

Education Strategies for Fragile X Syndrome

Anita Nicholls



Outline

- What is fragile x
- What to teach
- Setting a goal
- Strengths and needs
- Strategies
- Anxiety
- Problem solving
- Apps

Ben & James



Video: Faces of fragile x

- National Fragile X Foundation
- Is there anything in the video that reminds you of a fragile x child that you know?

Challenges

- Auditory processing
- Abstract reasoning
- Sequencing
- Attention
- Impulsive
- Anxiety

Strengths

- Visual processing and memory
- Simultaneous processing
- Copying/mimicking
- Computer skills
- Strong interests
- Innately social
- Sense of humour
- Likes routine



What to teach

- What parents are most worried about
 - Communication
 - Social skills, having friends
 - Functional skills/life skills
 - Behaviour
- Marcia Braden
 - Attention
 - Impulse control
 - Problem solving
- Setting goals for themselves

What new skill or activity would you like your child to achieve

- 10 minutes sharing with persons sitting next to you. Try to be specific
- Choose something that you can work on at least three times per week or revisit learning regularly

Strategies

- Visual strategies – sign language, model what to do, use a real object, video, script, book, social story
- Technology
- Special interests
- Humour
- Role play
- Routine
- Make it easier – backward chaining



Strategies

- Real experience/hands on/concrete examples
- Hook learning onto what is already known
- Use close activities
- Use Incidental Learning
- Multisensory approach



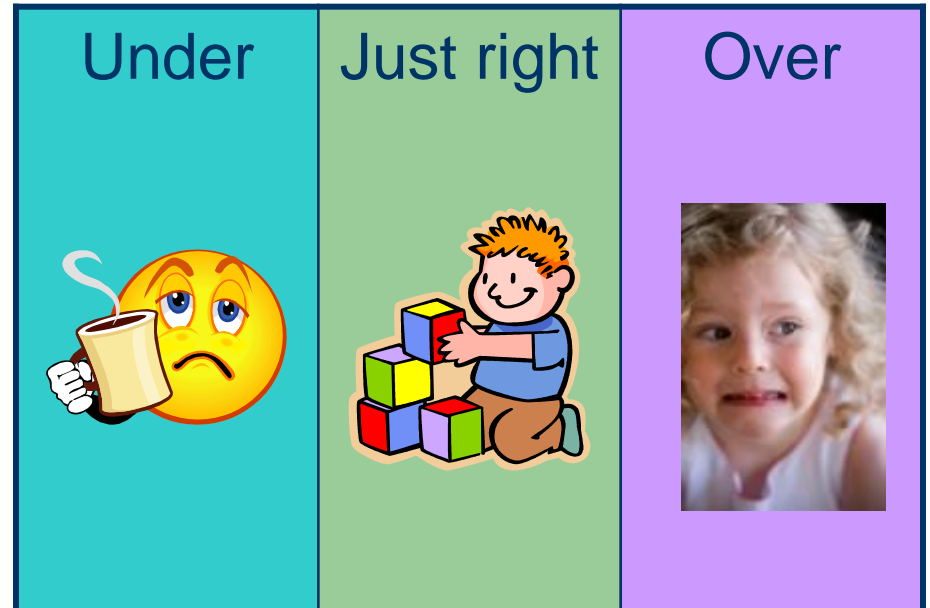
Anxiety

The experts say:

- “Most prevalent and troubling characteristic of FX”
- “Decreases ability to think clearly and adapt to situations”
- “Must be directly managed as a part of life at school, work and home”

Anxiety/Dysregulation

- Our level of arousal affects our ability to perform any task
- Research shows that fragile X children's normal arousal state is higher than their neurotypical peers



Strategies to reduce anxiety

- Know what it looks like
 - Avoids eye contact, make an excuse to leave or just runs away or hide, loud voice, rapid repetitive speech, swearing, moving around quickly, red face, red ears, challenging behaviour
- Know what the triggers are
 - Transitions, change, direct attention, social communication, noisy environment, new tasks

Before Strategies

- Act before the explosion
- Desensitise
 - Cognitive behaviour therapy
 - Teaches coping strategies - breathing
 - Very gentle desensitisation
 - Sensory diet



Before Strategies

- Support transitions
 - Make them more predictable
- Give the child a task
- Breathing exercise
- Medication

After strategies - a controlled burn

- If angry or very stressed
 - Remove, Relax, Refocus
 - Increase space
 - Decrease talk

Attention

- “If attending behaviour is forced in a direct way, the anxiety will become so intense that the child avoids the task by acting out”
- “Develop attention through a desensitization program. As the child becomes use to interaction, the child habituates behaviour and responds naturally”

Marcia Braden, Curriculum Guide

Attention

- Build on social behaviour
 - Sharing, pointing, turn taking, cooperative play/work
- Make it interesting, meaningful
 - special interest, computers, music, humour, real tasks, experiential learning, incidental learning from peers
- Keep tasks short, organised and provide a break



Attention

- Provide for sensory needs
 - Chewy tubes
 - Movement breaks
 - Weighted blanket
 - Heat
 - Change sitting position
 - Swiss ball



Direct communication

- Use visual information
- Parallel conversations
 - Let the student overhear you tell another person the information you want them to act on
- Mean what you say
- Authoritative, calm, relationship
- Provide choice
- Use action to test knowledge



What strategies do you use to reduce your child's anxiety?

- Thinking about the goal you set at the beginning – what strategies will you need to use to reduce anxiety

Challenges

- Executive functioning
 - Pulling information together from past events and relating it to the present
 - Seeing the wood from the trees
 - Planning
 - Thinking flexibly
 - Problem solving – using information about the past to solve a problem

Problem solving

- Observe what they are having difficulty with – then provide the support they need
- Notice the response to novel tasks – introduce carefully as required

Increase impulse control

- Learning to wait
 - Use sign, role-play situations, social stories, give the child something else to do
- Request help
- Stop, think, do

Problem solving

- Reinforce solution finding
 - Teach child to set own goals
 - Ask questions
 - Search for answers
 - Teach the importance of practice
 - “Stop! Find another way”
- Visuals, routines, incidental learning from peers

Reading

- Whole word rather than phonics
 - Logo reading, Clicker
- Word families
- Text colour
- Use a card to help visual tracking
- High interest

Writing and fine motor

- Magic Caterpillar - consistent verbal or visual cues
- Technology
- Stickers to correct quickly
- Word shape
- Routine
- Practice

Maths

- Maths is often difficult
- Use concrete materials
- Teach functional maths – money, time, weight
- Use experiential learning and incidental learning
 - Which is the shortest queue at the check-out?
 - Which All Black wears No. 7?
 - Cooking

Which App?

- What's your goal?
- When will it be used
 - Do you need to introduce it
- Will the child like it?
- Bug free
- Rewarding
- Adaptable
- Letter school
- Write My Name
- Clicker Sentences
- Proloquo2Go
- iWordQ
- iCan Count Money New Zealand
- Model me going places 2
- Bob books
- Book making apps – Book Creator
- Video editing app – imovie
- Apps with known movie or TV characters – Toy Story
- Story ideas
- Quiz games
- Jokes
- National Fragile X Foundation
- Nurdle Time

Links

- Fragile X New Zealand
 - www.fragilex.org.nz
- The National Fragile X Foundation
 - www.fragilex.org
- Marcia Braden
 - www.marciabraden.com
 - You Tube - Let's Talk Behaviour and Fragile X