statistics, it is important to realize that through continual communication with adults with Asperger Syndrome, we are able to learn how to make school days more comfortable and more successful for the child with AS.

Don't judge a book by its cover

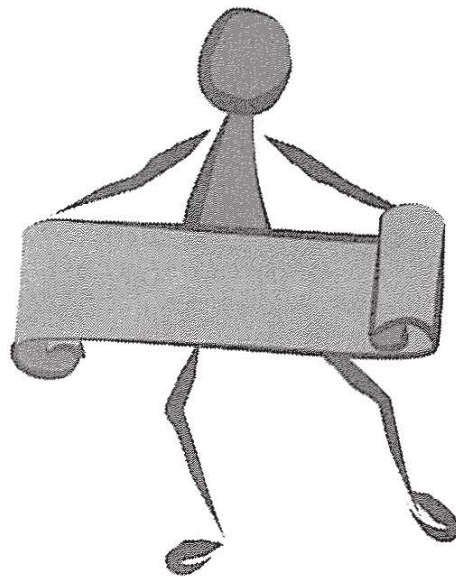
If you have ever watched *My Fair Lady*, you will remember Eliza Doolittle and her amazing transformation, due to Professor Higgins' beliefs and expectations of her, which led her to believe in herself.

Judging your students on first impressions or by their labelling can be devastating not only to their school year but also their future years. We all seem to think we are great judges of character, but how often after spending time with somebody are you pleasantly surprised (or devastated) to discover that person isn't as you first thought?

Your personal prejudices and beliefs shouldn't come into how you view your students either. If a previous year teacher had a particularly bad year with the child that you will attain,

it can be difficult not to already have formed an impression of this child.

You can unknowingly place your negative beliefs of this child into your behaviour towards them. This may result in the student viewing himself or herself negatively, which then becomes a vicious cycle of negative thoughts/thinking leading to negative behaviour. This then 'confirms' your negative beliefs about this child. The reverse situation is where you gain a student of excellent academic results and a quiet achiever – your expectations from this student are higher, in turn you are more lenient, thus the high achiever is allowed to progress at their own pace in a stress-free environment.



There are various ways of defining Asperger Syndrome. Josie's son, Damian, was diagnosed 13 years ago at the age of five, therefore she is able to share her first-hand experiences. We can learn from those who have already started this journey as she has learned from others also. She encourages you to research and learn as much about ASD as you can, to equip yourself with the tools to support yourself and your student. She also suggests you seek further information from special-

ists in this area, support groups, other teachers, parents, internet, and other resources. Knowledge is power – she can't state this enough. The more you learn, the more adept you will become in handling your student's journey.

On first meeting someone we make a number of judgements. We can tell their age and a lot about their character from their appearance, and we can tell from facial expressions and tone of voice what mood they are in. This enables us to react to them in an appropriate way.

People with AS don't find it so easy to recognize this information, and because they find eye contact difficult it is hard for them to interact easily with other people.

However, once they are diagnosed with AS, these difficulties can be understood and dealt with, and the benefits of AS can be appreciated.

Needs of your student with Asperger Syndrome

Within the teaching and learning environment your student may present with significant needs that will require extra assistance in the following four areas. This is because the social world is often a mystery to and for the child.

1. Social skills
2. Communication
3. Behaviour
4. Sensory stimulation.

Social skills

Two-way social interaction may be impaired due to the inability of the child to understand the rules and conventions

of social behaviour. There may be little or no eye contact used when listening or speaking.

A lack of empathy may be shown to others and to others' interests/activities unless they are of specific interest to the child.

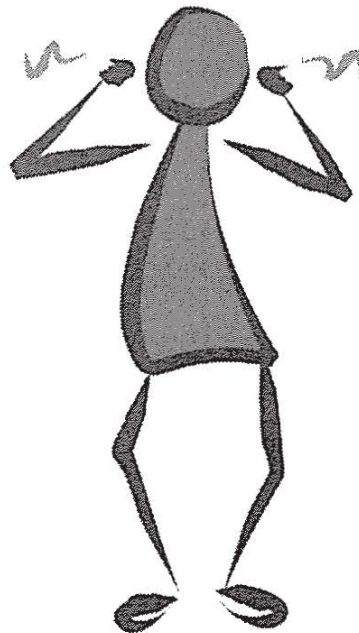
Communication

Speech may be delayed, and may be pedantic and/or repetitive. Usually there are comprehension difficulties with verbal instructions, etc. He/she tends to be a very visual thinker and learner.

Behaviour

He/she may be obsessive about particular possessions or objects.

Preferring life to be predictable they don't cope well with change in situations, structure or routine. They may not cope well with verbal instructions, therefore to avoid negative feedback they may become defiant in their behaviour.



Sensory stimulation

They may have difficulty directing attention due to hyper- or hypo-sensory input in the environment (e.g. they may need ear plugs/headphones in noisy places or have problems with the brightness of incandescent bulbs). They may require sensory opportunities, experiences and items built into or accessible during the day (e.g. stress balls or other fidget items, inflatable seat cushions).

Some characteristics of a student with Asperger Syndrome

| | |
|---|---|
| A nger and frustration | S ocial skills deficit |
| S tress and anxiety | Y our student may be intelligent |
| P roblems with speech and language | N o or little eye contact |
| E asily distracted | D oesn't like loud noises and crowds |
| R eality/Fiction confusion | R ote memory strong |
| G ross motor skills | O bsessional interests |
| E ccentric or odd behaviours | M aking friends may be difficult |
| R igid and resistant to change | E mpathy – lack of |

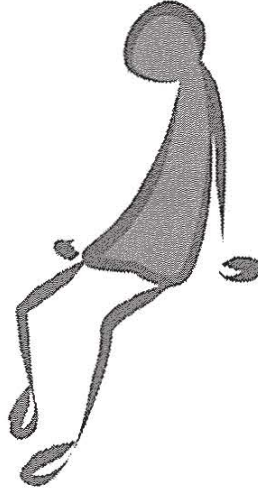
Anger and frustration

- Your student may have anger outbursts.
- They may find it difficult to ask for help when feeling confused or frustrated.

Stress and anxiety

- They don't cope well with teasing or bullying.

- They are sometimes anxious over changes.
- They may find the school environment highly stressful.
- They don't cope well with criticism or failure.



Problems with speech and language

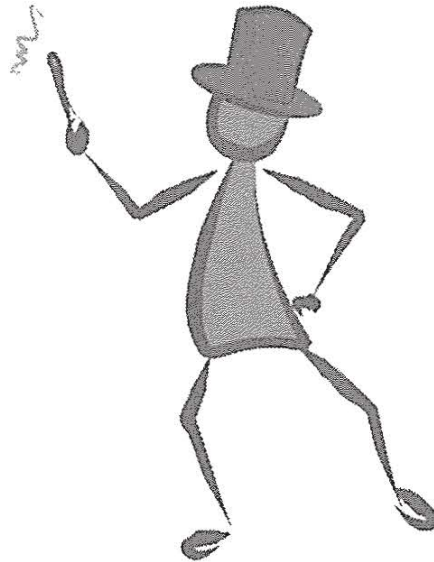
- They may not realize that their voice is too loud.
- They may have a monotone voice or unusual accent.
- They may require speech therapy.
- They may have difficulty explaining what they want to say.

Easily distracted

- Their school desk may appear to be untidy.
- They may have short-term memory problems.
- They may find it difficult to pay attention and concentrate within a busy classroom environment.

Reality/Fiction confusion

- They sometimes don't understand jokes or stories.
- They can be very literal and misconstrue language such as metaphors and sarcasm.



Gross motor skills

- They may have difficulty with gross motor skills.
- They may have poor co-ordination and find some sports (especially ball games) challenging.

Eccentric or odd behaviours

- They may display eccentric or odd behaviours.
- They may invent words or new languages.
- They can have pedantic qualities.

Rigid and resistant to change

- They may prefer routine, structure and predictability.

- They may work best when forewarned about events.
- They may not work well with transitions.

Social skills deficit

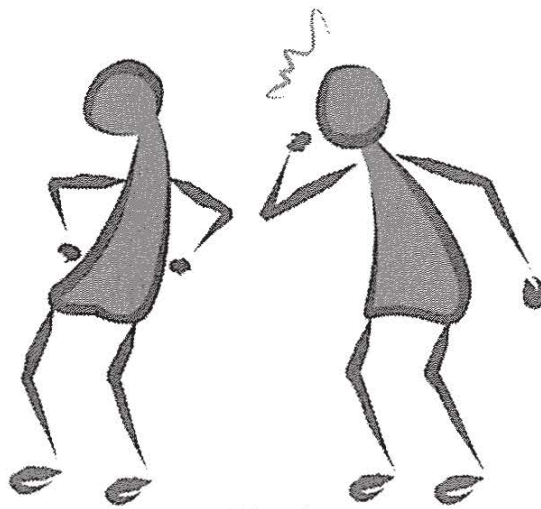
- They may require an ongoing programme to assist them in ignoring teasing and bullying.
- They can often be unaware of the social rules and therefore appear rude.

Your student may be intelligent

- They can be highly intelligent, particularly in maths, and science and computing.
- Some professionals call them 'little professors'.

No or little eye contact

- They may avoid eye contact if you are speaking with them, but can comprehend your speech.



Doesn't like loud noises and crowds

- They can be hyper- or hypo-sensitive to sensory stimuli.
- They may not like noisy or crowded places, e.g. assembly/line-up.

Rote memory strong

- They can have excellent long-term memory.
- They may be a walking encyclopedia for specific facts.

Obsessional interests

- Common to have an obsession with a particular subject, which can dominate conversations, play and daily life.
- Sometimes has a repetitive movement, e.g. flapping hands, touching face or blinking.

Making friends may be difficult

- They might not have many friends and find it difficult to make new friends.
- They may not necessarily have a desire to have friends, they may prefer to be on their own.
- They may prefer to play with older or younger people.

Empathy – lack of

- Sometimes they can't understand how other people are feeling.
- They may have difficulty interpreting body language and facial expressions.

Here's another acrostic to show some other characteristics of Asperger Syndrome:

| | |
|-----------------------|-------------------------------|
| A rtistic | S ignificant |
| S mart | Y why? Asks lots of questions |
| P unctual | N atural |
| E ngaging | D etermined |
| R epetitive movements | R esourceful |
| G ood natured | O ver sensitive |
| E xtraordinary | M aths wiz |
| R ules | E motional |

The benefit of diagnosis

As a young person recently diagnosed with Asperger Syndrome, I find it increasingly difficult for non-autistic people to understand what Asperger Syndrome is. It would be like someone I didn't know coming up to me and saying that they have a disability which is unknown to me. I think that more awareness of the condition is happening but it can be frustrating when you are in your late twenties as I am.

I think all people who have been diagnosed much earlier have the benefits of fewer hassles. Some people may choose to agree or disagree with me. At my age I find it difficult, as for all the years that I was undiagnosed, I knew nothing about Asperger Syndrome nor did anyone else. I find that as a seed that has existed frozen in time for all

these years, it is a lot of work to catch up with my peers who are all married, have partners or who are working.

I am beginning to realize the conventions, for at my age not many young non-autistic people want to make friends, and I keep telling myself that this is the way it is. I have always found talking to myself the best solution to overcome this problem. I tell myself that I need to understand people and why I don't fit in.

When I was younger I always knew that I was different. I look back on my schooling years and don't have happy memories of either high school or primary school.

I think sometimes that those with Asperger Syndrome have been specially chosen to carry the goodness on this earth.

Garry Burge (Brisbane, Australia)
Adult with Asperger Syndrome

Discussing the diagnosis with the student's peers

This is always a topic of discussion amongst the school community. How do you share the diagnosis of Asperger Syndrome with the student's peers in a gentle and non-threatening manner? How much do you share with the class without disrespecting the personal boundaries of the child with Asperger Syndrome?

Going by personal experience the 'when' came when Josie's son's peers began to question why he was getting 'special' treatment. Why did he lose control over small matters? When the other students begin to question the child's behaviours, and may also be a little intimidated by the AS characteristics or, even, on the other hand, when the AS student is being victimized and ostracized because of his disability, this would be a good time to have a talk to the class.

Here are some hints for this process:

- First discuss with the child with AS and their family whether they agree to the talk, and whether they would like to be involved.
- Put aside a session and be well prepared for this talk with the class.
- You may want to begin with 'talents and weaknesses' – an activity where everyone writes down their own talents and weaknesses.
- Eventually the topic can come around to the child in question and why they behave in certain ways, why the child has extra assistance, etc.
- Explain Asperger Syndrome in child-speak, don't overload them with unnecessary information.
- Ensure that the class knows they can come to you with questions or concerns at any time.