

# The Fragile X Society



**FRAGILE X SYNDROME:  
AN INTRODUCTORY GUIDE TO  
EDUCATIONAL NEEDS  
and how they can be met**

## INTRODUCTION

This booklet is a guide for teachers and other professionals. It gives examples of strategies that people have found helpful when working with an individual with fragile X. They are not prescriptive or an exhaustive list and do not replace the need to assess each individual's needs and how they might best be met.

The information it contains comes from a variety of published works and experiences and, though the booklet often refers to children, much of the content applies to adolescents and adults in educational and training settings.

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## WHAT IS FRAGILE X SYNDROME?

Fragile X Syndrome is the most common identifiable cause of inherited learning disability. It shows itself in a wide range of learning difficulties and developmental delay. Although this booklet describes many features of fragile X and their educational implications, it is important to note that any one individual may present only a few of the needs described, while another individual may show a wide range of features but in a relatively mild form.

Until recently fragile X was relatively unknown. Accurate diagnosis was difficult and many individuals went unrecognised. In the last few years medical understanding of the condition has developed considerably. Educational knowledge and experience, in terms of how best to support learners with Fragile X Syndrome, has also developed.

The genetic origin of fragile X was not discovered until 1969, when it was found that individuals showing particular learning and physical characteristics had a fragile area on their X chromosome. It is the absence of a particular protein (FMRP), important to brain development, that gives rise to the difficulties associated with Fragile X Syndrome. Individuals with fragile X are not themselves physically fragile. They are as robust as anyone else.

## SPEECH, LANGUAGE AND COMMUNICATION

### **1. Particular difficulties/speech characteristics**

Speech and language are almost always affected. Delayed development in these areas is often one of the earliest presenting features.

Repetition of words and phrases with up and down swings of pitch is common. Speech can be rapid with poor control of rhythm (dysrhythmia) and words seem to fall over each other with pauses

in the wrong place, making the speech difficult to follow. There can be articulation problems. An often narrow, high arched palate means that greater effort is required for articulation and low muscle tone in the mouth can limit the strength and range of oral movements. Ear infections, as a result of glue ear, can be a feature of fragile X and this can lead to some hearing loss. If a child has persistent ear infections, it is possible that grommets might help and families should seek medical advice.

Individuals may repeat the last word or phrase spoken to them (echolalia), repeat words or phrases they themselves have spoken (palilalia) or keep talking about the same topic (perseveration). Palilalia and perseveration are often exacerbated by heightened anxiety levels with the individual being unable to inhibit certain thoughts or retrieve the word that they need to continue with what they are saying. There is also the tendency to skip from one topic to another or say something unrelated to the conversation (tangential language). This can be related to the uninhibited expression of thoughts. Attention problems and difficulties make it difficult for children with fragile X to stay with a conversation. There are often particular problems managing language in social settings, such as expressing feelings, initiating a conversation, asking for help and knowing what is and is not appropriate to say in particular situations.

While many individuals with fragile X have difficulties in speaking and being understood, their understanding of speech may be significantly higher than at first appears. Teachers often comment on the surprising abilities of children with fragile X to take in what is said in the classroom. Characteristically, receptive language skills are generally better than expressive. There can, however, be a tendency to interpret language literally and to miss more subtle meanings and implications. All these speech characteristics are still evident in varying degrees in adulthood.

## **2. What can help?**

The advice of Speech and Language Therapy Services is essential here. An intervention programme may be individualised to suit each child. Such programmes are at their most effective if integrated between school and home. Co-operation between therapists, teachers and families is the most effective approach. New skills and concepts can be introduced in 1:1 sessions. These should then be regularly practised and reinforced in natural social contexts. Makaton sign language and PECS (Picture Exchange Communication System) can be valuable aids to communication and overall language development. Access to normal language experience is important.

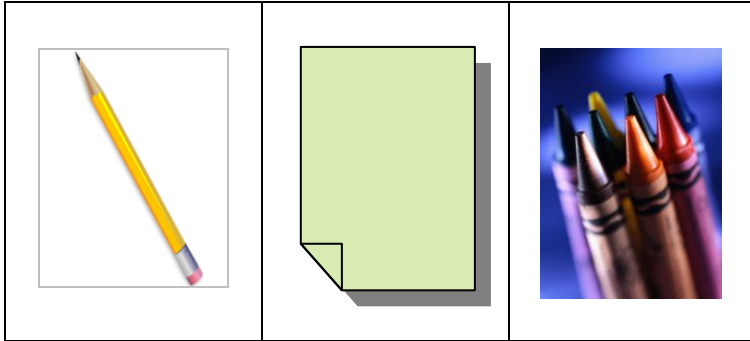
Here is a sample of some of the approaches and techniques that people have found helpful:

Chewing, sucking and blowing can help to increase muscle tone in the mouth. Repeating rhymes in a rhythmical fashion can be helpful in slowing down speech patterns. Games can be used to help encourage language development, for example, guessing what is being described, saying the last word in a rhyme to keep the game going. Individuals with fragile X tend to like to complete things and may respond better to completing a sentence rather than to answering a direct question - "The strawberry is red and the apple is ....." rather than "What colour is the apple?"

Fast mapping is a technique that can be used to teach new words. This means, for example, giving a child an array of 3 objects or pictures, 2 of which are well-known to them. Then they are asked for the unknown one.

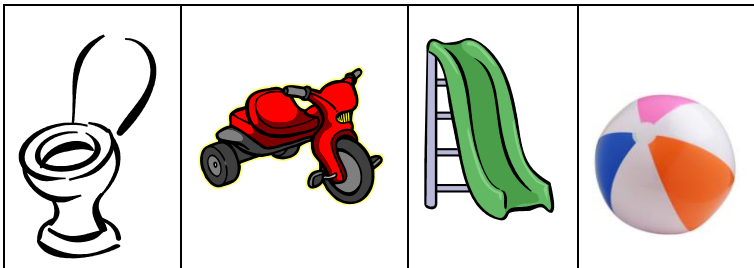
Instructions are best given in short sentences, with time to complete each section before the next part of the instruction is given. Children with fragile X often assimilate visual information more easily than auditory information. A picture of everything the

child needs to find to complete a piece of work may be more likely to get results than simply telling them.



Some children respond to having a key ring with symbols or pictures of things they may need to ask for. This approach can also be useful for adults, especially if they have to approach a person with whom they are not familiar.

This could be a typical set of such symbols for playtime:



## SENSORY ISSUES

### 1. Particular Characteristics

Children and adults with fragile X can find it difficult to make sense of and react appropriately to the wealth of information coming to them via their senses. They can find it difficult to pick out the

pertinent information. Some artificial lighting can be difficult for them. In busy environments they can be overwhelmed, sometimes responding with repeated behaviour patterns, withdrawal, disrupted speech patterns and general confusion. When these responses occur, a calm and comforting response should be aimed for.

## **2. What can help?**

Classrooms are busy environments. An environment that is alert to over-stimulation and aims to minimise this can avoid many of the potential difficulties.

There will still be times when a pupil with fragile X may need to spend some time in a quieter area. Group times such as assemblies and the dining hall can be particularly difficult. The children may be better able to manage them if they are introduced gradually, for example, watching assembly from the corridor, then watching from the back of the hall, then sitting with their class but possibly at the end of the row.

For some children, access to particular sensory stimuli can have a calming effect. Some children can find jumping up and down calming. Others find access to a sensory box containing items made of different textures helps to reduce anxiety.

When difficulties with sensory processing are pronounced, the advice of an Occupational Therapist with experience of Sensory Integration Therapy may be helpful.

## **EYE CONTACT**

### **1. Particular Characteristics**

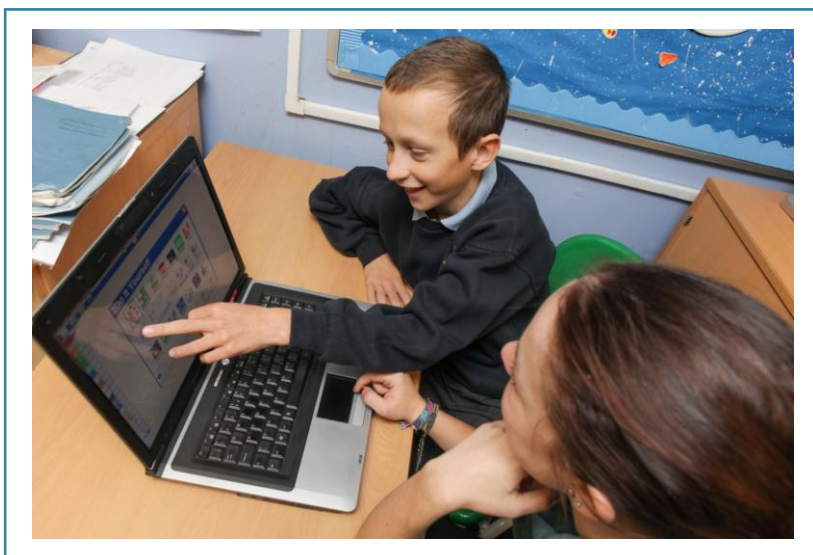
Individuals with fragile X are often very reluctant to give eye contact and will tend to avoid other people's gaze. Some may turn their whole head or body away from the person addressing them. They

may find eye contact particularly uncomfortable in social situations such as meeting new people, or when they are the centre of attention. This dislike of eye contact can be particularly evident in situations the individual perceives as stressful. Such social anxiety is often a trigger for what can be perceived as challenging behaviour. With fragile X, the difficulty in making or receiving eye contact is not a sign of social indifference.

## **2. What can help?**

Care should be taken not to enforce eye contact as this will heighten anxiety levels. Eye contact should never be insisted on, or be an IEP target for children with Fragile X Syndrome.

Children tend to manage better if supported in lessons by an adult sitting behind or beside them. Similarly, conversations are best undertaken standing beside rather than opposite a person with fragile X.





# THE EFFECTS OF FRAGILE X ON LEARNING AND CHARACTERISTICS AFFECTING CLASSROOM MANAGEMENT

## 1. Particular Characteristics

**Overactivity/Hyperactivity** Always rushing about, seldom sitting still. This usually moderates into adulthood

**Restlessness** Finding it very difficult to sit still

**Impulsivity** Not inclined to wait for anything, wanting things straight away, doing first and thinking later. This can decrease in adulthood, but not always

**Inattention** Not sticking to one activity or task for any length of time

**Memory Retention** Generally short, but can be very good over the long term in a topic where the child's interest has been engaged

**Liking for routines** Can become upset or confused when familiar routines are broken or things around them are changed, such as the furniture or layout of the classroom

**Problems managing transitions** Finding transition times (moving from one place or activity to another) very difficult

**Problems with initiation** Can find it difficult to initiate a conversation or ask for something, for example, asking for help

**Problems with being the centre of attention** Can find it difficult to manage when asked a direct question, when asked to the front in assembly or at their own birthday party

**Perseveration** A tendency to persist with a response even when they know it is wrong as they cannot think of an alternative

**Better able to manage visual than verbal information**

**A desire to complete things**

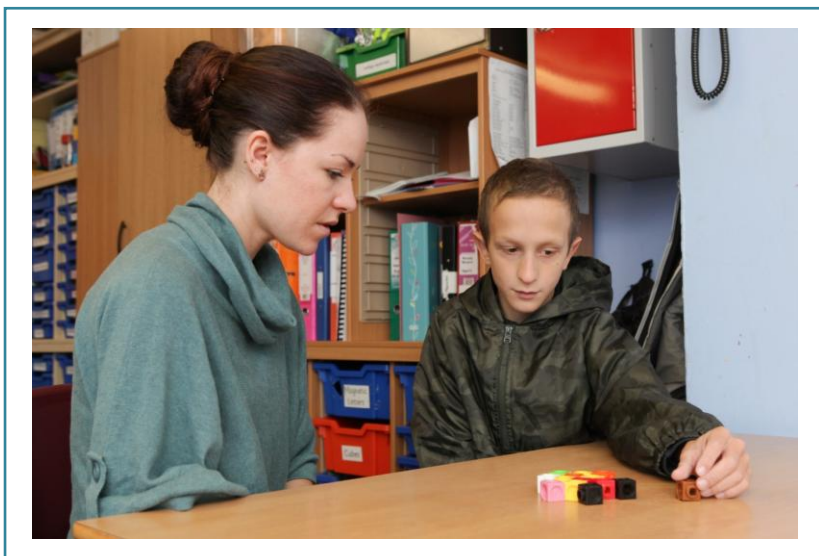
**Problems with sequential processing and better at simultaneous processing** Cannot think through how to carry out a task in a logical order or learn the constituent parts of a task

**Better at seeing the whole**

**Problems with Conceptual Learning** Explanations and other guidance needs to be explicit rather than implied

Some children, particularly those with more significant levels of learning disability, may not pick up on incidental learning in the way that typically developing children do and may need skills taught in a more structured way.

Standardised testing is not a particularly informative or useful way of assessing the attainments of children with Fragile X Syndrome. Context based curriculum assessment is most suitable for this purpose. It is important that an assessment of current attainments is made so that targets can be set, against which progress can be measured.



## **2. What can help?**

For most, if not all individuals, a substantial degree of curriculum differentiation will be necessary. In many cases, additional classroom support will be required.

### **School Placement**






Some children, particularly younger ones, will be able to manage, with support, within the normal run of the mainstream classroom. In some cases special schooling may be necessary in order to meet a child's educational needs. Given the facility for mimicry that many children with fragile X show, mainstreaming is, wherever possible, the preferred option. This is particularly important in respect of the development of language and appropriate standards of behaviour. The decision about which type of school placement is most suitable can only be made on an individual basis and in terms of matching an individual child's needs to the needs a particular school is able to meet.

### **The Classroom Environment and Teaching Techniques**

Direct and straightforward methods of teaching are, as a general rule, most suitable for children with fragile X. Busy worksheets can confuse the child and divert from what they are actually supposed to be doing. Work packages should be designed to achieve teaching goals in a direct manner. For example, if the goal of a particular lesson is neat hand writing, it would be counterproductive to insist that all the words are spelt correctly. Spelling or any other requirement, additional to the primary matter in hand, would be best dealt with as a separate aim.

It is important to establish familiar and consistent classroom or individual routines, keeping the child informed of impending changes. Visual timetables have been very useful here. A set of pictures, symbols, words or objects of reference, appropriate to the individual concerned, can be arranged in order from left to right or

top to bottom. Teachers can use the visual timetable to talk through the order of the day and also to point out any changes to normal routines. Children are better able to manage a change if they are prepared in this way. Removing the symbol, picture or object or crossing a word off a list can also be beneficial as it indicates the completion of that activity.




				
<b>Register</b>	<b>Numeracy</b>	<b>Playtime</b>	<b>Literacy</b>	<b>Dinner Time</b>

A class calendar can also help children count down to a particular activity. Some children do better if they can see when an event is going to happen. However, for some children, there is a risk that this could raise anxiety levels. For others, as soon as the trip is mentioned they are at the door, ready to go.





It is also important to make sure the child knows why and how things are going to happen. For example, when a child says, “Can we read a book?”, rather than saying “In a minute”, it would be better to explain: “We’ll have to finish our water experiment first”.

Timetables can be used to help children manage transitions. For example the child can be told that in 5 minutes it is going to be time to clear away Maths books and get ready for PE.

Schedules are a way of letting a child know what is expected of them. They can be particularly beneficial in Early Years settings where there is often an array of activities to choose from. Photos or symbols can be arranged from top to bottom or left to right and then removed as each activity is complete.

 <p style="text-align: center;"><b>bricks</b></p>	 <p style="text-align: center;"><b>sand</b></p>	 <p style="text-align: center;"><b>cutting and sticking</b></p>	 <p style="text-align: center;"><b>cars</b></p>
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If needed, favourite activities can be depicted to act as the reward after a new or more challenging activity. The sample schedule below shows trains as the reward activity.

 <p style="text-align: center;"><b>bricks</b></p>	 <p style="text-align: center;"><b>trains</b></p>	 <p style="text-align: center;"><b>cutting and sticking</b></p>	 <p style="text-align: center;"><b>trains</b></p>
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The **TEACCH** visual structure has also proved helpful.

A tick list can be used to depict the order of a task, with the child crossing or ticking off each stage of the task as it is completed. Two different tick lists are shown here:-

- **Name**
- **Date**
- **Write 2 sentences about how Sam got to the seaside**
  - **1**
  - **2**
- **Write 2 sentences about what Sam did at the seaside**
  - **1**
  - **2**
- **Write 2 sentences about how Sam got home**
  - **1**
  - **2**
- **Draw Sam at the seaside**

- **Name**
- **Date**
- **Draw Sam**
- **Write**

**Here is Sam**

Visual structures can also be used in adult settings. Visual diaries, using photos or pictures, to let the individual know the order of the day; pictures of staff on a pin board to show who is supporting the person that day; objects of reference (such as a coat) to indicate a transition and visual prompts about the order of a particular activity can all benefit the individual by increasing levels of predictability.

 <p><b>Bus to shops</b></p>	<p><b>Sainsbury's</b></p> <p><b>Shopping at Sainsbury's</b></p>	 <p><b>Buy new trousers</b></p>	 <p><b>Coffee and cake</b></p>	 <p><b>Bus back home</b></p>
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Computers can be useful. They allow repetition of tasks and are consistent. They give immediate responses and are not personally threatening.

The liking for completion can be used to encourage participation in tasks - e.g. putting in the last piece of a puzzle. "Backward chaining" can also be a good way to teach a new skill. Backward chaining involves the whole task being presented. Then the last part is left out for the individual to complete and then the last 2 parts and so on, until the individual is able to complete the whole task. For example, an individual can be shown how to make a sandwich; then the sandwich can be made with them completing the last part of cutting it in half; then they put in the filling and cut it in half, and so on until they are making the whole sandwich. This method does not rely on the individual having good sequencing skills so it can be used to promote activities in daily life such as washing and dressing.

Given their potential for distractibility, children with Fragile X make better progress if what they are to do is clear to them and achievable in a given time span. There needs to be a point where success can be identified. Schedules and tick lists are a good way of letting children know exactly what is expected and when and what the finishing point is before they start. Once the child has been told what is expected, it is important not to break the deal.

Children do better if work is packaged into blocks of time that fit their attention span. Some children manage better if they have a personalised work station. Others may be better in the group setting as they may follow what the other children are doing. Some may need the flexibility to be able to move round the classroom or to go to a designated place in or outside the classroom if things are getting too much. Some will need this style of break factored into a schedule or tick list, whilst others may do better if they are allowed this freedom, but at no specified time. Fidgetiness can also be a problem and some children manage group times better if they have a small object to fiddle with.

New targets should be set with small achievable steps. New skills are often best taught, using a skill already acquired or based on an existing behaviour, for example, extending grabbing for a desired object to pointing to what is wanted. Children with fragile X like to succeed just as much as other children. However, they can be particularly sensitive to getting things wrong. They also tend to persist with a response even when they know it to be wrong. For adults it is important, as far as possible, to acquire a new skill within its context as it can be difficult for them to transfer a skill learned in one setting to a different setting.

Praise is important for children with fragile X. They respond positively to evidence of their own success. It can also be helpful for the adult working with them to be clear about exactly what they are praising. However, many individuals with fragile X find it difficult being put on the spot, being the centre of attention or being different from everyone else, so praise may need to be cautiously applied. Using a peer as a middle man can be helpful if a direct question needs to be asked. Children may also find it easier if, once a task is understood, support assistants leave them to complete it, keeping an eye on them from a distance rather than sitting with them.



Teachers often express concern that the children are not doing as much as they should or that a child has not made as much progress as their classmates. This is not something to worry about if the teacher is confident the child's attention has been usefully engaged at points during the day. Like all children, those with fragile X need opportunities to explore for themselves the things they like, in their own way and at their own pace. Children do best when teachers and parents work together. Home/school books can be a very good way of each keeping the other informed.

### **Starting School/Changing Schools**

Change and new environments can be a major source of raised anxiety for anyone with Fragile X Syndrome. It is essential to prepare them. Opportunities to visit the new environment can be helpful as can photo books about the new place – e.g. the order of the day and who the adults are. When the child is moving to a new school it can help to pass on particular tips about what works well with them, such as their particular likes and dislikes. A passport style document can be useful here.

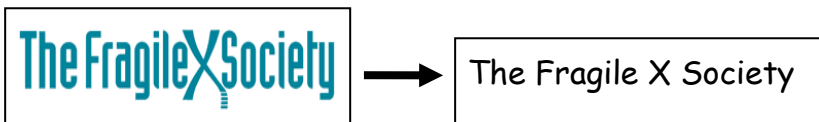
### **Reading**

It should not be assumed that because of their speech and language difficulties children with fragile X will be poor readers. In fact, reading can sometimes be a relative strength in those with fragile X.



Children with fragile X learn better with visual approaches than with auditory approaches. For example, learning a sight vocabulary is usually significantly easier than learning phonics. Children may be able to learn the sound that matches each letter, but have trouble putting the sounds together to make a word. Relative visual strengths mean that they find it much easier to recognise a whole word. Matching words to pictures can be a good place to start.

Reading schemes tend to be more effective the more visual they are. Children with fragile X also have a capacity for learning logos and environmental signs. This strength has often been used as a basis for reading development by, for example, teaching the word in its logo form and then removing the logo script.



Many children respond well when the reading matter is about something of particular interest to them.

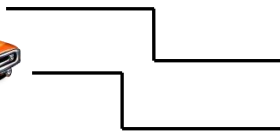
 <p>Thomas is blue.</p>	 <p>James is red.</p>
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Paired reading has inherent features which make it suitable for children with fragile X. In particular, it involves teaching alongside the child and so reduces the risk of potentially uncomfortable eye contact.

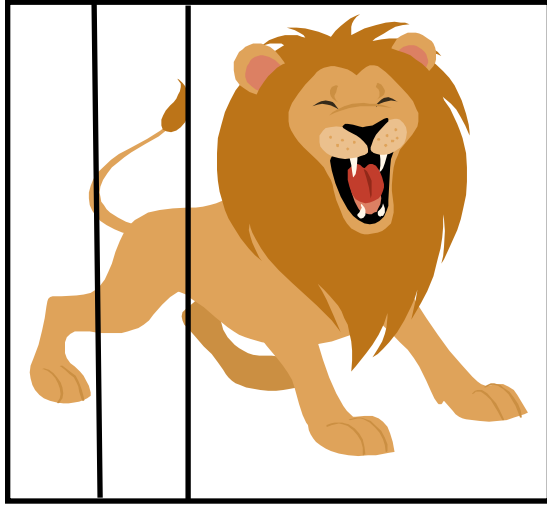
## Writing

The ability to learn writing can be seriously impeded by poor motor control often associated with low muscle tone, a feature of some children with fragile X. Pencil grips can be useful. Less pressure is needed when making marks with felt tips. Fun can be had painting in water with a large brush, or drawing on a specified wall/area with large chalks. Sensory methods can also be beneficial when teaching the mechanics of writing, for example, finger tracing letters made of different textures and writing letters in the sand with a finger.

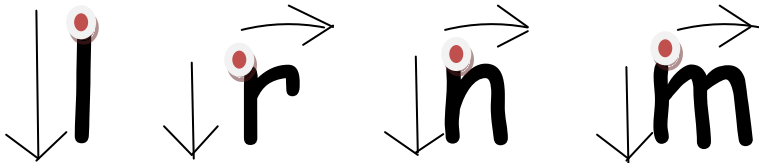
High interest areas can be used to teach pencil control, for example, taking the train to the station or the car to the garage.



Putting the cheese on the pizza can be more interesting than colouring a circle yellow. Putting the bars on the cage can be more interesting than drawing straight lines.





It can help to teach letters in groups according to how they are formed:



It has already been mentioned that children with fragile X have a need to complete tasks. Writing tasks to maximise this can be helpful, such as gradually building up the ability to write a name or filling in the missing words in a sentence:

<b>Alex</b>
<b>Ale</b>
<b>Al</b>
<b>A</b>

<b>red</b>	<b>blue</b>	<b>Thomas</b>	<b>James</b>
			
<b>T..... is b.....</b>			<b>J..... is r.....</b>

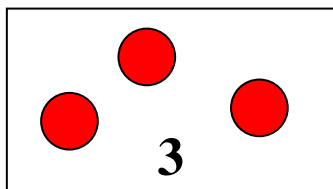
If writing is the tool of an activity rather than the purpose of the activity, other methods of recording can be considered.

## Maths/Numeracy

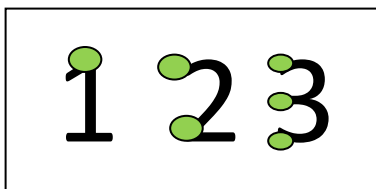
The need for suitably differentiated teaching may be particularly evident in Maths. Children with fragile X are apt to lose sight of what it is they are being asked to do, or even not see it in the first place. They tend to go down blind alleys, to attend to wrong or irrelevant aspects of the task. The difficulty becomes greater with more complex and involved teaching methods because the opportunities for following the wrong paths are more numerous. Direct, unequivocal teaching methods are more effective.

Visually-based methods tend to yield the best results, for example, 1:1 matching, dot numbers and number lotto games:

**1:1 matching**

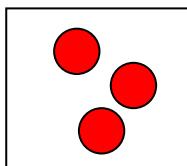


**dot numbers**



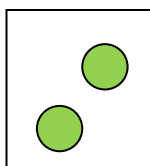
High interest materials can be used - e.g. counting cars, football players etc.

The other consideration is that children with fragile X respond better and engage more if a complete picture of the learning is presented to them. Again having to fill in the missing parts as shown below can also be helpful.



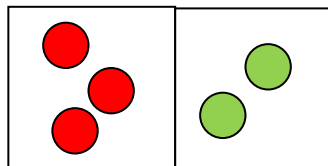
**3**

**+**



**2**

**=**



**5**

It is important that teaching concentrates on practical applications, such as handling money and telling the time. Initial money skills can be taught in the classroom environment and then transferred to a real shopping experience. Adults and children may need to learn the skill of giving more and getting change rather than trying to teach different coin values and putting them together to make the right amount.

## BEHAVIOUR

### 1. Particular Characteristics

Children with fragile X are not “badly behaved” in the commonly understood meaning of the term. Nevertheless they can still present teachers with management problems. Impulsivity and poor attention can mean they may get up and start meandering around the classroom. It can be easy to misinterpret some behaviours as willful and uncooperative, but, in reality, difficult, challenging or willful behaviours, as these are generally understood in education, are rare in individuals with fragile X. They are usually a sign of mounting anxiety. Many individuals with fragile X have to manage relatively high levels of anxiety on a daily basis due to the range of situations they find difficult. Difficulties with sensory processing may mean that they react vigorously and inappropriately to events around them. Common triggers for raised anxiety levels include problems with eye contact and difficulties managing social situations. Many will also begin to develop an understanding of situations that raise their anxiety levels and then get anxious when they know that this event is going to happen. Some are also sensitive to the feelings of others and may find it hard to manage if someone else is angry or distressed.

It is important to be aware of signs of rising anxiety levels. Repetitive behaviours, most typically hand flapping and hand biting, are common signs. Other signs of rising anxiety levels include

rocking, perseveration of language, deteriorating speech, poor attention, poor fine motor control, impulsivity or loss of self control.

Whilst children with fragile X are good mimics, they are not always particularly discerning about what or who they mimic and thus can copy bad language and slang.

## **2. What can help?**

While we might expect certain behaviours from a child with fragile X, that does not mean we have to accept them. Teachers need have no worries about insisting on appropriate behaviour in circumstances where the step is small enough and the child is capable of reaching it. As with other curriculum areas, however, longer term and supported practice will probably be required, and some individuals may require a permanent behaviour management strategy to be in place.

### **Distraction/Defusing**

For children with fragile X, once their anxiety levels start to rise and a particular behaviour starts to occur, the only way they know how to manage the situation is often to see the behaviour through to the end. It is important to interrupt the behaviour chain as near to the beginning as possible.

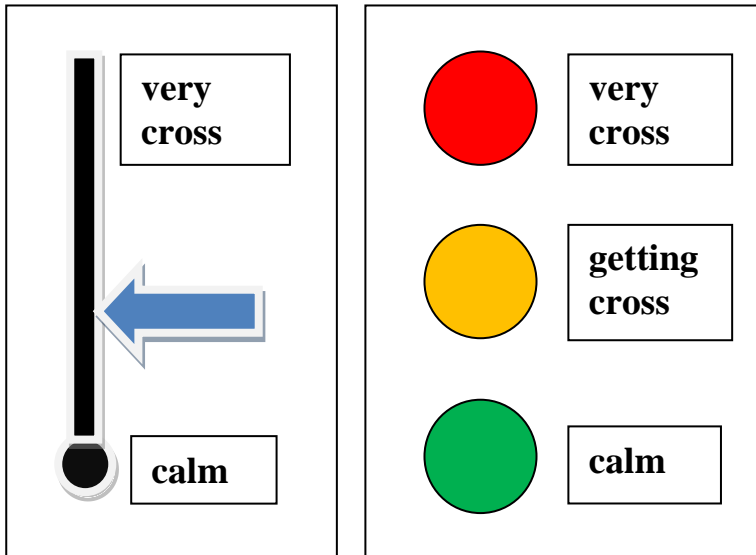
Reducing the noise or the amount of visual input in the environment can help to reduce anxiety levels. Music and heavy tasks like digging and physical activities can often be calming. Novelty items or just leaving the situation and going to do something else (such as going for a walk in the corridor for children or perhaps going to have a cup of tea for adults) can act as distracters.

### **Recognising Their Own Anxiety Levels**

Some individuals with fragile X can begin to recognise within themselves when their anxiety levels are rising. Visual prompts can



sometimes be used to help with this, for example, emotional thermometers and traffic lights may be useful.

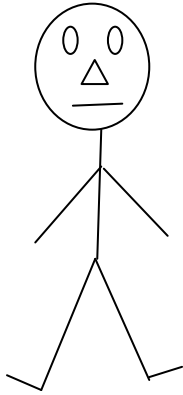


### **Indirect Ways of Managing the Situation**

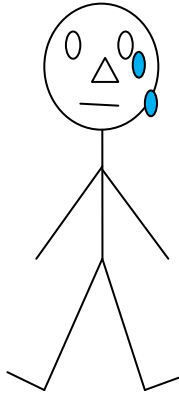
When someone with fragile X is in an anxious state, direct approaches can exacerbate the situation and end up “fuelling the fire”. Indirect approaches can be more productive.

**Side Talking** Talking to the individual as if you were experiencing the same feelings - e.g. “It’s getting noisy in here. Let’s go have a walk round the corridor till it gets quieter” rather than “You need to have a walk round.”

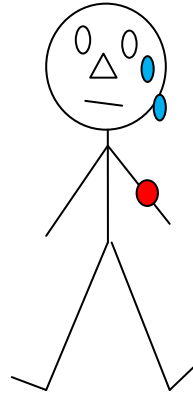
**Drawing Pictures** It can often be the case that someone with fragile X will not be able to say what happened in a particular situation or why they are cross. Drawing pictures can be a way of helping them to think about what happened, for example:



**Here is Tom.**



**Tom is crying.**



**Tom is crying because he hurt his arm.**

**Completing Sentences** Asking an individual with fragile X to finish a sentence rather than expecting them to answer a direct question can be a good way of discovering what caused them to be anxious or cross, for example, try “Today Tom went to school. Mrs Brown was doing the register. Tom.....” rather than “What did you do during the register Tom?”

**Areas of high interest** Using areas of high interest can be useful when discussing particular areas of concern with an adult.

**Alternative ways of getting what the individual needs, or of managing situations**

- As has been mentioned, children and adults with fragile X do tend to get overwhelmed by particular situations that raise their anxiety levels. They often need a time away from the situation and in a quieter space. When anxiety levels are rising, the ability to communicate effectively tends to decrease, even amongst the many individuals with fragile X who are verbal. For those who are non verbal, behaviour is often the only way they have

of communicating high levels of stress. It can help to have a recognised means that the individual can use to communicate a desire to get out of a particular situation such as pointing to the door, or using a get out card.



When this happens there needs to be an understanding amongst all working with the individual that they will be able to leave the situation.

- Some individuals with fragile X find it easier to manage a transition if they have something purposeful to carry such as the bag of beanbags to PE, a backpack with their lunch to the dining hall, a wallet if they are going shopping.

Once an individual has been overcome by their anxiety, it can take a long time for them to settle again. In these circumstances it is best to wait until the individual has calmed before discussing with them reasons for being upset or better ways of managing the situation.

### **Changing Behaviours**

It is important to work on one behaviour at a time. It is not realistic and potentially confusing to try to change everything at once. Start with the behaviour that is most likely to respond to change. This might not necessarily be the most challenging behaviour. Sometimes it can help to substitute one behaviour that gives the same sensation or gets the same result; such as chewing a chewy

tube rather than gnawing at a hand, or changing a push for a tap if the individual is trying to gain attention.

**ABC Charts** ABC charts can be used as a way of analysing a particular behaviour. A stands for antecedent or what happened immediately before the behaviour; B for the behaviour itself and C for consequence or what happened after the behaviour. When using these charts it is important to highlight one particular behaviour. Here is an example of such a chart.

<b>Time and date</b>	<b>A</b>	<b>B</b>	<b>C</b>
<b>21/4/2011 9.30</b>	Tom arrives in classroom	Tom sat in the kitchen corner	Tom taken to his seat
<b>22/4/2011 11.15</b>	Tom comes back to class after play	Tom sat in the kitchen corner	Tom taken to his seat

Once sufficient information has been gathered, the behaviour can begin to be examined. Things to consider include

- Is there a common antecedent – a particular sensory issue, for example, a noise? Does it always happen just after a transition?
- Does the behaviour always happen at the same time of day?
- Is there a common consequence, for example, is the individual always taken to his seat?

Once the behaviour has been analysed it can be easier to think about how best to manage the situation, for example, can Tom use something to signal that he is going to the kitchen corner? Can he

be diverted at that point? Might there be a more effective consequence than repeatedly returning him to his seat?

**Social Stories** Social stories can sometimes be a way of helping a child to think through a better way of managing a situation. In these, there are 4 main elements:

- **Descriptive** This part describes the situation – who was involved, possibly where etc
- **Perspective** This part gives a perspective of the situation – maybe the perspective of the person or maybe the perspective of other people involved in the situation
- **Directive** This part gives a statement about what the child will **try** to do or **can** do should the situation rise again – not something that they definitely will do as this has implications of failure should it not happen
- **Control** This part gives the person control over the situation, maybe something that will help them to remember the information in the social story

Social stories can be written in different formats to make them accessible over a wide range of age and abilities, using photos, pictures and symbols to aid understanding. For children with fragile X they are best written in the third person as shown below.

Alex hit Tom. *Description*

This made Tom and Alex sad. Tom was hurt. Tom cried. *Perspective*

If Alex is cross with Tom, he can say  
“Leave me alone” *Direction and Control*

This will not hurt Tom. *Perspective*




Social stories, accompanied by pictures or photos, can let an individual know about a particular new event, for example, going to the hairdresser, going to the dentist, going to the super market.

				
<b>Tom and mum go in the car</b>	<b>Tom and mum go to the shop</b>	<b>Tom and mum buy bread and milk</b>	<b>Time to pay</b>	<b>Now it is time to go home</b>

**Star Charts** Some children can be encouraged to behave in a particular way if they get a reward. For some children this reward will need to be immediate. Others will be able to work to a star chart. Every time the desired behaviour occurs, the child is awarded a star and, when they have collected a certain number, the reward is given. The star chart can be drawn to make it clear how many stars are needed before the child can have the reward.

However, with some children the star chart can be counter-productive in that it may raise the child's anxiety levels if they fear that they are not going to be able to rise to the occasion.

**Joe is trying to come back into class after play by himself.**

**When Joe gets 10 stars he can play with Thomas for 10 minutes.**



## **SOCIAL ISSUES**

### **1. Particular Characteristics**

Typically individuals with fragile X are friendly, interested in social engagement, enjoying the company of familiar people. However, many can be socially anxious, particularly in large gatherings or when meeting new people. Some can also be shy or have limited social understanding. They may not know how to negotiate with peers and prefer familiar people and routines. Many individuals with fragile X can also be very sensitive to the feelings of others and able to pick up when others are feeling low or upset.

### **2. What can help?**

- Many schools have buddy systems. These systems can be usefully employed with children with fragile X, particularly at playtimes

- Role play can be a successful tool to teach confidence. This involves teaching an individual how to manage a particular situation in a known, safe environment and then moving the role play activity into real life such as learning the words to use and sequence of buying something at home or at school and then reproducing this sequence in the shop. Role play also helps to keep the context of the skill being learned more meaningful
- Social stories can help an individual learn what to expect and the series of events in a new situation
- To maximise independence in adult years, it can help to take small steps to this during childhood years, for example, by joining children's groups like cubs

## FEMALE ISSUES

### 1. Particular Characteristics

The situation with females with fragile X is more complex. They have 2 X chromosomes and so, to some extent and in varying degrees, the "non fragile" X can compensate for the fragile X. Hence girls are usually more mildly affected than boys and some have no learning difficulties. Nevertheless, there are some girls who are more severely affected and who share all the characteristics already discussed in this booklet. Approximately 60% of girls with fragile X will have a learning disability.

- Generally, girls are more likely to show particular social, emotional and communication difficulties
- They can have problems organising their thoughts and planning ahead
- During a conversation females with fragile X may shift from one topic to another or they may blurt things out without stopping to think about what they are saying. Speech may also be overly frank and direct. They may have problems



with comprehension in terms of reading between the lines and generally interpret language literally

- They may have difficulty picking up social signals (verbal or otherwise) when trying to join in. This can make it difficult for them to make friends, despite an eagerness to do so
- Girls with fragile X, with or without learning difficulties, can suffer from extreme shyness in social situations, especially unfamiliar ones
- They may be oversensitive to perceived rejection or criticism
- They may have difficulty seeing the consequences of their own social behaviours
- Many will experience problems working in a group

Problems with Maths can be a particular feature of some females with fragile X and can appear later, as the concepts being taught become more complex. For girls who do have problems in this area, it can be helpful to concentrate on basic mathematical skills needed in everyday life, rather than persist with concepts that they prove unable to grasp. Girls who do not exhibit difficulties with Maths should still be taught the full Maths curriculum.

## **2. What can help?**

The main issue for teachers is that awareness of these sensitivities needs to be taken into account when supporting them to develop socially and academically.

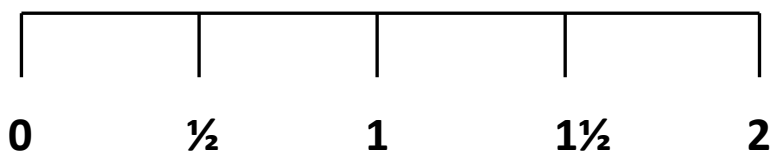
### **Early Intervention**

When they are young, it can help to talk to girls about the world around them, what is going to be happening during the day, what they need to take to school. Getting them to remember a sequence of events can be the beginning of developing their organisational skills e.g. remembering what they need to put in their school bag, what they will be doing after school. It can help to read books to

young girls and then to talk to them about the book, encouraging them to look at the picture to see what is happening. Providing opportunities for learning pre-Maths skills is also useful – sorting, counting out the knives and forks for the family at dinner time etc.

### **Maths work**

Visual methods of teaching Maths and the use of concrete materials tend to work better, for example, a number line to teach fractions plus other visual methods already covered in the section on Maths.



### **Group Work**

Whilst girls with fragile X may find group work difficult, it is important that opportunities to work in this way are still available. Careful thought will need to be given to group dynamics so that the girl with fragile X has the opportunity to interact.

### **Help in the Social Environment**

Role playing situations can be useful so that girls learn how to manage a particular situation or manage a new environment such as role playing what to do if they are lost. Friendships often work better with other quieter girls and it can help to encourage girls to participate in activities outside the home environment. Many girls with fragile X will find choice and decision making difficult. When the decision to be made is not of critical importance, a simple strategy like flipping a coin can be helpful, for example, to decide what to order in a restaurant.

## THE WIDER WORLD

The longer term aim of education is to establish for children a place in society. We need to keep that perspective as we design and develop aims for the learning and development of people with Fragile X Syndrome.

## THE SOCIETY'S BOOKLETS

are available **FREE** to Fragile X families, carers and individual professional enquirers.

- Leaflet "WHAT IS FRAGILE X?"
- Guide: "An Easy Read Guide to Fragile X Syndrome For Parents"
- Booklet "FRAGILE X : AN INTRODUCTION"
- This booklet, "FRAGILE X SYNDROME: AN INTRODUCTORY GUIDE TO EDUCATIONAL NEEDS and how they can be met"
- Booklet "FRAGILE X SYNDROME: MALE CARRIERS OF FRAGILE X"

## FURTHER INFORMATION ABOUT FRAGILE X

For more information please contact The Fragile X Society (full details given on the back cover of this booklet). The Fragile X Society has a number of publications describing specific aspects of fragile X including:

- Educational approaches
- Speech and language
- Behaviour
- Adolescence and adulthood
- Genetics of Fragile X
- Sensory issues
- Carrier issues
- Girls and women with Fragile X
- Welfare benefits
- Health issues

## THE SOCIETY'S DVD: FRAGILE X SYNDROME

"Fragile X Syndrome" awarded the British Medical Association's Bronze Award for Educational Merit.

This 20 minute documentary video costs £7.50 (inc. p&p) from the Society. It explains the inheritance patterns and features and behaviours of Fragile X and gives examples of intervention and teaching strategies.

## THE FRAGILE X SOCIETY

was formed in May 1990 and our aims are to:

- provide support and information to Fragile X families
- raise awareness of Fragile X Syndrome
- encourage research into all aspects of Fragile X Syndrome

We achieve these aims through our

- National Support and Information Service
- Newsletters, publications and DVD
- Conferences, talks and media campaigning
- Arranging for our family members to take part in research

## MEMBERSHIP OF THE SOCIETY

is FREE to Fragile X families and carers and we welcome as associate members those with a professional interest in Fragile X.

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