

# FACT SHEET: Let Me Tell you About My Autism

## Let me tell you about my Autism

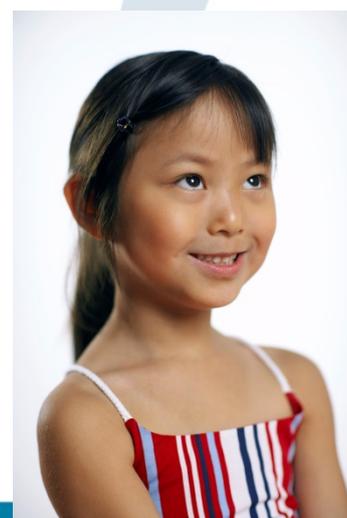
*“I am different, not less”.*

–Temple Grandin

Over the past few years we have received much information about what it is actually like to have Autism Spectrum Disorder. We have been able to read the words of some people with Autism who have the ability to describe their experiences. Those who are now mature adults often recall a difficult childhood, from the days when Autism was little understood. In many cases their diagnosis in adulthood was a turning point: a positive, new beginning. They could finally receive the support and understanding they so badly needed. For those unable to articulate their thoughts and feelings a number of writers have provided a voice, as if spoken by the person with Autism, presenting helpful information about their different life experiences. The reader learns, often in an entertaining way, how Autism impacts upon the person. The words speak as if from the heart, reminding readers that people with Autism do experience emotions, but dealing with those emotions can be extremely difficult. We also hear from those to whom we provide support at Autism Association of Western Australia. Some are able to tell us of their needs and desires which often seem so basic and universal. The fact that we are told, either directly or indirectly, what it's like to live with Autism enhances our knowledge and understanding. This article will consider some of those voices from various sources. Their message is clear: when other people understand Autism and when appropriate support is provided they can thrive and lead a more contented life. Others must understand: they are “different, not less”.

### I am a child

Ellen Notbohm's award winning book, *Ten Things Every Child with Autism Wishes you Knew*, written from the child's perspective, could be considered “essential reading” for anyone new to Autism. In its brief, ten point format, it covers all the important facets of Autism that everyone who is involved with a child with Autism needs to know. Our good understanding “has a tremendous impact on their ability to journey towards productive, independent adulthood” the author writes in the introduction. Point one, headed “I am a child” reminds readers that Autism is only a part of the child: he or she has many of the same needs of any other child. They will develop and grow so we must not set up an expectation that may be too low. Through the voice of a child this small book tells us much about the impact of Autism. We're



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told of the difficulty with communication: “I may be hungry, frustrated, frightened, or confused but right now I can’t find those words.” We’re told how visual supports will help them through the day; how we should focus on what they can do, rather than what they can’t do; how they need help with social interactions; how we should understand what might trigger a meltdown, “because I may not be able to tell you”; and that we should view their Autism as a “different ability rather than a disability”. Their success, we are reminded, depends upon us.

### The social jungle

The characteristics of Autism that are frequently highlighted as causing difficulty and pain are, predictably, those related to social interaction. Temple Grandin, a person with Autism well-known for her work with animals, tells of her problems dealing with the “social jungle” and being helped throughout her life by understanding teachers and mentors. Of prime significance to social interaction, a core feature of Autism - impairment in Theory of Mind - impacts upon the person in all areas of his or her life. Theory of Mind refers to the ability to understand the perspective of another person, to be able to “step into someone else’s shoes”. This ability obviously facilitates every human interaction from the most casual exchange with a stranger to our warm relationships with family and friends; and to the more formal exchanges of school or employment.



### Assisting social interaction

From a very early age most typically developing children quickly acquire some ability with Theory of Mind, developing social awareness without specific teaching. It has long been known that children with Autism, however able they may be in other domains, do require specific guidance in this area.

### Practical resources

Fortunately, there are many practical resources to help people with Autism navigate the social world today. Along with friendship clubs, social skills groups and role play, Social Stories™ which were introduced and developed by Carol Gray are extensively used to provide guidance to children and adults with Autism. Social Stories™ provide a specific format for describing social situations, an important feature being the perspective of the other person (or people) involved in a given situation. Michelle Garcia Winner and Pamela Crooke, who we have had the privilege of hosting as speakers at acclaimed Masterclasses in Perth, have been forerunners in social skills training with their innovative concept of Social Thinking®. Their publications including *You are a Social Detective* and

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*Thinking about You Thinking about Me* provide a wealth of information on ways to approach teaching social skills and perspective taking.

### **I grinned even though I was sad**

As the research of recent years points to different brain development in people with Autism, it's now more widely understood that an "inappropriate" response from a person with Autism is unlikely to be deliberately mischievous. Having difficulty understanding the perspective of other people, emotion-charged situations may be a minefield for children and adults with Autism alike. It is now acknowledged that as well as not understanding other people's emotional state, people with Autism have great difficulty interpreting their own emotions. John Elder Robison, who was diagnosed with Asperger's Syndrome in adulthood and has written of his life experience, recalls when he was a child and was told his aunt had died he grinned even though he was sad.



His "inappropriate" response resulted in a smack. Throughout the literature are many stories of bewilderment and anxiety in dealing with emotional situations. While we can help people to understand emotional states by way of explanations, role play and visual strategies according to the person's ability to understand, it is important that anyone involved with a person with Autism should be aware that what might be deemed an inappropriate response in an emotional situation is not deliberate, uncaring behaviour. For the most part, people with Autism want to fit in and do the right thing. Generally, because of the impairment in Theory of Mind, people with Autism do not have the

capacity to be deliberately unkind in the way that some other individuals might be unkind to their peers. When people thoroughly understand Autism they will soon learn not to take a seemingly uncaring response personally.



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### An admirable, well intentioned character

In the best-seller novel *The Curious Incident of the Dog in the Night-time*, a story of blunders and mishaps is told from the perspective of Christopher, a teenager with Autism Spectrum Disorder. Christopher is skilled in various ways but he has great difficulty with personal interactions. Siobhan, who provides support for Christopher at school, tries to teach him the meaning of facial expressions with line drawings. It is shown throughout that he has great difficulty with the subtleties of people's feelings. Although Christopher doesn't express emotion when told his mother has died it is made clear to the reader that he cared for her. Later, when he discovers that she is still alive and his father had concealed the fact from him, Christopher is overwhelmed and physically sick. Throughout the story we are presented with a young man whose behaviour and responses are not what people might always expect or appreciate, but Christopher is certainly an admirable, well-intentioned character. People who are not familiar with the Autism spectrum are likely to misunderstand people with Autism, in the same way that Christopher is misunderstood throughout much of the novel. It was once thought that most people with Autism simply wanted to be alone, and they were incapable of forming close relationships. Now we know how wrong that thinking was. Children and adults who have very limited ability to communicate verbally show, in their different ways, that they value the company of the special people in their lives. Although *The Curious Incident* is fiction, it does show how a good person with a disability can be misunderstood and wrongly judged. Fortunately, it also shows how, with appropriate support, that same person can continue to learn and grow.



### Tony's story

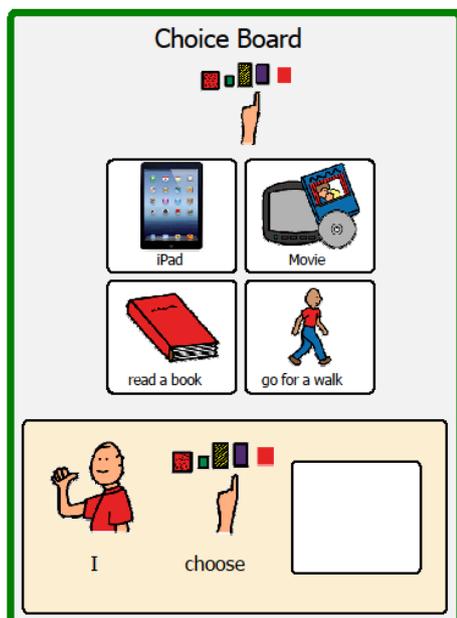
Tony\*, a young man currently receiving support through Autism Association services, speaks of the importance of other people understanding the nature of Autism. He has painful memories of days at school and at a previous workplace where there was little understanding. Tony recalls feeling so "afraid" without the support of people who understood his needs he became reluctant to venture beyond his own home. Fortunately, he is now able to talk about the way his life has been turned around and how he appreciates the support that he receives from the Autism Association AIM Employment Services. In his new-found employment Tony is developing his skills in web design and administration work. With support at home and in the community the young man is enjoying life while working steadily towards greater independence.

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### What makes a good support worker?

As Tony now speaks of feeling “safe” and “less anxious” in the community, it is a reminder of the importance of appropriate support which can be positively life-changing. When a person with Autism is placed in a situation with people who have no understanding of the nature of the disability it is almost inevitable that they will be extremely anxious. Now, with the positive changes to Tony’s life his confidence has grown to the extent where he is able to speak to new staff joining Autism Association as support workers. He tells them what, he believes, makes a good support worker. First and foremost Tony wants his companions to understand Autism; that is, to be aware of situations that might be extremely stressful for him. As with the child in Ellen Notbohm’s book, Tony needs people to understand the stress-igniting “triggers”. He asks to be involved in making decisions – something very relevant to every person with Autism with whom we engage (see below). Tony tells his audience that he would like his support people to be friendly and to help him to relax and have fun and he hopes that they won’t be talking on their mobile phone. Tony’s needs and desires are very basic, he asks for so little. He would simply like the respect which is due to all. Tony might consider himself to be “different”, but like Temple Grandin and many, many others, certainly not less.

*\*Names have been changed to protect privacy.*



*Those without Tony’s verbal skills should still be involved in decision making by way of visual strategies. A visual choice board, showing two or more choices depending on the person’s abilities, provides an effective method for a child or adult to choose what they would like to do, eat or drink, or where they would like to go.*



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## References

Grandin, Temple. *Thinking in Pictures: My Life with Autism*; (1995) Random House, New York 2006.

Haddon, Mark. *The Curious Incident of the Dog in the Night-time*; Random House, Oxford 2003.

Notbohm, Ellen. *Ten Things Every Child with Autism Wishes You Knew*; (2005) Future Horizons, Arlington 2012.

Robison, Elder John. *Look Me in the Eye: My Life with Asperger's*; (2007) Random House, New York and Reading UK 2008.

Winner, Michelle Garcia. *You are a Social Detective*; Think Social Publishing, California 2009.

Winner, Michelle Garcia. *Thinking About You Thinking About Me*; Jessica Kingsley, London and New York 2003.

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