

Child With Fragile X Syndrome

Education When Teaching Me:

- I don't like being centre of attention
- give me compliments in 3rd person
- use incidental learning
- include me in small groups & instruct my peer
- prompt for answers rather than use open ended sentences
- sit beside me rather than in front of me

Think "INDIRECT"

Prepare for transitions

- give 10 & 5 minute prompts
- let me go first or last
- use social stories for routine changes
- provide purposeful errands

Encourage me to be calm by

- sound
- light
- textures
- taste
- smells that provoke hyper-arousal so it's hard to concentrate

- integrating "heavy" work
- providing vestibular input
- using visual timetables & calendars
- give me praise when I am successful
- manage anxiety by giving me choices
- using fidget toys and sensory gadgets

Teach to my strengths

- use visual cues
- make learning fun
- let me help
- encourage providing emotional support to others
- use modelling
- embed academics in practical tasks
- Instructions are best given in short sentences
- assessment should be context based
- don't give me busy worksheets
- keep tasks and materials organised to help maintain my focus
- use my peers as teaching models
- use social stories

Give me lots of breaks

- keep tasks brief
- keep breaks short
- keep moving

Challenges I find it difficult to:

- managing my time
- planning things / getting started
- find and organise information
- regulate my emotions
- concentrate and focus on tasks
- be flexible in my thinking
- find the words to say what I am thinking & feeling
- look you in the eye
- deal with transitions or changes in the routine
- learn abstracts / conceptual learning
- do well at tests
- do things sequentially
- participate in team sports due to low muscle-tone & missing social cues

Strengths I am good at:

- imitating others
- remembering things that happened ages ago (long term & incidental memory)
- concrete and relevant tasks
- completing repetitive tasks
- doing things for myself (life skills)
- remembering entire words
- following routines
- vocabulary in things I'm interested in
- reading facial emotion
- checking off tasks as I complete them

Personality I am:

- friendly & social
- helpful to others
- generally happy
- funny & have a good sense of humour

Genetically

- Fragile X is the most common known inherited cause of developmental disability - for both girls and boys
- I have a mutation on my X chromosome with a repeat sequence > 200
- If I am a boy, I am probably more affected than my sisters because I have only one X chromosome

Developmentally

- speech and language are almost always affected.
- my understanding of speech is significantly higher than it first appears (receptive language is better than expressive)
- chewing, sucking and blowing can help to increase mouth muscle tone

Context Having FXS means that I:

- am more likely to have a narrow face, high forehead & prominent ears
- my joints are hyper-extensible
- have flat feet
- have low muscle-tone
- more likely to get ear infections
- may have epilepsy

Physically

Learning Style I learn best :

- visually
- by copying others
- doing activities I find relevant
- doing many things simultaneously (divergent)
- by learning the whole, not the Parts
- learning the whole word by sight (not phonetics)
- when you use backwards (not forward) chaining
- using checklists to show progress toward a result
- I like to complete things rather than answering a direct question
- achieving skills in small, achievable steps
- make maths concrete (visual-based)
- if you relate learning goals to things I am interested in

Behaviour Sometimes I:

- get overwhelmed with sensory stimuli
- have a meltdown
- get stuck in the details
- want things to be too perfect
- don't always process what I hear
- become stressed if you force eye-contact
- look away if you look at me
- flap or bite my hands
- am anxious
- may be aggressive or injure myself
- may have ASD and/or ADHD
- may need to spend some time in a quieter area if am in a busy environment such as in school assemblies
- become hyperactive and restless
- don't like being the centre of attention
- get easily distracted
- am not badly behaved but may become restless when I get anxious or uncomfortable
- copy bad behaviours or language
- am a fussy eater and have strong likes / dislikes
- have automatic fear / fight / flight responses

Source:

1. **Living with Fragile X** (Braden, 2015) <https://www.fragilex.org.au/fragile-x-disorders/fragile-x-syndrome/living-with-fragile-x/employment-opportunities/>
2. **Top 10 Things to Know about the FXS learning style** (Yankowitz, 2020) <https://www.fragilex.org.au/back-to-school-resources-for-teachers-on-the-fragile-x-learning-style/>
3. **Fragile X Syndrome: Part 1. Medical Observer** (Cohen et al, 2012)
4. **An Introductory Guide to Educational Needs** (The Fragile X Society UK, 2016) https://issuu.com/www.fragilex.org.uk/docs/fragile_x_syndrome_-_an_introducor
5. **Daily Living Skills & Learning Strategies** (Braden, 2020) <https://www.youtube.com/watch?v=SFidVVR7lyc>