

Organisation for Anti-Convulsant Syndromes

Autism

Children with Fetal Anti-convulsant Syndrome face many challenges including a vast range of potential physical problems and physical features that set them apart from their peers, as well as general cognitive difficulties. A diagnosis of autism (this is especially recognised in those whose mothers took sodium valproate during pregnancy). This means the challenges faced are much greater both child and parents/caregivers.



Autism is a lifelong developmental condition that can affect a person in different ways at different stages of their life. There is no cure for autism (Kanners Syndrome) and Asperger's Syndrome was traditionally believed to be two different conditions. However they are now believed to be two extremes of the spectrum. Autism is variously described as Autistic Spectrum Disorder (ASD) Autism, Asperger's Syndrome etc. People with autism have different degrees of severity and abilities but there are similarities between those traditionally described as having Asperger's, and those traditionally or autism and those at the most extreme ends of the spectrum. The most commonly described symptoms on the ASD are a set of three symptoms/behaviours' sometimes referred to as a 'triad of impairments'.

Difficulties in Social Communication:

Examples include:

- speech delays
- difficulties understanding and processing verbal communication
- inability to detect and interpret tone of voice, sarcasm, jokes, etc.
- A tendency to understand things literally (e.g. "You're too big for your boots" would be taken literally to mean that their footwear is too small)

Difficulties in Social Interaction

This includes:

- An inability to understand the rules of social interaction such as turn-taking, when to speak, or not speak.
- They may appear to be insensitive to the needs of others (they may talk continually about one subject for an extended period of time without pause and not recognize that the other person is bored, uninterested or even annoyed). They prefer to spend time alone or when in company appear to behave strangely or inappropriately (eg. A person with ASD may learn a social script such as 'Hello, How are you today?' and respond with 'I'm fine thanks'. When asked how they are however, when the script is finished they may seem rude and say I've had enough now, thank you, goodbye' and just go).

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Difficulties with Social Imagination

There is inability to understand situations or predict behaviour from others or learn from situations.

- There have difficulty understanding the concept of danger or to overestimate dangers where none exist.
- Imaginative play is limited - they may seem to act out 'imaginative' scenes but this is often repetitive behaviour based on things they have observed (e.g. my 16 year old son used to watch me play Lara Croft Tomb Raider and would act out the actions of Lara Croft including 'tunnelling' under the coffee table and running across beams with a pairs of Uzi's (the back of the sofa with two kitchen knives!)
- They have problems understanding what will happen and when - a trip may have to be discussed and planned well in advance and the arrangements will be repeatedly brought up and the person appears anxious or agitated if they do not get the information. Many people with ASD find new situations very difficult and prefer routine.

As well as the triad of impairments which, to a lesser or greater degree, affect all people on the spectrum, they may also have sensory sensitivities (My son would remove ALL of his clothing if he managed to spill a tiny drop of water on his cuff). There may be one or a few special interests that occupy most of their time such as train spotting, lining up toy cars or watching films repeatedly.

Many people with ASD have learning difficulties and require special needs education and intervention appropriate to their age and ability. However there are some exceptions and a few people with ASD may demonstrate an exceptional talent in one area such as music, art or math's.

People with ASD can be excitable and constantly on the move and/or displaying stereotyping movements such as hand flapping, twitching, flicking their fingers in front of their eyes and other repetitive behaviours. On the other hand they can be very placid and passive, completely avoid eye contact and rarely, if ever, instigate physical or social contact. People on the ASD spectrum can look perfectly normal until they are spoken to or somebody tries to interact with them and then the difficulties become obvious quite quickly. People with ASD tend to become anxious and frustrated by their inability to understand the world they live in or the social rules that most of us instinctively understand. Because of this they are prone to tantrums or 'melt-downs' if they cannot remove themselves, or be removed, from the situation that is making them uncomfortable.

It is especially difficult for those that have fetal anti-convulsant syndrome and autism. The complex challenges faced by these children/adults are difficult to express without the addition of autistic tendencies To be the parent/carer of a child/adult with fetal anti-convulsant syndrome, one has to develop tactics not just for every day circumstances, but for the many nuances of this condition, and the many situations one finds them in because of this, as well as the obvious, medical, educational and social challenges faced. Helping a FACS child to develop a story of their challenges is one way in which some of these children might be able to

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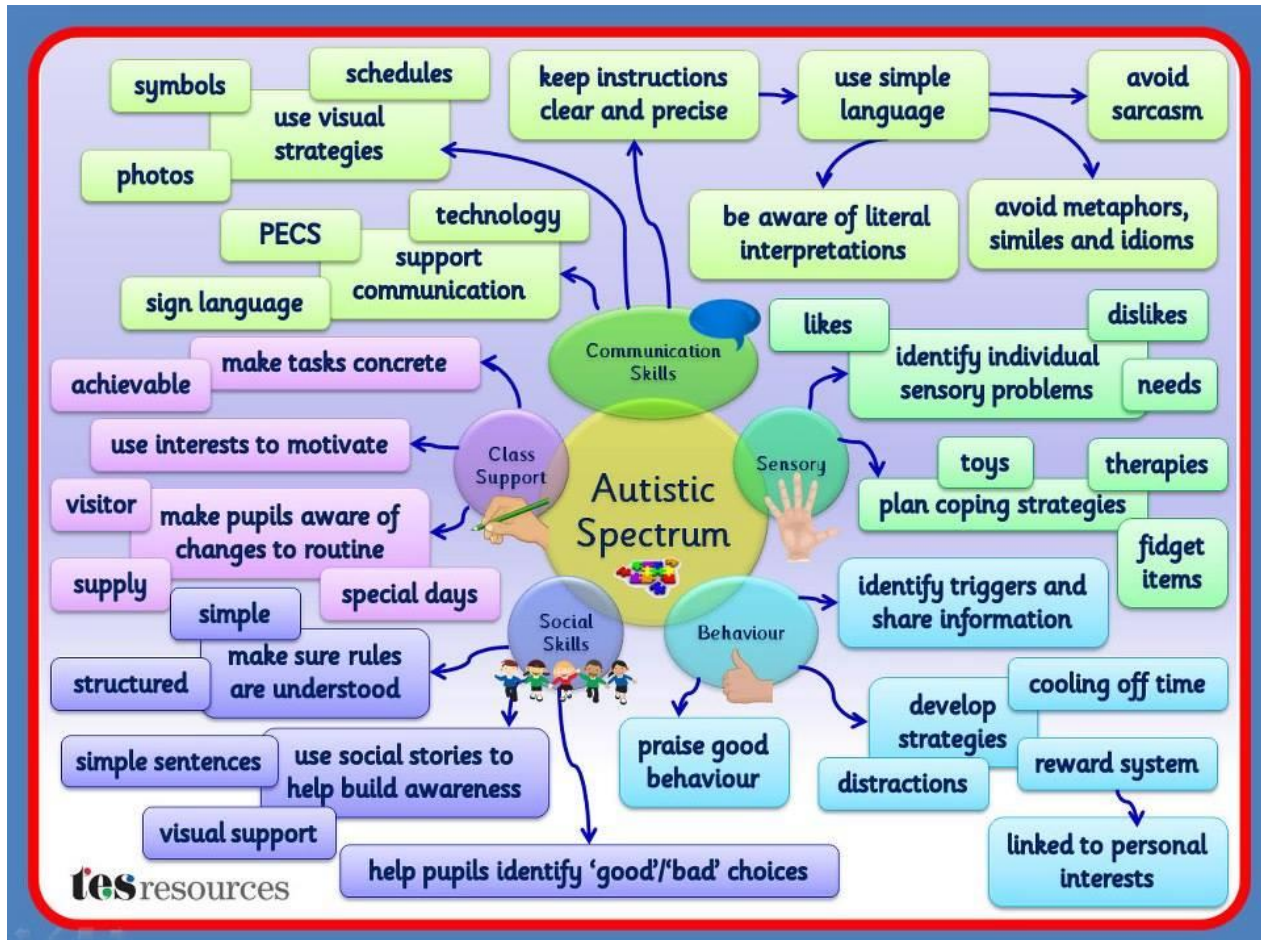
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express their life experience to someone trying to provide them with the support that they need.

Although this chart is for the use of teachers it can be adapted to any situation



Branwen Says

Both me and my sister were diagnosed as being on the autistic spectrum. Because I have been studying health and social care level three; focusing on those with learning difficulties I have learnt a lot about myself and my sister. I think that there are good and bad sides of living on the autistic spectrum, but it are not easy, even though I am quite shy I say what I think. My sister was diagnosed quite early, but I had to wait a long time before I had a diagnosis. This is so important if you want the right help. If you don't want someone to know you don't have to tell them, but it means that they may not understand you properly or be able to help.

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