

## COMPLEX LEARNING DIFFICULTIES AND DISABILITIES RESEARCH PROJECT (CLDD)

### FRAGILE X

#### What is Fragile X Syndrome?

Fragile X syndrome, like Down syndrome, is caused by one particular chromosome, known as 'chromosome X', appearing to be breaking but is not quite separating. Sometimes, children with fragile X will have features which may include a large head with a long face, prominent ears, flat feet and a curved spine.

#### **Strengths** may include:

- expressive language
- a good vocabulary
- short- and long-term memory for information that interests them
- a good visual memory recognising and understanding how others are feeling
- being friendly and helpful
- being curious, with a good sense of humour (particularly boys).

#### **Difficulties** may include:

- eye problems, such as a squint or 'wobbly eye' (strabismus)
- ear infections (eg 'glue ear')
- outbursts and even aggression in boys
- social anxiety issues which can lead to avoiding eye contact or hand-flapping for example
- speech may be hard to follow as it comes in short bursts with a lot of repetition
- repetitive use of language; wanting to talk about favourite topic whether or not it is appropriate
- gross and fine motor difficulties mean that students have difficulty with handwriting, dressing, manipulating tools and eating
- integrating information from different senses, such as ignoring noise when concentrating on work
- being sensitive to touch, so may not like messy activities, washing hands, or even being touched
- oral sensitivity can lead to not liking the texture or taste of certain foods or cutlery
- being sensitive to smells can provoke a strong reaction.

**Girls** with fragile X syndrome may struggle to organise their thoughts, plan ahead or shift between topics. They are likely to be very shy and anxious in social situations, not always picking up signals as to how others are feeling, and reacting badly if they think they are being criticised. This affects their self-esteem, and their ability to make friends, however much they want to.

**Boys** may have language delay, constantly repeating the same words or phrases, muddling up their ideas and having problems with turn-taking. They may find it hard to remember abstract ideas, including concepts to do with maths, and have difficulty concentrating.

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#### Helping students with fragile X

The following approaches may be helpful:

- 1 Instructions given directly to individuals may be better received by sitting or standing alongside students, rather than directly in front of them. This avoids too much eye contact, which some of these students may find distracting or difficult to cope with.
- 2 Give small chunks of information at a time, particularly when dealing with abstract ideas. Use their verbal skills by talking about new concepts in contexts they will understand. This will help them to remember what they have learned and offer meaning to the concepts.
- 3 They may understand better when they are given the whole picture of what they are learning, rather than breaking things down into small steps. For instance, when learning to read, they may respond to building up a sight vocabulary through learning whole words, rather than using phonics, which requires abstract thinking and good sequencing skills.
- 4 Using visual aids in teaching (pictures, photos, symbols, diagrams, maps), combined with making tasks practical and hands-on, will be easier for them to understand than detailed spoken instructions.
- 5 ICT based learning can be helpful as material is delivered visually, with an instant response to action, while interaction with others is reduced.
- 6 Tasks need to be made very clear, achievable and not to last too long. This will make learners more prepared to tackle them and boost their self-esteem.
- 7 Students will benefit from a structured and predictable routine, within which changes are kept to a minimum.
- 8 For sensory integration difficulties, massage, use of weighted blankets or jackets, or wearing backpacks may help those who feel comforted by pressure. Activities such as hiking, rolling, gardening, or activities involving the sense of smell can help maintain levels of arousal or calm, depending on each students' particular difficulties, needs and preferences. See an occupational therapist for further direction.
- 9 When out in the community, it may be necessary to have activities that will keep them calm, so that they can cope with being in public places.
- 10 Lots of praise, and maybe a reward system, may boost self-esteem and focus on the positives and strengths the students have, rather than focusing on their difficulties