

AUTISTIC SPECTRUM DISORDER - HOW YOU CAN HELP YOUR SON OR DAUGHTER.

It is essential to bear the “triad of impairments” in mind when trying to understand the person with an autistic spectrum disorder (Asperger’s, A.D.H.D etc). The diagnosis not only explains past difficulties and the behaviour patterns that have emanated from them; once you are aware of the three problem areas you can anticipate the areas in which they will have difficulties and be able to help them overcome them.

1. Communication – over-use, over-complex use, under-use or inappropriate use of language when communicating with others (known as “semantic pragmatic language difficulties”); very literal understanding of language; often wrongly assuming prior knowledge in the listener; talking irrelevantly or excessively on pet topics; talking over-argumentatively; poor auditory memory for the words of others; while often being of higher than average intelligence they can nevertheless experience difficulty sequencing words/actions/remembering multi-part instructions, etc.

2. Social interaction – while in Asperger’s there is usually a high IQ with no cognitive impairment (learning difficulty), they experience *difficulty relating to others on a social level*. Inability to read the thoughts and feelings of others (Theory of mind); forming relationships is a problem area as there is disruption of the ability to interpret social situations and adapt behaviour appropriately. *Rules which are learnt by the child are applied in a blanket way, regardless of how relevant the rules may or may not be in a given situation.*

3. Imagination – this is a confusing term: it does not refer to creativity, for those on the autistic spectrum are often exceptionally creative; however it does mean that they typically show rigid, inflexible ways of thinking. In childhood this is displayed sometimes through play, eg., they may prefer to line up cars in exact lines rather than have races or build a garage for them etc; attempts by parents or other children to expand these set play patterns are often rejected; they tend not to play in ways that need imagination due to difficulties with Theory of mind; far prefer to help adults with their tasks.

The triad leads to the following associated characteristics:-

1. Repetitive behaviour patterns Due to dysfunction in sensory input your child encounters a lot of chaos in her world, she experiences confusion with communication and social understanding. Repetitive behaviour patterns are a way of bringing order and predictability to her unstable world. This explains the distress verging on tantrums when these cherished patterns are interrupted or broken: rooted in frustration and fear.

2. Resistance to change in routine They are characteristically *extremely rigid in their thinking and find it difficult to cope with change*. Even slight change to normal routine can cause enormous distress to a person on the spectrum.

3. Obsessive interests. These vary in each case.

THOSE WHO SPEND TIME WITH YOUR SON OR DAUGHTER WILL NEED CERTAIN STYLES OF COMMUNICATION:-

1. Only use necessary words. Try to remove any language that is not providing key information. For example DON'T SAY... 'Would you mind coming over here and sitting down there on the chair?' DO SAY ... 'Tom, sit here' (indicate with your arm what chair you mean)

2. Provide as much information as you can. Although the child may be distressed by change, they will cope better if informed in advance so that they can anticipate it. It is better to manage things before they happen, rather than waiting for the (unpredictable) response. It is sometimes only when routines are broken that we see how much a child relies upon them. DO ... Prepare him: 'Tom, tomorrow you will go to school. Mrs White will not be there. She has a bad cold. Mr Simon usually teaches you maths. Tomorrow Mr Simon will be your form teacher for the day.' DO ... Provide as

much information as you feel your child needs. Be prepared to answer questions. Be honest, if you are not sure if the teacher will be back the next day - say that. Explain what will happen in that eventuality. As long as your child is informed they will feel more secure.

3. Be positive. DON'T just tell your child what they shouldn't be doing, tell them what they should be doing. DON'T SAY ... 'I don't want you to throw your toys all over the floor'. This tells the child nothing, apart from what they have already done! DO SAY ... 'Tom, pick your toys off the floor. Put them into the toy box.'

4. Avoid sarcasm. If you indicate that you want your child to do something use a direct style. DON'T SAY ... 'My, my what a tidy room you have' (in a sarcastic voice which you use to indicate the room is a real mess). Your child may well take your words genuinely. This may seem infuriating - as if the child is being cheeky, or perhaps even using sarcasm back, but this really is a misunderstanding! Sarcasm is a complex use of language that children with ASD have great difficulty with. (Some more able children may imitate or eventually learn rules of sarcasm and can recognise and respond to the most obvious forms). DO SAY ... 'What a mess. Put your clothes in the drawer.'

5. Use concrete terms where possible. Your child has a better understanding of concrete language. This point also ties in with providing enough information to reassure your child. DON'T SAY ... 'We can't do that now, we will do it later'. DO SAY ... 'Tom, I know you want to go swimming. I will take you swimming at 5 o'clock tonight'. If more questions are asked, try to respond - obviously a balance needs to be struck between being informative and being concise. Only you know how much information your child can understand and process: Eg., 'We can't go swimming now. Dad wants to come with us. He comes home from work at 5 o'clock. When he gets home, we'll go swimming'.

6. When praising your child - be specific. Provide enough information when praising your child - you need to make it clear to them why you are happy with their behaviour, to encourage them to repeat the behaviour in the future. TRY TO SAY ... 'You've tidied your room, that is brilliant' RATHER THAN ... 'You are good'.

7. Provide them with extra thinking time. Your ASD child needs much longer to process information you give them. Acknowledge this. If necessary come back to them a few minutes later for the answer to a question. Check they have understood what is expected of them particularly if they are in a group of children. (If you know they have understood you the first time, try not to repeat yourself. This can be frustrating to a child who is trying to respond but needs more time to formulate a reply - I am sure we have all experienced this ourselves).

8. Where possible give notice of change and introduce it gradually. (Try to remember that the distress and anger shown when cherished patterns are interrupted or broken are rooted in frustration, anxiety and confusion) If change is inevitable, introduce it as gradually as possible within a clear structure that the child can anticipate and come to terms with. If clear boundaries are provided the child can usually work well within them. You will need to think ahead for this! EXAMPLE: 'we will go to the park tomorrow morning, unless it rains. If it rains we will go in the afternoon'.

9. Try to understand how things that do not appear important to you, or to less informed adults, are crucial to your child. *From her point of view, she has difficulty filling in the gaps by using empathy (an understanding of the feelings or intentions of others) - she rather memorises given rules. If routines are broken, and unexpected change occurs, she can feel her whole structured world is falling apart.*

10. Try allowing obsessional activities to reassure and calm them on disrupted days. Obsessional activities can serve a very useful function. They are reassuring to your child. On a *normal* day you may restrict their frequency, but you may have to make allowances for those activities on *disrupted* days.

11. Choose the right incentives - try using special interests to motivate them. These children can be very hard to motivate unless you find which rewards will be an attractive incentive. A special interest

can be used to motivate them. Rewards have to be meaningful for the child themselves. Do not assume what they will enjoy - ask them, or their parents, directly. Every ASD child has their own needs due to their sensory input oversensitivities and undersensitivities, these should be expected and respected.

12. When allowing special interests/obsessional activities, the use of boundaries is important.

EXAMPLE: If their interest involves asking lots of questions on a particular topic, impose limitations. Make clear to them that you will answer a certain number of questions at certain times ('you can ask me 3 questions during breakfast about x. I will answer your 3 questions but then I will not talk about x any more until we are having lunch. At lunchtime you can ask me 3 more questions' etc.) This takes patience and time, but once it is accepted and established it becomes the new routine and is strictly adhered to.

13. Expand interests gradually If you feel your child is too rigid about things she will and will not do, try to expand her interests gradually. Eventually, you should be able to extend her interests to include quite a few activities before the inevitable obsessive interest is taken up again that day. It is completely understandable for parents to have goals of their own that they want their child to achieve, but there does need to be some overlap, rewarding them with doing some of their obsessional interest, so that they can be motivated sufficiently.

14. Keep to your word If a child has been told they can expect something, they can become distressed (and aggressive) if that expectation is not fulfilled. It is a common habit to agree to things we really can't fulfil - it is essential not to do this with someone on the autistic spectrum. It is better to say 'No' and explain why than to give false assurances. Children with ASD are very insistent. Be honest, if you do not think it can happen. Your child has to deal with much uncertainty (disruptions in communication, difficulties with social understanding) so there are certain things they are banking on, which is why routines and rituals are so important to *them* although they may not appear so to us.

15. Do not underestimate the effect of a permanent change on your child. They may seem unaffected by a bereavement or house move but this may be a coping strategy which masks the true distress. Instead of normal channels of communication (talking about loss, crying, discussing the changes) you may notice a deterioration in behaviour, broken sleep or eating patterns, or increase in aggression or anxiety.)

16. Take into account their difficulty with Theory of Mind (lack of empathy, putting yourself in someone else's shoes) Through experience and parental input, the normal child's Theory of Mind develops and becomes fine-tuned and they can make hypothetical calculations about the knowledge another person may have and about what effect their words or actions will have upon the thoughts and feelings of others. The ASD child will have a lower capacity for this, which means:-

- a) She may behave a certain way because she thinks you know a lot more about her thoughts, wishes, needs than you actually do.
- b) She will have difficulties understanding how what she says or does can affect someone else. Eg., how saying 'you are fat' to George, may cause George to become upset! If you try to explain the effect her words had on the child she may have difficulty making the connection between the words she spoke and the other child's response. A typical retort may be 'but they *are* fat', or 'it is not *my* fault they are fat' etc.!!!

17. Clearly tell the child what effect their words have had, in very simple terms, EXAMPLE: 'What you just said has really hurt me/George. It has hurt me/George because ...' *With support and patience, a child can improve their understanding of ToM, although they may only understand the simpler principles, or respond appropriately when prompted, or in familiar situations.*

18. Relate explanations to the child's experience so that they are meaningful. Choose language that you know your child understands. Use special interests as a way of communicating with your child. For example if they are obsessed with trains, DON'T SAY ... 'You have broken my vase. Don't you know

how much it meant to me?' DO SAY ... 'You would be upset if I broke your train. I like my vase as much as you like your train. I am upset at what you have done.'

19. Double check your child understands *specifically* what they have done wrong and why. All disciplinary measures are useless, if the child does not understand why their behaviour is unacceptable. DON'T SAY ... 'You've been very naughty today' DO SAY ... 'You took your sister's sweets. That was not fair'.

20. Tell your child you are unhappy with what they have done, not what they are. Focus on the behaviour, not the child. All children should feel happy and reassured in their home environments. Suitable punishments may be appropriate at times, but withdrawal of parental love should not be used as a sanction. DON'T SAY ... 'You are a naughty boy' DO SAY ... 'What you did was naughty'.

21. Use a cool down period. If you walk in and catch your child in the act of misbehaving, it is essential to *help them to calm down before talking to them.* Our natural instinct is to respond immediately (and if they are doing something dangerous this *is* essential) but at this point their energy levels are up, their dysfunctioning sensory nervous system is overstimulated, they are aroused, agitated and have lots of chemicals zooming round their body. If it is not an SOS situation, approach them 5 - 10 minutes later, *after the cool down period.* You will be able to reason with them to a greater extent and they will be in a better frame of mind to listen. Do not leave it too long, as they need to be aware of the reason you are not pleased, & remember to make the connection for them ('I am not pleased *because ...*').

22. Think of ways that behaviour can be channelled more positively The energy has to go somewhere. If it is not channelled, it may well result in disruptive behaviour. Simple measures - showing the child how to scream into a pillow, providing a punch bag, can prevent negative behaviour occurring. Encourage them to go to the designated 'safe place' whenever they feel themselves getting angry, upset etc. - make sure they can get there easily and quickly without encountering obstacles on the way.

23. Allow them to help you. Because of their difficulties with imaginative play they will often prefer to help with adult tasks. If these are straightforward with clear boundaries (not open-ended), and safe, allow and encourage this.

24. Try preventive calming measures. For children on the autistic spectrum, who have a deficit in processing sensory input, their nervous system often actually needs certain stimuli. Be prepared. If you have learned that a simple stimulating activity like body spinning or shredding paper helps your child to relax, encourage trampolining or hoolaHooping, or always have some paper handy in your pocket.

25. Bear in mind the Iceberg effect, when trying to understand their disruptive behaviour We may see the behaviour, but the reason for it may be out of view. Do not assume you have gained the whole picture. You need to investigate past history of behaviour and talk to the child themselves when they are calmer, to try to gain a true perspective as to the frustration lying behind that behaviour. Try to understand the part the characteristics of ASD have played in the behaviour.

26. Acknowledge that a child with ASD often does not learn from experience. It may be infuriating, but your child is not intentionally winding you up by repeating today what you asked them not to do yesterday. The child on the autistic spectrum will need regular and consistent instructions.

Conclusion:-The problems referred to give outsiders the impression that the child or adult with an autistic spectrum disorder (such as Asperger's) is rude, arrogant, selfish, disrespectful or undisciplined (among other accusations). These judgements are wholly inappropriate. These guidelines are important, useful, and in an ideal world can be easily followed. Unfortunately, we do not live in the ordered, structured and predictable world that the child with ASD prefers. Days will go badly, patience will run out and tempers will fray. In these situations, even with the very best intentions parents cannot always respond in the desired model way. I speak to many parents who are doing a brilliant job, in the face of constant ignorance and misjudgements from onlookers, little professional input and limited resources. I once heard someone say that a parent is the best resource a child can have. I couldn't agree more.