

# **Behavioural Characteristics and Intervention Strategies with Adolescent and Adult Issues**

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**Précis of talk (as relating to  
children)  
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## **Behavioural Characteristics and Intervention Strategies with Adolescent and Adult Issues**

### **Talk 2 – Adolescent and Adult Issues**

Obviously a lot of this talk was aimed at adults, but I think there are points to bear in mind in terms of children and young people.

Marcia talked about children engaging in some outside interests and her work with young people had shown that cubs and church activities were some of the most successful. She also spoke about helping children take small steps towards independence and managing different things. There is a lady, who attends the support group that we have in Essex and has two boys (twins) with fragile X. She works very hard with them to get them used to activities that they initially find quite difficult. The first trip to the school disco ended in screaming, but she took them every time, starting off with sitting outside, then looking in etc. Now she reports that they love it. The next venture is to help them get used to animals, which neither of them like and so every holiday means a short trip to a zoo or farm. The boys have come on a long way and will now touch an animal as long as it's asleep or not looking at them. If it turns or come towards them they will still panic. I know that for many families such trips/events are just too much and I am not advocating torturing yourselves or your children, but it is worth thinking about whether this or a similar venture is something that could be managed by preparing the child for the trip and taking each step very gradually.

### **Talk 3 – Behavioural Characteristics and Intervention Strategies**

#### **What affects Behaviour?**

Marcia began this session with a clear definition of fragile X as a recognised medical disorder. Amongst other things she talked about the lack of the FMRP protein in the brain. FMRP acts as something like a brake stopping the production of other proteins that are responsible for connections between areas of the brain. Hence protein production goes into over drive and in some parts of the brain connections get too strong. This is particularly evident in the amygdale or anxiety centre. This is interesting when we think about how, typically, difficult behaviour in those with fragile X can be a communication of their anxiety.

She went on to talk about how children with fragile X often find physical transition and eye contact even harder to manage than children affected by autism. Other factors affecting behaviour include managing sensory information, speech and language difficulties and the other characteristics of fragile X like the impulsivity, level of learning difficulty and over activeness. She talked about not being misled by a smile on the face - it does not mean that a child is totally at ease in a social interaction. They may be happy to be seeing the person, but still anxious. Another factor affecting behaviour can be physical health. If a child suddenly behaves in a very different way, it is worth looking into if they are unwell. Likewise when a child is unwell is not the time to work on a particular behaviour!!

Marcia also talked about how children with fragile X live so much on the edge. So many things that typically developing people manage almost without thinking raise their stress levels. It is therefore unsurprising that it does not take much to tip them over the edge. I know when talking to parents we have likened this to water dripping into a glass – there comes a point when the glass just gets too full and the water spills over the edge! Maybe our cup of anxiety is only half full and it will take a lot of extra drips to tip it over the edge. However for people with fragile X, their anxiety cup is nearly full to the brim with everything they are already managing – it is not going to take much to tip it over the edge. Over the edge can lead to all sorts of behaviours from argumentative and aggressive, to panic attacks and to hiding away plus all things in between.



### Managing Behaviours

This is just a set of short bullet points to summarise some of Marcia's points. There is more information on some of the strategies mentioned here in some of the society's publications. Many of them may be best put into practice with some professional back up e.g. from a psychologist or your child's school.

- An ABC chart can be useful in managing behaviours and working out where they come from. There is more information on this at the office. Knowing what caused the behaviour can sometimes let us know what the child is finding difficult to manage and take appropriate steps. It helps to narrow it down and just log the incidences of 1 particular behaviour over a period of time in a chart something like the one below

<b>A - Antecedent</b> <b>What happened before the behaviour</b>	<b>B - Behaviour</b> <b>A description of the behaviour</b>	<b>C- Consequence</b> <b>What happened as a result of the behaviour</b>

- Do not work on more than 1 difficult behaviour at a time. Once you have decided which behaviour to work on, it helps to work on it at home first as this is a place where there is more control over what is going on.
- Once you have decided which behaviour to work on, it is important to be as consistent as is humanly possible in managing it.
- It is OK to get it wrong when managing a difficult behaviour – it happens to everyone and it can help to let you know what to do next time.
- If a child is exhibiting a difficult behaviour, it is very often their way of dealing with a situation they find difficult/their way of communicating that there is something they are finding difficult to manage. Can we give them an alternative way of dealing with the situation/letting us know they cannot manage e.g. stamping a foot rather than kicking a person, throwing a red hankie rather than a chair?

- Children often follow a behavioural chain. They start to get agitated, showing this in various ways e.g. getting fidgety, biting their hand. Continual stress tends to up this reaction until the child gets to total meltdown. Marcia made the point that, as with all things, children with fragile X tend to see behaviours globally and once they start to get agitated, the only way out and to get to the end is to have the total meltdown. Providing a distraction at the beginning of the chain can sometimes mean that it is possible to steer the child away from the road which leads to total meltdown. Distracters could include an album of family pictures, soft music, a CD of favourite TV themes, pictures of favourite characters or DVDs. Marcia talked about how having an emergency kit with novel/sensory items (e.g. a squashy or koosh ball, chewing gum or a chewy tube) can sometimes help to diffuse a situation.



- Side talking can sometimes help to diffuse a situation e.g. "I think I don't like it in this shop. There are too many people. Let's go outside." This will only be helpful if you manage to catch the situation as the child's anxiety levels are just on the rise – not when they have reached the point of no return.
- There is some information on social stories available from the society. Marcia spoke about writing social stories in the third person to help a child manage a particular situation.

Sometimes Alex kicks people when he is cross.  
People get sad when Alex kicks them because it hurts.  
Kicking people is not a good idea.

- Giving a particular job or something to carry can sometimes help a child manage a transition from one place to another.
- Wearing formal wear or a uniform can sometimes raise behaviour standards e.g. wearing a suit to a wedding or a cub uniform to cubs.



**Finally Marcia did point out** changing behaviour is never easy and any difficult behaviour will often get worse before it gets better. It is impossible to change everything at once.