

A Holistic Approach to Managing Challenging Behaviours **Geoff Evans from The Options Group**

Geoff trained as a Probation Officer and then moved onto developing an expertise in Autistic Spectrum Disorders (ASD) with a particular interest in behaviour.

What is meant by a holistic approach to managing behaviour?

Managing behaviour is complex. There will always be days when things go right and days when things go wrong. It is not an exact science!!

A holistic approach involves looking at everything – not just the behaviour itself. Everything includes the moment (what is going on around the individual); what the individual finds difficult; previous experiences that the individual has had; what other things the individual has to manage at that moment (this could include other difficulties that have occurred during the day); the family; how we are behaving etc. Part of the equation is ourselves and a good starting point is to change what we are doing particularly as we should be able to manage change better than individuals with fragile X.

What is meant by Challenging Behaviour?

We all either feel like behaving in a way that challenges or do behave in a way that challenges those around us some days – what stops us is that we have the mechanism to stop ourselves before things go too far. We can think things through and have an understanding of the consequences of our behaviour. Individuals with fragile X have problems with thinking things through and so are unable to predict these consequences.

There is also the consideration that what is challenging for one person is not challenging for another. It is harder for parents than for professionals to watch their child self harm, hurt their sibling or engage in any behaviour detrimental to their health. There is no hierarchy of challenging behaviours. We all have different thresholds and recognising what we ourselves can and can't do or manage is the start to managing challenging behaviour in others

Managing Challenging Behaviours

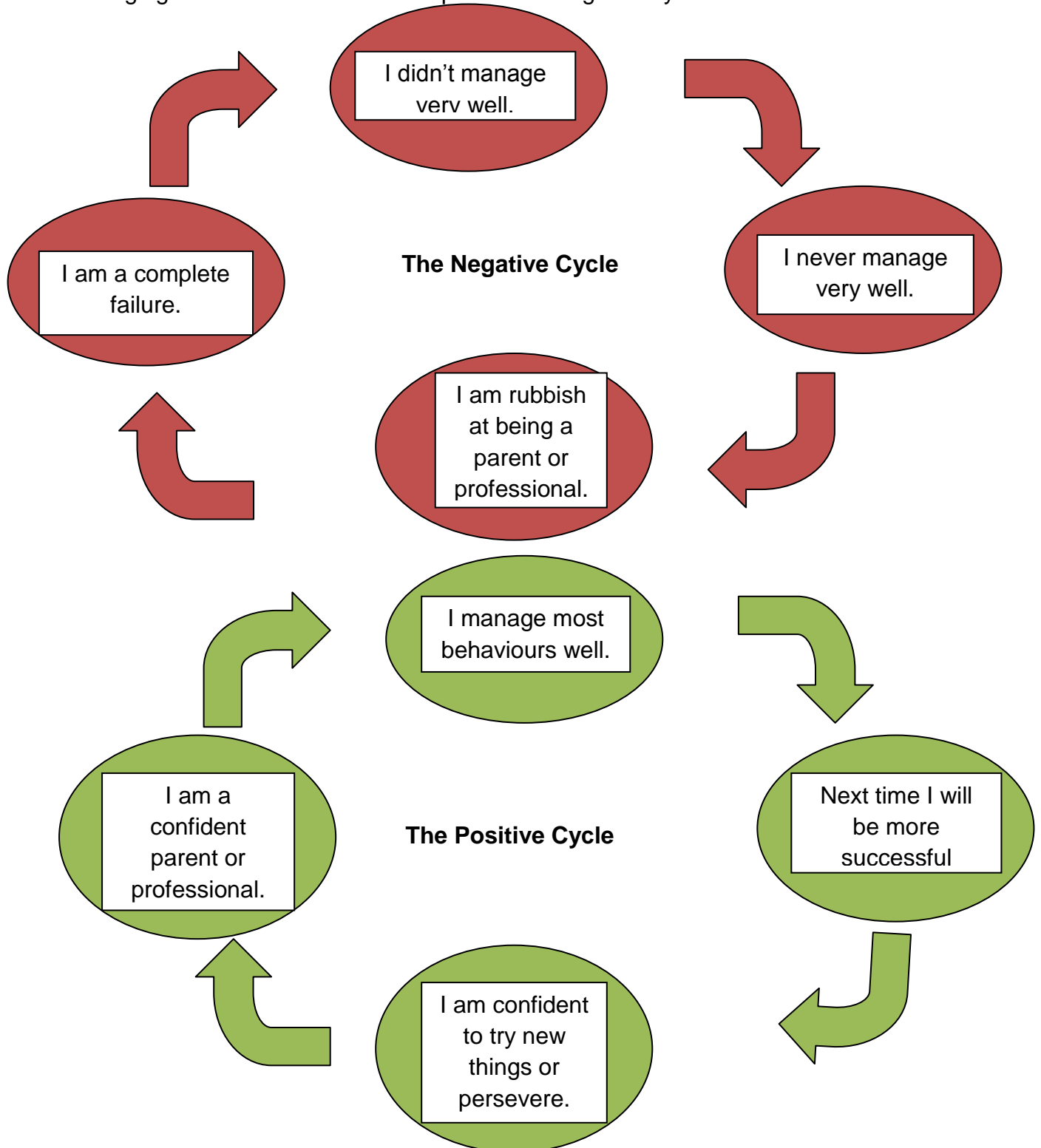
We need to keep the problem in perspective. People tend to see the problem and not the individual, almost defining the individual by their behaviour. However, the important thing is to focus on the individual and think about what the solution looks like and not what the problem looks like. The first point to thinking about solutions is to describe the behaviour rather than the individual so using terms like "He runs away" rather than "He is a runner." Using vocabulary like "violent" or aggressive is not helpful as it does not describe the behaviour – what is meant by aggressive?

Very often behaviour is described as "attention seeking". So how do we deal with that? Geoff had never come across a child who sought attention when he didn't need it. Hence if a behaviour is ignored, those managing the situation need to make sure that is the right strategy. What can happen is if the individual's behaviour is ignored,

they will increase the behaviour until it can no longer be ignored. So unless you are absolutely sure that ignoring the behaviour is going to work, it is best to respond straight away and give the attention.

Successfully managing behaviour is not about one person being the victor – both the child and the parent should come out of it, feeling good about themselves.

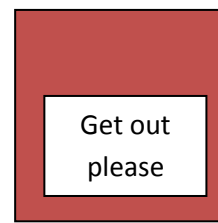
Managing behaviour can become a positive or negative cycle



Understanding the behaviour from the perspective of the person and their environment.

One of the key factors in managing the behaviour of an individual affected by fragile X syndrome is to understand that behaviour from the perspective of the individual and their environment. So it can help to learn about the behaviour by watching your child and trying to see things their way.

Sensory difficulties, common in fragile X syndrome, mean that many individuals have difficulty managing all the information coming in so there will be moments when their brain can just not take in any more. At this point the ability to communicate with words tends to decrease even in individuals who use verbal communication. Hence they may do better if they have a symbol or picture card that shows they need to get out and have some re-grouping time. We all find it easier to understand visuals when we are in a panic – fire exit signs are always visual.



As far as possible it can help to manage the environment and keep distractions and possible triggers to difficult behaviour at a minimum. Providing a known safe haven like a pop up tent, where the child can go when they are feeling stressed or anxious, can be useful at home and school. Managing the environment in the outside world is much more difficult and busy places like supermarkets are very common triggers to behaviours that challenge. On days when the child's anxiety levels are down, having a distracter to give them (maybe a favourite toy) may be enough to avoid a challenging incident, but on days when anxiety levels are already high, this is less likely to work and the individual may need to just get out of there.

The role of stress and anxiety in behaviour

Challenging behaviour tends to come from where a child is and anxiety has a very important part to play here. Individuals affected by fragile X have to manage high levels of anxiety on a fairly regular basis. Some individuals will know when they are getting stressed and others may need more support with this.

Many individuals will develop their own strategies to manage this anxiety. Sometimes it can help to make a list of these strategies – biting the hand at the base of the thumb is a very common one. With some strategies it is best to leave well alone, with others it may be necessary to replace the child's strategy with something that has the same impact but causes them less harm. So, for example, it may help to replace biting the hand with biting a chewy tube or a chewable bracelet if they are biting their hand so severely that they are causing calluses.

There will be times when anxiety levels are incredibly high and a meltdown seems imminent – a bit like being on the edge of the cliff.



Things could go either way – the individual could go over the edge and have that behaviour meltdown or they could be pulled back from the edge and avoid the meltdown. What we also have to remember is that the person dealing with the behaviour is also on the edge of the cliff. This is not the time to teach the child ways of managing their behaviour – this is the time to do whatever is

necessary to bring things back down and calm the child – basically doing whatever is needed to bring them “away from the cliff edge”. This could be deemed by others to be “giving in”. It may be something like suggesting to the child that they leave the situation/go to a place they find calming/ do an activity they find calming like listening to music or watching a favourite DVD.

Medication has its place in terms of getting people away from the edge of the cliff. It should never be the first thing that is tried when an individual is showing challenging behaviours. But when all other measures are in place, it may be that an individual needs some form of regular medication to keep their anxiety down and improve the quality of their life. Other measures include things like preparing for change and transition, visual input, and all the other things mentioned here and in our other papers on behaviour.

Once the individual has fully calmed down, that is the time to talk to them about how they may have been better able to manage their high level of anxiety.

Functional Analysis of Behaviour

A functional analysis of an individual’s challenging behaviour is helpful. This involves looking at the behaviour in minute detail.

- Where did the behaviour happen?
- Who was involved?
- When did it happen?

This has its place in trying to understand the behaviour of individuals affected by fragile X, but it is worth bearing in mind that sometimes the behaviour does not come about just as a result of what happened before. On many occasions there will have been lots of little triggers building up through the day until something relatively trivial just tips the balance and that is when the behaviour occurs.

Other tips to managing challenging behaviour

- A lot of difficult behaviours result from sensory difficulties. This can include difficulties with managing busy environments as already mentioned. It can also include difficulties with the proprioceptive system. This is what we use to understand where our body is in relation to its environment so things like

understanding we are sitting on a chair and how to stay on that chair. If you can access it, support from an Occupational Therapist (OT) can be helpful. They may be able to put together a sensory profile of the individual with suggested regular calming activities to keep anxiety levels down.

- Behaviours are never simple. They are about a whole lot of things. In terms of managing behaviour in individuals with fragile X, it is important to remember that we are the ones less averse to change. Hence we are able to change what we do easier than individuals with the syndrome. Is there any way we could change something that may make the situation better?
- It is more difficult to change society – supermarkets are what they are!!!! However, is there any way we can build up an individual's ability to manage them. This may be going in to buy one thing and coming out. When the individual can manage that can we move onto buying two things and so on?
- Social stories can help children to think through how to manage a situation. They are also very visual and individuals with fragile X are much better able to manage visually presented information. We do have information on social stories so please do contact us about this.
- Transitions are known times of difficulty for individuals affected by fragile X syndrome. Coming home after a busy day at school/wherever can often be a challenging time for many. Many manage better if they are in the routine of having some time to themselves, possibly in their bedroom, as soon as they get home. Some individuals may also benefit from a "debrief" time at the end of a day at school whilst others manage better if just left alone.
- Having good established routines in home life can help to keep anxiety levels down.
- A physical programme of regular exercises can help to keep anxiety levels down.
- Power cards can help an individual manage a situation they find difficult. This may involve using an object or person of interest e.g.



Thomas says when I get home from school, time to go to my bedroom.



Dr Who says when I get home, time to go to my bedroom.

- Coaching cards that talk people through the stages of managing something can also be helpful. These can always feature pictures as well as words if pictures have more meaning.

- When I get home
- Say hello to....
 - Get a drink
 - Go upstairs
 - Go in my bedroom
 - Put on.....DVD

And Finally

- Everyone makes mistakes when trying to manage challenging behaviours. It is important not to get paralysed by mistakes. What is important is to learn from them and try something different next time.