

# Impact of fragile x syndrome on learning



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A critical understanding and application of creativity, inclusivity, pedagogy and practice in relation to supporting a learner with the Protected Disability: Fragile X Syndrome.

Abstract

*Working within a classroom which includes a pupil with Fragile X Syndrome encouraged the consideration of approaches which could potentially improve his inclusion in the classroom as well as stimulate his interest and engagement in lessons and thereby improve the learning for this pupil or others with similar disabilities.*

*Existing legislation and policies both at an International and National level ensure that guidelines on provision for inclusivity, equality and diversity are in place. This alongside school policies and the application of 21<sup>st</sup> Century teaching strategies and support, as used during the micro-teach session, could create a learning environment which recognises the importance of the lifeworld and uniqueness of the learner with Fragile X Syndrome and the experiences his disability provides.*

*By using differentiation strategies that are adapted to the pupils' own characteristics, ability, interests and background, this could increase levels of interest and engagement for the pupil and result in a more inclusive and improved learning outcome.*

This statement will discuss the critical understanding of the lived experiences of a learner with Fragile X Syndrome. and how this impacts the learners' ability to learn, together with how the application of creativity,

inclusivity, pedagogy and practice can support a learner with the protected characteristic of disability including Fragile X and other similar disabilities.

According to The Fragile X Society (Fragilex.org) 'Fragile X Syndrome is the most common known inherited cause of learning disabilities, affecting around 1 in 4000 males and 1 in 8000 females. It can cause a wide range of difficulties with learning, as well as social, language, attentional, emotional, and behavioural problems'.

The United Nations Educational Scientific and Cultural Organisation (UNESCO) states that 'every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning' (1994, p8). UNESCO goes on to discuss the uniqueness of every child including ability and learning needs but also that the education system should take account of these differing needs. The Salamanca Statement of 1994 acted as a major turning point for inclusive education systems across the world, and described inclusive institutions as 'the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all' UNESCO, (1994, p10).

Within England the National Curriculum inclusion statements for primary and secondary schools include the key principles for inclusion – setting suitable learning challenges, responding to pupils' diverse needs and overcoming barriers to learning and assessment Department for Education & Skills (DFES) (2001b, p47, 62). Diversity was identified as including pupils with special educational needs, pupils with disabilities, pupils from all social and

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cultural backgrounds as well as pupils of different ethnic groups. It was intended to enable pupils to participate in lessons ‘fully and effectively’ to encourage pupil diversity and that pupils learned to appreciate and positively view differences in others DfEE (1999). The Ofsted guidance (2000, p9) sets out key guidelines for school inclusiveness and school inspections include reporting on whether active strategies are in place within school policies for promoting inclusion within schools.

When considering an inclusive approach to pedagogy Davis & Florian (2004, p36) commented on their admiration for teachers who were able to span a considerable range of expertise and knowledge, and were ‘expert teachers who responded to the diversity of learners’ needs found in every classroom’, and it is this understanding of pupil needs that is important for any differentiating strategies chosen for a Fragile X pupil.

According to Imray & Colley (2017, p1) ‘Education needs to be seen as a means of fostering pupils’ opportunities to maximise their potential to do the very best they can and to be the very best they can be’ regardless of their individual level of disability, and adopting a ‘Capabilities Approach’ (Sen, 1992, 1999, 2005, Nussbaum, 2004, 2011). However, the authors accept that their views lack research into the learning

of those with severe learning disabilities but rely instead on their years of practice. For Nussbaum the Capabilities Approach was promulgated as ‘an approach to comparative quality-of-life assessments and to theorising about basic social justice’ (2011a, p18), an approach which is about the potential to make the most of opportunities available to each person and one which is

focused on individual choice and freedom. The view put forward by Freire (1970, p28) states that ‘ no pedagogy which is truly liberating can remain distant from the oppressed by treating them as unfortunates’ and that the solution is ‘ not to integrate them into the structure of oppression, but to transform that structure so that they can become beings for themselves’ (p47) and it is this ethos which should determine the choice of teaching and learning strategies in order to support the independence of a pupil with Fragile X. The learning process itself, according to Freire, should be regarded as a creative force.

The Fragile X Society (Fragilex. org) discusses aspects of functioning to be considered for pupils with Fragile X, and these include intellectual as well as speech and language functioning. Attention deficits are common, and may be seen alongside restlessness, impulsive behaviour and distractibility. The main difficulties are seen in performance skills, in particular numeracy, and in visio-spatial abilities.

Pupils with Fragile X can have ‘ a range of learning difficulties from mild to severe, and effects on boys are more severe than on girls’ Pritchard (2014, p91). Difficulties can be summarised under cognitive, physical and behavioural. Those with Fragile X can share similar traits to pupils with autism; such as anxiety in crowded or noisy places or dislike of direct eye contact, and may find change difficult and are typically more relaxed with familiar regular routines. In contrast, Fragile X pupils are able to read faces and emotions and understand that people have different perspectives and experiences and this is reaffirmed by Garner et al (1999) when discussing this as having ‘ theory of mind’.

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Pritchard (2014, p92) comments that some Fragile X pupils may also have ‘poor motor control and difficulties with speech and language’ or show signs of repetitive speech. The Fragile X Society notes a general sensory sensitivity in Fragile X syndrome, and difficulty coping with incoming stimuli and gaze aversion is common. A useful classroom strategy would be side-on or teaching from behind, to help reduce the potential for anxiety, allowing for social interaction and the pupil can maintain the proximity. In a London study (Turk, 1998) it illustrated that boys with Fragile X displayed greater difficulties with inattentiveness and restlessness than boys with learning difficulties generally. Sequential information processing difficulties and social anxiety can cause behavioural problems and an intervention would be to help an individual to communicate freely and by whatever means, thereby relieving frustration and reducing anger or the potential for disturbed behaviour. In the same way this suggests that learning tasks are presented to Fragile X pupils as a series of specific instructions making it easier to process.

Within the classroom setting a number of pedagogical approaches can be employed using a range of learning styles that would focus on the pupils’ ability, and include the provision of creative and innovative practices to stimulate pupil development. As part of motivating pupils, teachers and support staff could plan work which builds

on the personal interests and experiences of the pupil, and can make use of flexibility in the curriculum to ensure that subjects are relevant to the pupils’ own experience and to develop the curriculum to meet pupils’ individual needs DfES (2003b, p3-5).

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It is important for teachers and support staff to consider differentiating when planning for pupils at different levels, ability and experience, and work set for a Fragile X pupil must be at the appropriate level of difficulty, providing a range of opportunities to the learner by using imaginative pedagogies that involve appropriate scaffolding of learners' efforts (Craft et al, 2007) enabling the pupils' understanding to move forward across the zone of proximal development (Vygotsky, 1983).

Pritchard (2014, p96) puts forward the notion of multisensory teaching, involving the different senses in the process of learning, and that such approaches have been shown to be of particular value for pupils with reading and writing problems, and using tactile, kinaesthetic and learner led activities would encourage a Fragile X pupil to share more of their life experiences with the classroom, in ways which are best suited to them. The Fragile X pupil within my classroom particularly enjoys football and other outdoor activities and readily shares his experience in classroom discussions and project work. Tomlinson (2014) argues that differentiating strategies might shape teaching in five different dimensions including curriculum, process, resources, required learning activities as well as pupil outcome. On the other hand, any differentiating strategies employed need to ensure that smooth classroom functioning is maintained for all pupils. (Roija, 2012).

Creating an environment which is social, stimulating and supportive to learners' motivation and enthusiasm is an important element of creativity according to Collins & Amabile (1999), and to ensure that flexibility and support for independent thinking are maintained and nurtured when teaching. Esquivel (1995) commented that children are naturally creative

and this can diminish unless nurtured by favourable environments. Everyday creativity ' can be demonstrated in any subject at school or in any aspect of life' according to Lucas (2001, p38) and classroom teaching and support should include creativity in order to make learning more interesting and effective for pupils according to National Advisory Committee on Creative and Cultural Education (NACCCE) (1999, p89).

According to Turk & Cornish (1998) those with Fragile X are good at understanding facial expressions and how people are feeling, and that they are usually friendly and sociable even though they may be shy or anxious. Opportunities for collaborative learning and work with others should be included in planning as it can be a stimulus to greater enjoyment and learning and to higher levels of understanding. The social constructivist views of learning and works of Vygotsky and Bruner both refer to the importance of communication and language as a medium for learning, which is heavily influenced by relationships and social engagements. For the Fragile X pupil modelling could also be provided by peers within small collaborative groups. However, guidance may need to be provided to ensure that sufficient time and space is given to the Fragile X pupil to process and organise information in order to contribute in group activity. According to Padgett (2013, p6) ' effective creative learning is a social landscape and that we learn better when we learn together' social settings can include the classroom, but also family, community, and the wider environment.

Classroom support for the Fragile X pupil should allow for a varied approach at different times and allow for choice on the part of the learner, so that they can work with their preferred learning style and within their intelligence

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profile of strengths. (Cropley, 1999) noted that a 'novel' approach to creativity included a choice in both learning activity as well as response style and suggested that learning opportunities given to the learner should arouse curiosity and interest and include levels of learner input, ideally where the learner can be divergent with alternative perspectives. This echoes the approach used in the micro-pedagogy whereby a number of tasks were offered to the learner, allowing for flexibility of interpretation and different response.

The classroom can provide a learner-centred workplace for a collaborative culture, and when discussing 21<sup>st</sup> Century learning Trilling & Fadel (2009) commented that learning projects can deeply engage students in their learning activities and build creative skills, and on-going project work within the classroom can facilitate this. As part of a small heterogeneous peer group the contribution of the Fragile X pupil would be valued without the potential for anxiety in a larger whole class approach. Working within small groups would enable the pupils to work together to maximise their own and each other's learning (Johnson, Johnson, & Holubec, 2008). Indeed, Bellanca & Brandt (2010, p202) state that 'when pupils cooperate together they can accomplish shared goals, provide one another with support, encouragement and

assistance to make academic progress'. However, this approach could lead to disagreement among members of cooperative groups when decisions or agreements need to be made, although according to Johnson & Johnson (1989) this could be considered to be enjoying constructive controversy whilst leading to positive interpersonal relationships, greater social support

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and better self-esteem. On the other hand care needs to be taken in communication with Fragile X pupils who often display ‘cluttering’ a combination of rapid speech and emphasises a need for careful speech and language input and Fragile X pupils may display ‘Echolalia’ (repeating what someone else has said), and peer collaborative groups need to be aware and understanding of this.

By encouraging the use of 21<sup>st</sup> Century tools such as iPads and laptops as well as other information and communication technologies, the Fragile X pupil is able to build upon knowledge, self-directional skills and skills to use these newer technologies whilst working at a pace suitable for their own ability. Bellanca & Brandt (2010, p244) comment on the responsibility of educators to ensure that today’s students are ‘ready to live, learn, work and thrive’ in our global, highly participatory world.

In conclusion, supporting a pupil with Fragile X requires consideration and planning in order to ensure their varying needs are understood. However, the provision of a consistent and predictable routine with a limited number of distractions as well as a behaviour plan in the event of social anxiety would provide the necessary environment for the pupil to engage and thrive in the classroom. By exercising flexibility in the curriculum and differentiating learning strategies by changes to resource, process or learning tasks, it is possible within the classroom to develop skills which are consistent with the pupil’s age, whilst remaining cognisant of their level of skills and abilities when determining assessment rationale.

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