Telling other people about autism

For people who live with, work alongside or are in the same class as someone with autism, knowing about the person’s autism can help them to be more supportive and understanding. This information sheet gives some tips on how to approach this topic.

You may feel it is unnecessary to tell other people about autism because this information should be private. However, sharing information about autism can prevent misunderstandings and even prejudice.

Where possible, involve the individual on the spectrum with telling people about autism. If it is a child or young person or someone with an additional learning disability, then parents and carers should also be involved.

There are four key areas to cover when explaining autism to someone new:

1. Communication
2. Social interaction
3. The need for sameness and routine
4. Sensory processing

These four areas are interconnected and difficulties in one area are often linked to difficulties in another. The central point to remember is that every person with autism is different.

1. Communication

Some people with autism experience a processing delay when communicating. This means that it is important to allow extra time (sometimes up to 30 seconds) for the person to process what has been said. Repeating or structuring the question before the person has had a chance to process it may cause further confusion. This is not because the person with autism cannot understand what is being said, they may just need more time to process the language and formulate their answer.

2. Social interaction

Social interaction is a skill that most people pick up without realising. For example, saying “hello” when you meet people, knowing who to say it to, when and how often to say it. It is often considered a very basic skill that we are not aware we have, until we meet someone who does not seem to grasp the concept. Many people with autism, like Temple Grandin and Clare Sainsbury, talk about social interactions and relationships as being a bit of a mystery. Not knowing what to do at break time at school, or during a coffee break at work can be a difficult experience when other people seem to have acquired the necessary ‘secret code’ to succeed. It is these ‘codes’ of life and interaction that we take for granted, so it is important to get across to other people just how much of a mystery this is to someone with autism.
3. The need for sameness and routine

For people with autism, the desire for sameness and routine is much more than just liking a routine. People with autism may not know what will happen if the expected plan or routine changes, which can make them very anxious. When explaining to others, it is important to get across the rapid rise in anxiety levels for people with autism when things become unpredictable.

4. Sensory processing

Many people with autism experience their senses differently. They may be over- or under-sensitive to any of their senses. They may be sensitive to noise levels and some specific sounds. They may have difficulty with their sense of balance and sense of where their bodies are in space, which can be both frightening and challenging to live with. Sensory issues around the taste and texture of food can lead to people having a very restricted diet.

You can also explain that the brains of people with autism are wired differently. This is not because they are brain damaged but because their brains developed differently. The differences in brain function help us understand the great skills and gifts many people with autism may have, and the difficulties they may encounter with what most would consider ordinary, everyday activities.

Taking into account the skills of the individual and the areas above will help in understanding the best ways of supporting the person with autism.

Bibliography and further reading

- Freaks, Geeks and Asperger Syndrome by Luke Jackson
- Martian in the Playground by Clare Sainsbury
- The Blue Bottle Mystery by Mary Hooperman
- The Curious Incident of the Dog in the Night Time by Mark Haddon
- Can I tell you about my Asperger Syndrome? by Jude Welton
- What is Asperger Syndrome and how will it affect me? by the National Autistic Society
- I am Special by Peter Vermeulen
- Asperger’s .... What does it mean to me? by Catherine Faherty
- Asperger’s Syndrome by Tony Attwood
- The Complete Guide to Asperger Syndrome by Tony Attwood
- Different Like Me – My Book of Autism Heroes by Jennifer Elder
- Asperger’s Syndrome and High Achievement – Some Very Remarkable People by Ioan James