

# **Behavioural Characteristics and Intervention Strategies**

**Jane Oliver  
Family Support Worker  
The Fragile X Society**

**Précis of talk (as relating to  
adults)  
by Dr Marcia Braden  
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Rood End House, 6 Stortford Road, Great Dunmow, Essex CM6 1DA  
Tel: 01371 875100

Email: [info@fragilex.org.uk](mailto:info@fragilex.org.uk) Website: [www.fragilex.org.uk](http://www.fragilex.org.uk)  
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## Behavioural Characteristics and Intervention Strategies

Marcia's third presentation of the day was entitled **Behavioural Characteristics and Intervention Strategies**. Again you can ask for a copy of the power point presentation from the office if you wish. The first part of her talk covered the neurobiology of behaviour or the biological basis of behaviour. It was fascinating stuff and so important! Because the Fragile X gene "methylates" or switches off when the gene expands to over 200 repeats (i.e. a full mutation) a protein called FMRP is not made. FMRP is vital for brain development. If there is not enough FMRP acting like a brake on other substances, then the connections and pathways in the brain don't develop in the expected way. If you then imagine the brain as being divided up into different regions, controlling different aspects of our behaviour, then the neurobiology of behaviour starts to make more sense. Marcia said that the connections in some areas of the brain are too strong like in the amygdala or the anxiety centre - hence high anxiety levels. So there is a "biology" behind what is going on and I think this is really useful for those supporting someone with fragile X to know. It may help them think things through more and plan changes/ transitions more carefully.

Marcia went on to highlight the differences between FXS and autism which led again to an important point that people with FXS value and want to be with people usually, but that social anxiety prevents them. How confusing and upsetting that must feel. But I felt that Marcia was saying how, again, with careful thought and planning, this could be helped. It is possible that some services may be too quick to conclude that someone doesn't want social interaction or they're not interested when they actually are, but need support to overcome their very real worry about it.

A big focus of Marcia's presentation also included the time people with fragile X need to process information and understand what is going on around them. If this is factored in to what they are doing, it will help to decrease anxiety levels. An interesting comment from her presentation was "characteristics must be understood, but should not be viewed as excuses." A way towards meeting this is to understand the "arousal" or anxious state that many people have to manage. If you or I are anxious, our body goes in to flight or fight mode – fairly self explanatory. So when we have to make an awkward phone call, speak in front of lots of people, confront something that frightens us or annoys us, our body gets ready to "face the music". But a person with fragile X has to manage feeling like this much of the time. Marcia listed the "perceived threats" that people have to face.

- Social
- Verbal
- Sensory
- Motor
- Transitions

- Failures
- Frustrations
- Physical

There are probably others too!! So how can people be helped with these difficulties, which they have to face pretty much on a daily basis? Here are some thoughts from Marcia.

- Give people time to process information
- Use visual cues like visual schedules, diaries and calendars
- Use transition objects –like a rucksack, a coat or wallet and explain to all supporters how this works
- Give someone a job or task to do to help with transition.
- Gently pace introductions to new experiences if needed
- Don't force eye contact
- Be indirect in conversation or use “side scheduling” to move things on in a more positive way before anxiety levels become too high.

The final part of the presentation dealt with positive behaviour support - trying to overcome some of the difficult behaviours that can have such an impact on a person's everyday life. The starting point is to try and keep a schedule as predictable as possible **and** learn to recognise those signs that tell you some things are going awry . What's key here is knowing when you can intervene with a distractor – like let's find a quieter spot, how about looking at your favourite DVD etc **or** whether actually things have gone beyond this. It is quite a complicated thing to do and I think families sometimes need support with this, especially if behaviours are escalating. In this situation professionals should look at the “functional assessment” of the behavior as well as what triggers it. You have to be realistic too because it may not be possible to completely stop the behaviour and you may have to “replace” it. Marcia used an example of a handkerchief to literally signal “I don't want to be in this room right now” rather than getting the idea after the chair has been turned over. I think things can be more problematic because of the sensory difficulties that people experience, so Marcia stressed the importance of reducing sensory input as a method of interruption. She also said “People with fragile X must be provided with ways they can meet their sensory needs in a more adaptive way”

I hope this overview has given you an idea of what Marcia was saying. Please don't hesitate to let the office know if you would like copies of Marcia's presentations. They are in power point, but families, I know, have found them useful to look at and pass on.