

The Fragile X Society

What I tell teachers about fragile X

Presentation by Charles Gibb, Educational Psychologist, The Educational Psychology Practice, Edinburgh to the Fragile X Society's National Family Conferences in Birmingham 2002 and Stirling 2003

Email: tepprac@aol.com

What is fragile X?

Fragile X is the most common identifiable cause of inherited learning difficulties. It shows itself in a wide range of difficulties with learning and in developmental delay.

Frequency of fragile X

Fragile X affects an estimated one in 4000 males and one in 8000 females.

Features which may be associated with fragile X

Behaviour

- Overactivity
- Impulsivity
- Distractibility
- Mimicry

Speech and Language

- Cluttered speech
- Litany-like phraseology
- Dysarthria, dysphasia, echolalia, palilalia
- Jargon, perseveration

Intellectual

- Better verbal skills than reasoning skills
- Reasoning is relatively easily diverted
- Difficulty grasping number ideas and processes
- Relative strengths in reading from the page

Emotional Development

- Sensitive to criticism or rejection (especially girls)
- Inclined to react badly to minor upsets
- Need for security and reassurance

Physical

- Some children (especially post pubertal) may show particular facial and other characteristics. But most look the same as other children.

The range of fragile X effects

- All the way from virtually indiscernible to Severe Learning Difficulties.
- Most children are in the mild to moderate category.

- A diagnosis of fragile X does not tell you what a child is like, what their educational needs will be, what any of their other needs will be, or what resources or techniques will be required to meet them.
- However, diagnosis is vitally important because of the gene's heritability and the consequences for the family.
- It is also essential for framing understanding of the problems.
- From a parent's point of view, it is good to know what ails your child.

Can fragile X be cured?

No, it can't. But the answer is often confused with the answer to a different question. That is, can anything be done to bring about new learning and development? The answer to this is yes. While fragile X means we might expect certain things, it doesn't mean we have to accept them.

What are the implications of fragile X for education?

The general issues arising centre around the following:

- Resources
- Curriculum
- Mainstream vs. Special Education
- Working with Parents
- Staff Development & Training

Comparisons with other conditions in education

Take this list of conditions:

- Fragile X
- Cerebral Palsy
- ADHD
- No condition
- Visual Impairment
- Aspergers Syndrome

Now try to answer these questions on the basis of the diagnosis:

- Which is going to find learning most difficult?
- Which will need help from a behaviour support unit?
- Which will need most resources?
- How should responses to their tantrums differ?
- Which will need an assessment from an Educational Psychologist?
- Which will go to special school?

You will see it is not possible to answer any of the questions.

So what are the advantages of a diagnosis?

- Safety
- Appropriate medical treatment and understanding
- Possible medical prognosis
- Access to support groups, systems and others in the same boat
- Encapsulates and focuses parents concerns

- Resets the frame within which the child is perceived
- Heritability issues
- Access to literature and a body of knowledge
- Acknowledgement of root cause

Issues that can arise from a diagnosis

Some people cannot resist the notion that a diagnosis tells them everything they need to know about an individual. They then assess and intervene on the basis of what “a fragile X child” should be like rather than what it is like. They ignore observed performance in favour of expected performance.

Since fragile X is a medical condition it is tempting for some to assume that working with it in education is a medical procedure. Some medics compound this by expressing views on topics about which they know very little.

Sometimes, diagnosis can be used in an exculpatory way. That is, people can feel absolved of responsibility to take action because an irremediable root cause lies within the child.

There is a potential for conflict if educationalists appear to challenge a medical diagnosis. Sometimes they can be perceived by parents as doing so even when only challenging ill-informed advice about the consequences of fragile X.

Asserting educational expertise

Here are some questions I ask teachers on this subject. There are in this case correct answers and they are given in brackets after each question. Should we:

- Question the relevance of a medical diagnosis to the educational process? (no)
- Debate whether or not a “condition” really is medical? (no)
- Work with the medical diagnosis within the educational context? (yes)
- Expect and seek medical specification of a child’s educational needs and appropriate educational intervention? (no)
- Welcome a medical role in specifying medical needs? (yes)

How do you assess the educational needs of children with fragile X?

You look at them and see what they do in context just the same as for children who do not have fragile X. Similarly, you use all the information you can get from parents and enlist their help.

Learning

- Curriculum referenced assessment
- Structured teaching with clear steps
- Straightforward methods
- Loads of praise for getting it right
- Use the child’s strengths
- Don’t be afraid to insist
- Teaching that is one step ahead
- Avoid overwhelming the child

Behaviour

- Don’t make demands you can’t or won’t enforce

- Nip bad habits in the bud
- Set realistic and relevant objectives
- All adults should be as consistent as possible
- Set positive objectives for change

The Classroom

- Consistent layout
- Calm, quiet and ordered
- Established routines
- A personal workstation
- As many normal experiences as possible

Teachers' experiences with fragile X

Activities liked and disliked by children with fragile X

There is clear preference for practical work and being active while engaged in a concrete task.

- PE and swimming
- Music and singing
- Play
- Cookery
- Computer
- Trips
- Stories

Activities disliked by children with fragile X

Strong dislikes are for situations rather than subjects, especially when these involve large groups.

- Dinner time
- Assembly
- Play time
- Whole class story time
- Circle time
- Class discussion

The only subject dislike reported by teachers is related to fine motor skills – e.g. writing.

Time of day

- Mornings are best for brain work
- Children need a settling-in period in order to carry out rituals and routine
- Pushing them before this is often futile and might cause distress and inappropriate behaviour

Classroom environment and organisation

Teachers find they get better results where:

- The classroom is quiet, calm, orderly with minimum disruption and noise
- The classroom is as free as possible from distraction in terms of visual displays, sounds, sudden events
- There are clear and consistent routines
- The child has own space
- Other children are well behaved
- There is enough flexibility for the child to move around periodically

Behaviour

The behaviour teachers find most difficult to cope with is:

- Aggression to self, others and the environment
- Not staying in seat
- Extreme reactions to change
- Distractibility and need for 1:1 attention in some work
- Habits such as hand-flapping and making noises

Behaviour management and fragile X

Tips

- Tell the child what you want and don't want (don't leave them guessing)
- Don't threaten or put down
- Back up words with actions
- Don't excuse bad behaviour on the grounds of fragile X
- Get your own way without getting over anxious in the process
- Express both good and bad feelings constructively

Barriers

- Low expectations in the adult about his or her ability to effect change, or of the child's capacity to change
- Impossibly high expectations
- Uncertainty in the adult, or in the child about what is expected of him or her
- Over reliance on outside experts. The only way to bring about change is in situations where the events occur, and led by the adults who are on the spot

Do's and Don'ts for fragile X in Education

Do

- Value what parents say
- Be aware a diagnosis has huge implications for them
- Take their worries and questions seriously
- Accept responsibility for the teaching and learning process
- Be positive and open
- Be confident about your own expertise
- Be clear and jargon free
- Keep records
- Accept a diagnosis of fragile X
- Do the things you said you'd do
- Return communications
- Be clear it's a joint process

Don't

- Appear to imply a diagnosis is irrelevant
- Deny expertise in educational matters
- Be negative about a child's attainments and prospects
- Produce long verbal or written reports
- Use jargon
- Make excuses

- Imply there's not much you can do
- Be an advocate
- Hand over educational authority to medics or paramedics
- Appear to dismiss medical opinion on medical matters

The Fragile X Society

- Established in 1990
- Very active, practical, supportive
- See teachers, schools and LEAs and parents as the same side. Do not aim to be an advocate for any one against another.
- Keenly interested and supportive in genetic and other medical research. Aware that this is different to the social and educational issues presented in the classroom.
- Not to be regarded as a pressure group or as otherwise defensive
- If ever you have occasion to seek support from the Society you will get a high-quality and practical response – free in the bargain

References

Gibb C (1992) The most common cause of learning difficulties: a profile of Fragile-X Syndrome and its implications for education, **Educational Research** Volume 34 Number 3 Winter 1992

Gibb C, Holliday J (1992) Fragile-X Syndrome and Education, *British Journal of Special Education*, Volume 19, No 2 June 1992

Saunders S (1999) Teaching Children with Fragile X Syndrome, *British Journal of Special Education*, Volume 26, Number 2 June 1999

The Fragile X Society
 Rood End House
 6 Stortford Road
 Great Dunmow
 Essex
 CM6 1DA
 Tel: 01371 875100
 Email: info@fragilex.org.uk
 Website: www.fragilex.org.uk

The Fragile X Society is a registered charity no 1003981.