

## Should You Explain the Diagnosis to the Child?

By **Tony Attwood, Ph.D.**

The immediate answer is yes. Clinical experience indicates that it is extremely important that the diagnosis is explained as soon as possible and preferably before inappropriate compensatory mechanisms are developed. The child is then more likely to achieve self-acceptance, without unfair comparisons with other children, and be less likely to develop signs of an anxiety disorder, depression or conduct disorder.

### **When and How do you Explain the Diagnosis?**

At what age do you explain the diagnosis? Children who are younger than about eight years may not consider themselves as particularly different to their peers, and have difficulty understanding the concept of a developmental disorder as complex as Asperger's syndrome. The explanation for young children will need to be age appropriate and provide information that is relevant from the child's perspective. The main themes will be the benefits of programs to help the child make friends and enjoy playing with other children, and to help in learning and achieving success with school work. There can be a discussion and activities to explain the concept of individual differences, for example, those children in the class who find it easy to learn to read, and others who find it more difficult. The clinician or parents can then explain that there is another form of reading, namely reading people and social situations, and that we have programs to help children who have this particular reading difficulty.

### **The Attributes Activity**

For children over the age of about eight years, the author has developed the Attributes Activity to explain the diagnosis to the child and family, including siblings and grandparents. The author arranges a gathering of family members, including the child or adolescent who has recently been diagnosed as having Asperger's syndrome. The first activity is to have temporarily attached to the wall of the room large sheets of paper, or to have the use of a large white board with coloured pens. Each sheet is divided into two columns, one column headed 'Qualities' and the other 'Difficulties'. The author suggests the child's mother or father as the first person to complete the activity, which involves identifying and listing both personal qualities and difficulties (these can include practical abilities, knowledge, personality and passions). After the first focus person has made his or her suggestions, which the clinician writes on the paper/board, the family adds their own suggestions. The clinician ensures that this is a positive activity,

commenting on the various attributes and ensuring that there are more qualities than difficulties. Another member of the family is then nominated or volunteers to suggest his or her qualities and difficulties. The child or adolescent with Asperger's syndrome is able to observe and participate, and understands what is expected when it is time for his or her turn. Sometimes the person with Asperger's syndrome is reluctant to suggest, or may not consider him- or herself to have, many qualities or attributes. The family is encouraged to make suggestions and the clinician can nominate a few suggestions from knowledge of the person. There will need to be some care when nominating difficulties so that the person does not feel victimized. The following is a representation of the Attributes Activity for a child with Asperger's syndrome.

| Qualities  | Difficulties   |
|--|--|
| Honest   | Accepting mistakes                                       |
| Determined expert on insects and the Titanic                       | Making friends   |
| Aware of sounds that others cannot hear                            | Taking advice  |
| Kind   | Managing my anger  |
| Forthright   | Handwriting  |
| A loner (and happy to be so)                                       | Knowing what someone is thinking                         |
| A perfectionist  | Avoiding being teased                                    |
| A reliable friend  | Showing as much affection as other family members expect |
| Good at drawing  | Tolerating specific sounds                               |
| Observant of details that others do not see                        | Explaining thoughts using speech                         |
| Exceptional at remembering things that other people have forgotten | Coping with surprises                                    |
| Humorous in a unique way   |  |
| Advanced in the knowledge of mathematics                           |  |
| Liked by adults  |  |

The clinician comments on each quality and difficulty nominated by the child

with Asperger's syndrome and then explains that scientists are often looking for patterns; when they find a consistent pattern, they like to give it a name.

Reference is then made to Dr Hans Asperger who, over 60 years ago, saw at his clinic in Vienna many children whose characteristics he observed to be similar. He published the first clinical description that has become known as Asperger's syndrome.

The author usually says to the child, 'Congratulations, you have Asperger's syndrome', and explains that this means he or she is not mad, bad or defective, but has a different way of thinking. The discussion continues with an explanation of how some of the child's talents or qualities are due to having Asperger's syndrome, such as his or her extensive knowledge about spark plugs, ability to draw with photographic realism, attention to detail and being naturally talented in mathematics. This is to introduce the benefits of having the characteristics of Asperger's syndrome.

The next stage is to discuss the difficulties and the strategies needed to improve specific abilities at home and at school. This can include the advantages of programs to improve social understanding, Cognitive Behaviour Therapy and/or medication that can help with emotion management, and ideas and encouragement to improve friendships. The clinician provides a summary of the person's qualities and difficulties that are due to having Asperger's syndrome, and mentions successful people in the areas of science, information technology, politics and the arts who benefited from the signs of Asperger's syndrome in their own profile of abilities (Ledgin 2002; Paradiz 2002).

Hans Asperger wrote that:

It seems that for success in science or art, a dash of autism is essential. For success, the necessary ingredient may be an ability to turn away from the everyday world, from the simply practical, an ability to re-think a subject with originality so as to create in new untrdden ways, with all abilities canalized into the one specialty. (Asperger 1979, p.49.)

As Temple Grandin, a woman who has Asperger's syndrome who has become a successful engineer, author and academic, said, 'If the world was left to you socialites, we would still be in caves talking to each other'.

The Attributes Activity can also be used with adults and family members or partner. If using the activity with a couple where one partner has Asperger's

syndrome, the author asks the typical partner to explain his or her love for the partner with Asperger's syndrome, and what the appeal was when they first met. The author has noted that the attributes of the partner with Asperger's syndrome can include being physically attractive (the silent handsome stranger) and loyal, having a remarkable intellect and original ideas, being a man with a feminine side, being a challenge to get to know and, during the time of dating, being very attentive. As with all relationships, over time other attributes become more noticeable and some diminish, but a few of the relationship attributes can be explained as being associated with the characteristics of Asperger's syndrome in an adult.

When explaining the development of the profile of abilities associated with Asperger's syndrome to an adolescent or adult, the author sometimes uses the metaphor of a clearing in a forest. The clearing represents the development of the brain, and the emergence of plants and saplings in the clearing represents the development of different brain functions. In the clearing, one sapling grows very rapidly and creates a canopy above the other plants and a root structure that restrict access to sunshine and nutrients, thus inhibiting the growth of competing plants. The dominant sapling, which soon becomes a tree, represents the parts of the brain dedicated to social reasoning. If that 'social reasoning' sapling does not develop quickly and become dominant, then other trees, or abilities, may become stronger. These plants represent abilities in mechanical reasoning, music, art, mathematics and science, and the perception of sensory experiences. The person may then see Asperger's syndrome as an explanation of his or her talents as well as difficulties.

The Attributes Activity closes with explanation of some of the author's personal thoughts on Asperger's syndrome. Such individuals have different priorities, perception of the world and way of thinking. The brain is wired differently, not defectively. The person prioritizes the pursuit of knowledge, perfection, truth, and the understanding of the physical world above feelings and interpersonal experiences. This can lead to valued talents but also vulnerabilities in the social world, and will affect self-esteem. The person will perceive the diagnosis according to how the clinician explains it.

### **Who else needs to know?**

After explaining the diagnosis to the child or adult, it is important to discuss who else needs to know. Children may be concerned about how their peers will respond to the news and any potential negative reaction. Adults will want to know if it is wise to tell friends, prospective employers and colleagues. The clinician

will examine and discuss the issues surrounding disclosure for the client, based on his or her circumstances, the advantages and disadvantages of certain people knowing, and how much information to disclose.

The child's opinion is respected regarding the question of whether or not peers should be told. If the child does want the other children to know, there needs to be an agreement as to how widely the information will be disseminated, who will provide the explanation, how, and whether the child with Asperger's syndrome should be present. Carol Gray has developed a program, The Sixth Sense, to explain Asperger's syndrome to a class of children in an elementary or primary school (Gray 2002). She has designed a range of classroom activities based on learning about the five senses that is extended to include a sixth sense, the perception of social cues. Children can then discover what it would be like to have difficulty perceiving the social cues and thoughts and feelings of others, and what they can do to help someone develop the sixth sense. We now have other published resources to help explain Asperger's syndrome to peers and siblings (see resources section of this chapter).

An adult who has recently been diagnosed will also need to discuss who to tell and how to explain Asperger's syndrome to the family, social network and work associates. Some adults have a more reserved personality and are very cautious regarding disclosure, deciding to limit the news to carefully selected individuals. Other adults are more open and brazen in their disclosure. Liane Holliday Willey chose to have a 'coming out party', while others have had a special T-shirt created with a message such as, 'Asperger's and Proud' or 'Asperger's - a different way of thinking'. The diagnosis is then very conspicuous.

### **What are the Advantages and Disadvantages of Having a Diagnosis?**

The advantage to the child of having a diagnosis is not only in preventing or reducing the effects of some compensatory or adjustment strategies, but also to remove worries about other diagnoses, such as being insane, and to be recognized as having genuine difficulties coping with experiences that others find easy and enjoyable. The child with Asperger's syndrome has no physical characteristics to indicate that they are different, and having intellectual ability may lead others to have high expectations with regard to social knowledge. Once the diagnosis is confirmed and understood, there can be a significant positive change in other people's expectations, acceptance and support. There should be compliments rather than criticism with regard to social competence, and acknowledgement of the child's confusion and exhaustion from learning two curricula at school, the academic curriculum and the social curriculum.

The advantage of acknowledging and understanding the diagnosis for parents is that, at last, they have an explanation for their son's or daughter's unusual behaviors and abilities, and knowledge that the condition is not caused by faulty parenting. The family may then have access to knowledge on Asperger's syndrome from literature and the Internet, resources from government agencies and support groups, as well as access to programs to improve social inclusion and emotion management that will greatly benefit the whole family. There may also be greater acceptance of the child within the extended family and family friends. The parents can now provide an acceptable explanation to other people regarding the child's unusual behavior.

Siblings may have known for some time that their brother or sister is unusual and may have been either compassionate, tolerant and concerned about any difficulties, or embarrassed, intolerant and antagonistic. Each sibling will make his or her own accommodations towards the sibling with Asperger's syndrome. Parents can now explain to their children why their brother or sister is unusual, and how the family has had to, and will need to, adjust and work cooperatively and constructively to implement the remedial strategies. Parents and professionals can provide the siblings with age appropriate explanations about their brother or sister, to give their friends, without jeopardizing their own social networks.

Siblings will also need to know how to help their brother or sister at home when friends visit, and be made aware of their role and responsibilities at school and in the neighborhood.

The advantages for school services, especially teachers, is that the child's unusual behavior and profile of social, cognitive, linguistic and motor skills are recognized as a legitimate disorder that should provide access to resources to help the teacher. Confirmation of the diagnosis should also have a positive effect on the attitudes of other children in the classroom and other staff who have contact with the child. The teacher can access information from textbooks and resource programs specifically developed for teachers of children with Asperger's syndrome. The teacher can also explain to other children and staff who teach or supervise the child, why he or she behaves and thinks in a different way.

The advantages of the diagnosis for the adolescent or adult with Asperger's syndrome can be in terms of support while a student at college or University or in employment (Fast 2004; Harpur, Lawlor and Fitzgerald 2004; Hawkins 2004; Meyer 2001). Acknowledgement of the diagnosis can lead to greater self-understanding and better decision-making with regard to careers, friendships and

relationships. The adult may benefit from joining an adult support group that has local meetings, or an Internet support group or chat room. This can provide a sense of belonging to a distinct and valued culture and to enable the person to consult members of the culture for advice. We also know that acceptance of the diagnosis can be an important stage in the development of successful adult relationships with a partner, and invaluable when seeking counseling and therapy from relationship counselors (Aston 2003).

The author has noted that when an adult is diagnosed with Asperger's syndrome there can be a range of emotional reactions. Most adults report that having the diagnosis has been an extremely positive experience (Gresley 2000). There can be intense relief: 'I am not going mad'; joy at ending a nomadic wandering from specialist to specialist, at last discovering why they feel and think differently to others; and excitement as to how their lives may now change for the better. There can also be moments of anger at the delay in being diagnosed and at 'The System' for not recognizing the signs for so many years. There can be feelings of despair regarding how their lives would have been much easier if the diagnosis had been confirmed decades ago. Other emotional reactions can be a sense of grief for all the suffering in trying to be as socially successful as others, and the years of feeling misunderstood, inadequate and rejected.

There can be a new sense of personal validation and optimism, at last not feeling stupid, defective or insane. As Liane Holliday Willey said exuberantly on learning of her diagnosis, 'That's why I'm different; I'm not a freak or mad'. There can be the benefits in terms of self-esteem and moral support in identifying with other adults with Asperger's syndrome by using the Internet and support groups specifically for and organized by adults with Asperger's syndrome. The group meetings can initially be organized by a local parent support group or by disability support staff at a large University or college that has several students registered with Asperger's syndrome (Harpur, Lawlor and Fitzgerald 2004). Some support groups have formed spontaneously in large cities as occurred in Los Angeles when Jerry Newport, a man with Asperger's syndrome, formed and coordinated the support group Agua. There can be an affinity, empathy and support network with fellow members of the same 'tribe' or clan who share the same experiences, thinking and perception of the world. Rebecca Everhart has Asperger's syndrome and in her play 'Aspie' writes: I am what you might call one of the idiosyncratic members of society. I am one of the unforgiven. I have been referred to as a space cadet or freak. Or, depending on your generation, a nerd, a geek, or spaz or a dweeb. But what's in a name? I am an Aspie. Of all the names I have been called in my lifetime, I like Aspie the best because it means that I am in

good company.

When talking to adults with Asperger's syndrome, the author often refers to the self- affirmation pledge of those with Asperger's syndrome written by Liane Holliday Willey (Willey 2001, p.164).

- I am not defective. I am different.
- I will not sacrifice my self-worth for peer acceptance.
- I am a good and interesting person.
- I will take pride in myself.
- I am capable of getting along with society.
- I will ask for help when I need it.
- I am a person who is worthy of others' respect and acceptance.
- I will find a career interest that is well suited to my abilities and interests.
- I will be patient with those who need time to understand me.
- I am never going to give up on myself.
- I will accept myself for who I am.

The last pledge, 'I will accept myself for who I am' is considered by the author as a major goal when conducting psychotherapy with an adolescent or adult with Asperger's syndrome.

One reaction, although rare, is for some people to deny that they have Asperger's syndrome, insisting that there is nothing wrong with or different about them.

Despite acknowledging that the clinical descriptions match their developmental history and profile of abilities, they may question the validity of the syndrome and reject any programs or services. However, this may only be an initial reaction and given time to reflect, they may eventually accept that their personality and profile of abilities includes the characteristics of Asperger's syndrome, and that this is invaluable information when making major decisions in aspects of life such as employment and relationships.

There could be disadvantages in having a diagnosis in terms of how the person and others perceive the characteristics. If the diagnostic news is broadcast widely, there will inevitably be some children or adults who misuse this disclosure to torment and despise the person with Asperger's syndrome. Care must be taken when using the diagnostic term Asperger's syndrome as some children may consider the condition is infectious (or tease the child that it is), or corrupt the term in a variety of ways

Asparagus syndrome, Sparrow syndrome, Hamburger syndrome or Arseburger syndrome, among others. Children can be quite inventive in stigmatizing differences but more compassionate people may be able to repair some of the damage to the self-esteem of someone with Asperger's syndrome who has been ridiculed for being different.

One of the concerns of adults with Asperger's syndrome is whether they should include reference to the diagnosis on a job application. If there is considerable competition for a particular vacancy, an applicant having a diagnosis that is unknown to the employer might lead to the application being rejected. A potential solution is for the adult to write a brief, perhaps one page, description of Asperger's syndrome and the qualities and difficulties that would be relevant to the job. This personalized brochure could also be used to explain Asperger's syndrome to colleagues, juniors and line managers. A shorter version can be reduced to a business card that can be given to anyone who needs to know about the person's diagnosis.

Having a diagnosis of Asperger's syndrome could limit the expectations of others, who may assume that the person will never be able to achieve as well as his or her peers with regard to social, academic and personal success. The diagnosis should facilitate realistic expectations but not dictate the upper limits of ability. The author has known adults with Asperger's syndrome whose successful careers have ranged from professor of mathematics to social worker; and those whose ability in the area of relationships ranges from enjoying a fulfilling but celibate life, to having a lifelong partner and being a much loved parent.

As a society, we need to recognize the value of having people with Asperger's syndrome in our multi-cultural and diverse community. In summary, maybe we should consider the comment from an adult with Asperger's syndrome who suggested to the author that perhaps Asperger's syndrome is the next stage of human evolution.