

Explaining ASD to the individual who has ASD



Many families as well as teaching and support staff are often reluctant to talk to a person with ASD about their condition and what it means. If we read books written by people with ASD we soon see a very similar picture: They knew they were different and gaining an understanding of why was helpful. 'Freaks, Geeks and Asperger Syndrome' by Luke Jackson and 'Martian in the Playground' by Clare Sainsbury are two such examples.

That is not to say that being told you have ASD is always received well and understood, but it does suggest it is very much the best thing to do rather than ignore questions like,

"Why haven't I got six friends like Jake?"

"Why doesn't my brain work properly?"

Trying to understand your own ASD can be quite a challenge but then fitting into a neurotypical world that does not make sense to you is also a tremendous challenge.

Tips

Don't try to tell a person with ASD everything at once, give small amounts of information and allow them to come back and ask questions at a later stage.

There are lots of useful tools around now to help the process starting with stories where one of the central characters has ASD. Two such examples are 'The Blue Bottle Mystery' by Mary Hooperman and 'The Curious Incident of the Dog in the Night Time' by Mark Haddon.

Then there are books that do it for you like 'Can I tell you about my Asperger Syndrome' by Jude Welton, written very much with her son in mind and as a tool for youngsters with Asperger Syndrome to share with others and to help other people to understand as well. Another example is the NAS booklet 'What is Asperger Syndrome and how will it affect me?'

'I am Special' is an actual work book written by Peter Vermeulen that an adult can work through with a young person, where they are encouraged to complete worksheets about themselves, highlighting their gifts and abilities as well as the areas where they have difficulty.

'Asperger's....what does it mean to me?' by Catherine Faherty goes into great detail but is worth looking at. Tony Attwood's first book on Asperger Syndrome can be helpful if you are sharing information on diagnosis with someone older. It gives diagnostic criteria and individuals can see for themselves how they fit into this category. This can be a valuable experience. His more recent publication, 'The Complete Guide to Asperger Syndrome', is a very full and detailed account but it certainly includes a really positive slant about having Asperger Syndrome that may help with self esteem issues.

It may be helpful for the person with ASD to know about the wide range of famous people with ASD who have been successful in their careers and there are now several books providing such examples

(see bibliography). There may even be individuals that are known locally who are using effective coping skills. They could be seen as role models for young people just coming to understand their own ASD.

If the person with ASD has an associated learning disability don't let this prevent you from being honest about the ASD.

Autism can often mask ability and with support and help to understand you may be surprised by how the increased self awareness can help progress in other areas. Though there will be some individuals for whom the severity of their learning disability means they will not be able to understand, they may still have a sense of their 'difference' so work on self esteem is just as vital. We all need to be helped to feel good about ourselves. It is important to be aware of the poor self esteem that people with ASD can experience: They need help to know they are valued and that their gifts and abilities are worth just as much as others. Praise is probably more important for people with ASD to hear than others, though take care how this is given. Some people with ASD don't like to be praised if they themselves don't think they are worth it. Self worth can be a struggle for many people and it is important that we support people with ASD to recognise their own self worth but we may need to find ways of doing this that work for each individual. When they are more confident and at ease with the knowledge of their own ASD and abilities they may be ready to find ways of explaining it to other people.

A key issue is that the ASD does not go away and waking up in a neurotypical world can be a real challenge every day.

It is important that the support to help someone understand their ASD is always around, even if in the background. There will be more questions to ask at different stages in life. There are some ASD specific websites organised by people with ASD offering opportunities to share experiences and these may prove helpful for some people. There is also a self-help newsletter run by and for people with Asperger Syndrome. The aim of the newsletter is to put people in touch with each other and to share information so they can lead more independent lives. To subscribe (and it is free to people in the UK with a diagnosis of ASD or Asperger Syndrome) call 020 7903 3595 or email asp.utd@nas.org.uk

It is true to say that we never really know ourselves; we always have more to learn whether we have an ASD or not. The danger is we forget that for people with ASD.

Further reading: A booklist of titles available for sale from our Information Service can be downloaded from our website www.autismwestmidlands.org.uk