

**Submission
No 278**

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

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Submission to the

**NSW Legislative Council Inquiry into the provision of
education to students with a disability or special needs
2010**

On behalf of the Fragile X Association of Australia (FXAA)

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A. What are Fragile X-Associated Disorders (FXDs)?

Fragile X-Associated Disorders are a group of associated genetic disorders that include:

- Fragile X Syndrome (FXS) - most common cause of inherited intellectual disability, behavioural disorders and speech and language delays that manifest in early childhood in boys and girls;
- Fragile X-associated tremor/ataxia syndrome (FXTAS) - neurological disorder which may set in at age 50 years or over, causing tremors, balance and memory problems, and cognitive decline in pre-mutation males and females; and
- Fragile X-associated primary ovarian insufficiency (FXPOI) - causes irregular menstrual cycles, infertility and premature menopause in pre-mutation females.

If the number of repeats of the FMR1 gene on the X chromosome expands to over 200 then this usually results in the FXS phenotype (full mutation - FM) in males and variable affects in females. There has been no national screening in Australia for FXDs, so estimates are gleaned from various sources both here and overseas. A recent US study shows that rates of FXS may be as high as 1/2,500 for males and females. Thus estimates range from 1 in 2,500 to 1 in 4,000 males and females being full mutation FXS. While FM FXS females may have IQs in the normal range, many are 'affected by the behavioural, emotional, and/of learning disabilities of FXS' (Hagerman, 2008:2).

Individuals with a repeat size between 55 and 200 are described as having a pre-mutation expansion. Expansion of a pre-mutation into the full mutation range may occur during transmission from a 'carrier' mother. Estimates on carriers are also variable but the latest estimates suggest that between 1 in 282 to 1 in 800 males and 1 in 125 to 1 in 200 females fall in the pre-mutation range.

The X-linked pattern of inheritance of the disorder means that females with large pre-mutation expansions or full mutations have up to a 25% chance of having an affected male child in each pregnancy. Carrier males pass the gene to all their daughters.

B. Implications of FXDs for Education (mostly from FXAA website)

Depending on the age, abilities and needs of the child with Fragile X, the facilities provided by the education systems and the wishes of the family, schooling may take place in mainstream classes, special classes in mainstream schools or classes in schools geared specifically for those with special needs.

Considerable research has been conducted in the US, UK and elsewhere as to how children with FXDs learn. There are a number of experts in Australia, including Dr Lesley Powell in Perth. Children with the full mutation tend to experience a higher degree of intellectual disability (though not necessarily in girls) and need much more support than those with the pre-mutation. Full mutation girls may not be intellectually impaired but usually have psycho-social difficulties. Each child varies and schools should cater for individual needs.

Teaching Recommendations:

- Establishing structured routines
- Making careful preparation for changes
- The use of calming techniques and the elimination of distractions.

- Being able to see ‘the whole picture’ of what is going to happen, for example knowing in advance the full schedule for the day’s schooling.
- Placing them with good role models in the classroom, wherever possible, as they are excellent imitators.

Pre-school and school teachers should be encouraged to work with the particular strengths of those with Fragile X.

Strengths:

- They generally have very good long-term memories.
- They tend to learn visually. Use of pictures can be very helpful, and illustrated social stories can assist with behaviour.
- A particular strength of many students with fragile X is their computer skills. There is a wide range of software available, which can assist in all aspects of learning.

To assist in their child’s learning, parents should give teachers as much information as they can.

Weaknesses:

- They have great deal of trouble with abstract concepts, including mathematics.
- They often have attention problems (see Figures below).
- They may become fixated on particular issues.

Ways around these issues can be found if the school environment is aware of FXDs and is supportive.

C. The Fragile X Association of Australia (FXAA)

<http://www.fragilex.org.au>

The Fragile X Association of Australia is a non-profit organisation composed of family, friends, therapists, doctors and carers of people with a Fragile X-associated Disorder. The national association was formed in 2008, bringing together various state and territory support and advocacy groups.

The **overall goal** is to help people with Fragile X to realise their full potential, provide information and support to those people whose lives have been affected by Fragile X, promote acceptance and integration of people with Fragile X into the community and raise public awareness of Fragile X Syndrome.

We aim to:

- (1) promote the detection, relief, treatment and prevention of Fragile X through:
 - Supporting intervention and other programs in relation to Fragile X
 - Supporting research into Fragile X
 - Promoting awareness and education in relation to Fragile X through lectures, meetings, classes, conferences, seminars and the publication of booklets, reports and media releases
 - Advising and lobbying government and other agencies.
- (2) enrich the lives of those who are impacted by Fragile X by offering channels for

educational and emotional support by:

Providing points of contact for families to support and information.
Encouraging mutual support among our members.
Producing and distributing information on Fragile X.
Peer counselling.
Holding information sessions, conferences and social get-togethers.
Producing a quarterly newsletter.

- (3) directly aid people with Fragile X-associated Disorders through any or all of the following:

Medical treatment
Diagnosis and assessment
Counselling
Speech and language therapy
Occupational therapy and physiotherapy, assistive technology support and vocational support
Case management

D. Estimated Prevalence of FXDs in NSW

Professor Laurie Brown at the National Centre for Social and Economic Modelling (NATSEM), University of Canberra is currently calculating data on prevalence rates for Australia. Using ABS data for 30 June 2009, it is possible to extrapolate the number of children with FXDs in NSW.

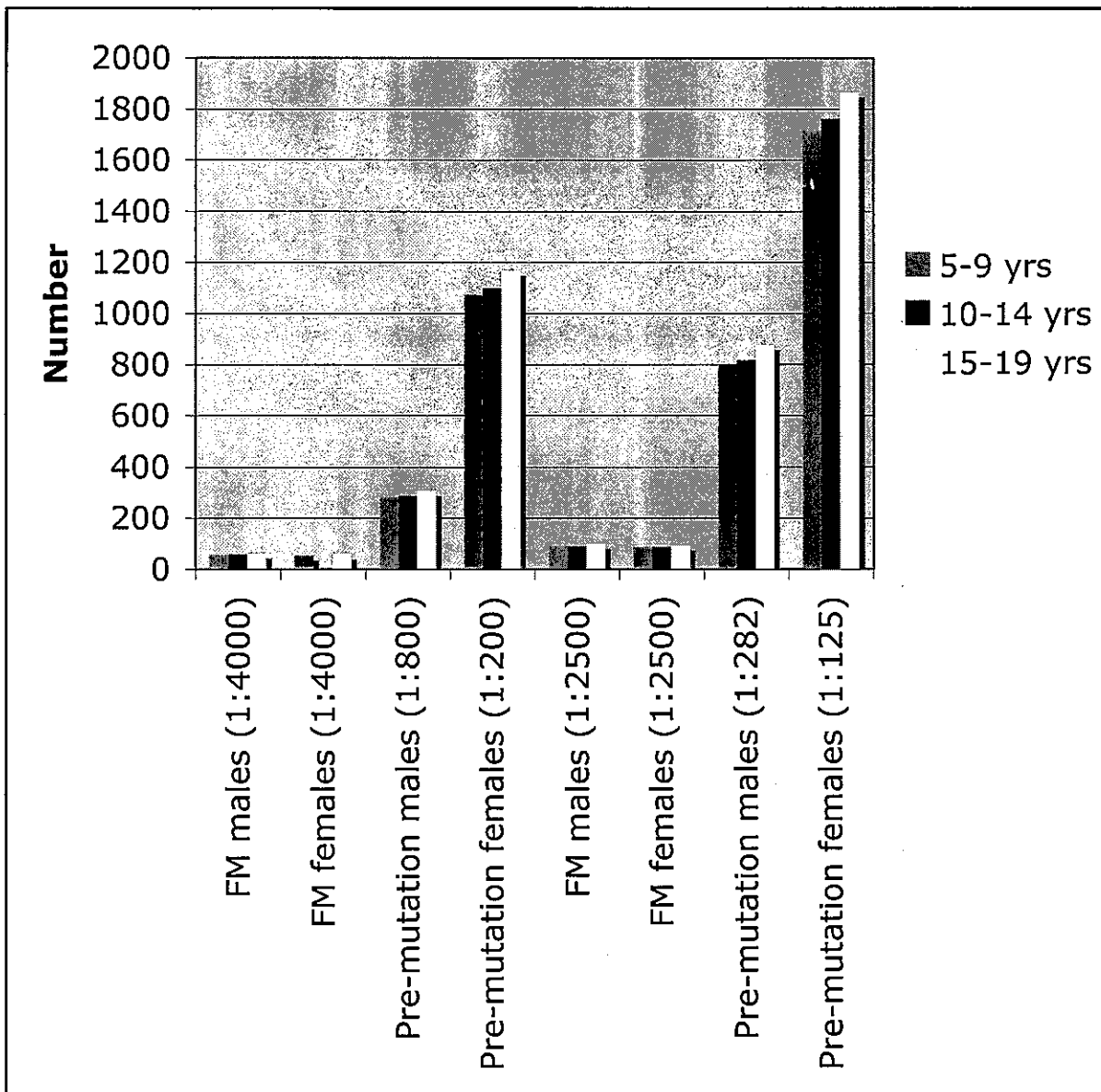
In all age categories, the proportion of the Australian population that reside in NSW is around 32.5%. Using this we can hypothesise that approximately 32.5% of children with FXDs also reside in NSW. In the absence of newborn screening or general population screening there is no information to suggest that there is a variation in prevalence or frequency by state/territory.

In the absence of comprehensive data bases and the fact that many carriers are as yet undiagnosed we estimate, conservatively, that there are 4,565 children aged 5 to 19 in NSW who have a FXD: 344 with the full mutation and 4,221 with the pre-mutation. Full mutation numbers have been calculated using the ratio of 1:4000 for both males and females, and pre-mutation numbers have been calculated using the conservative ratios of 1: 800 males and 1:200 females.

If more recently reported ratios from the US are used, the numbers would be a total of 8,392 children aged 5 to 19 in NSW who have a FXD: 548 with the full mutation and 7,844 with the pre-mutation. These numbers are based on ratios of 1:2500 for the FM in males and females and pre-mutation ratios of 1:282 for males and 1:125 for females.

Figure 1 provides two sets of estimates for the number of children with a FXD in NSW, by age and sex. The four sets of columns on the left hand side are based on conservative prevalence estimates while the four on the right hand side are based on less conservative ratios.

Figure 1: Two sets of estimates of children with FXDs in NSW, by age and sex, 2009



Source: Prevalence estimates calculated from ABS population statistics for NSW, 2009.

E. Characteristics of children with FXDs and co-existing conditions

FX males with the full mutation or pre-mutation have varying degrees of intellectual disability. FX females with the full mutation may have varying degrees of intellectual disability or may have no intellectual disability. Psycho-social issues are also common. The Australian FX survey found the following prevalence of co-existing conditions in full males and females.

Figure 2: Full mutation FXS males (n=111)

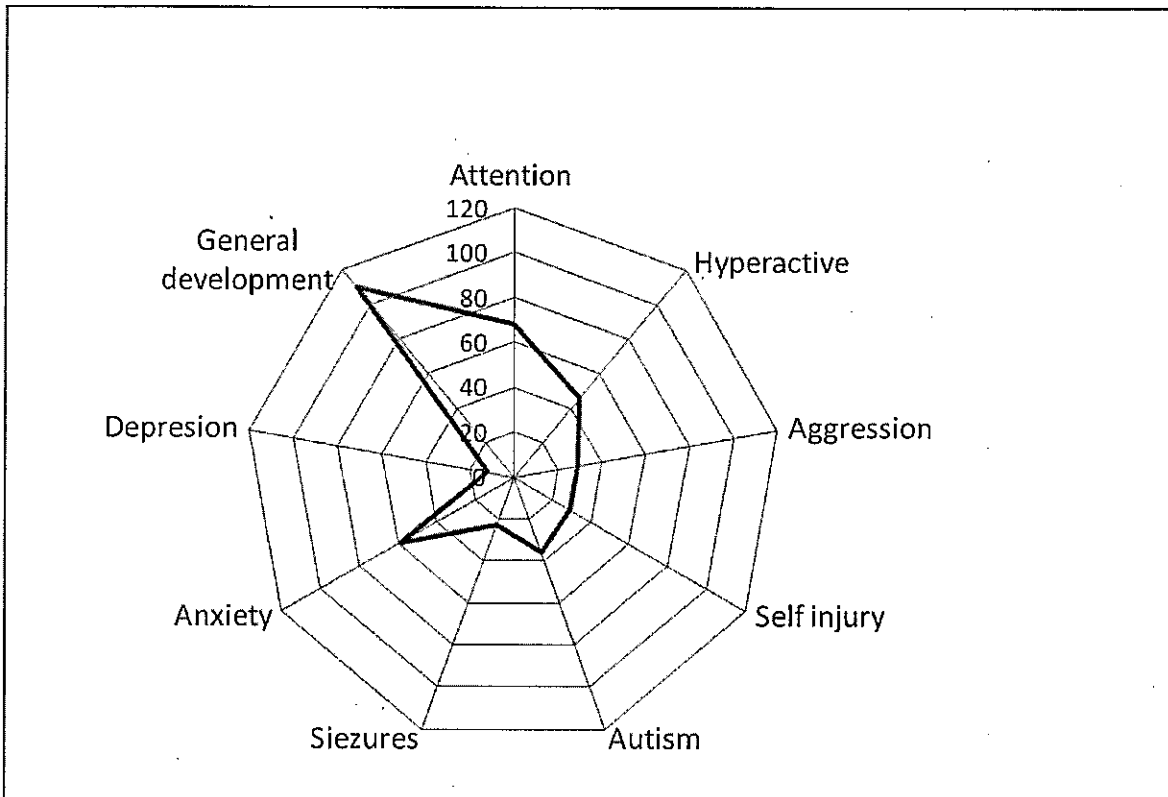
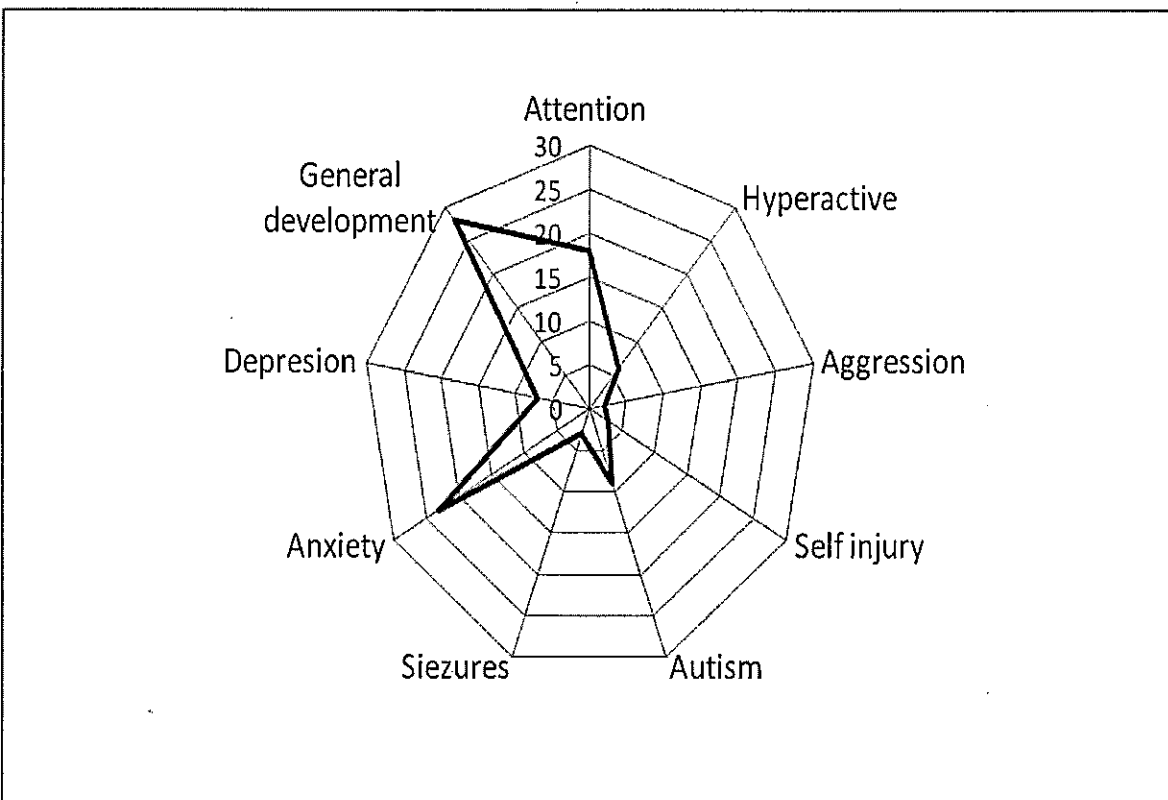


Figure 3: Full mutation FXS females (n=41)



Source: FXAA, Australian FX survey, 2009.

Pre-mutation FX people also experience co-existing conditions. For males, attention problems are clearly most prevalent, followed by problems with general development, autism and anxiety. For pre-mutation females, anxiety is the overwhelming co-existing condition, followed by depression.

Figure 4: Pre-mutation FXS males (n=13)

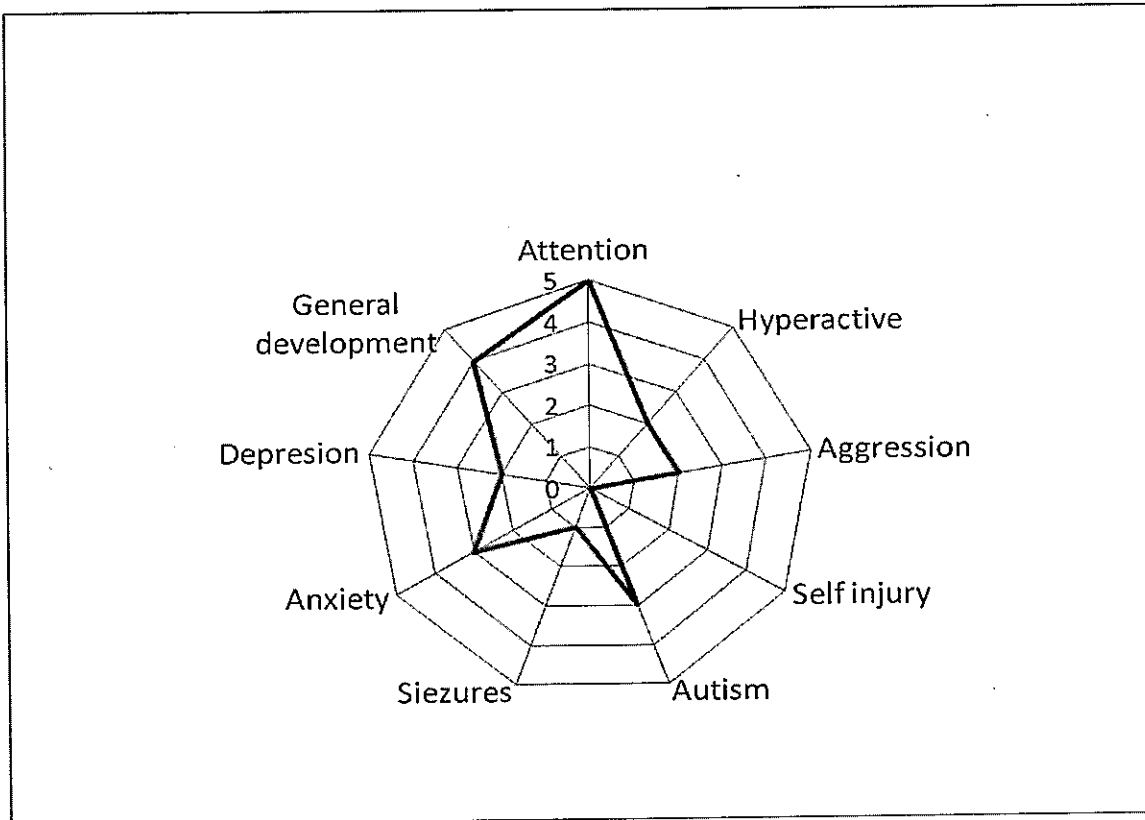
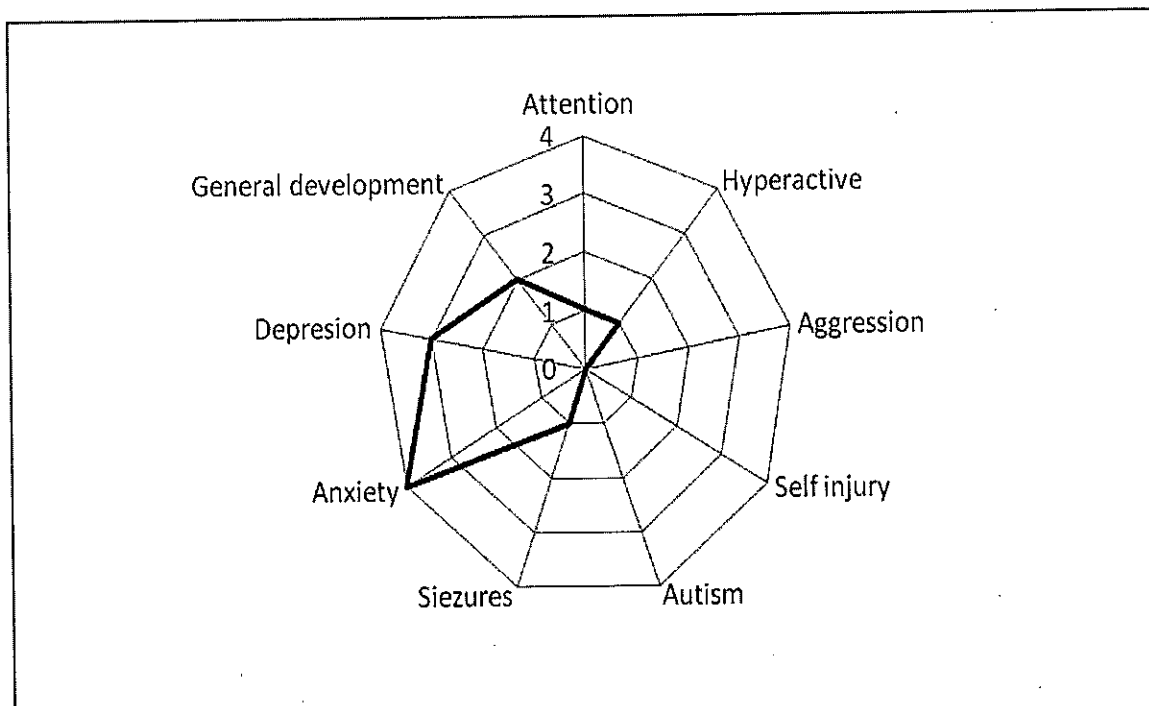


Figure 5: Pre-mutation Females (n=18)



Source: FXAA, Australian FX survey, 2009.

F. Sources of Information for this Submission

In 2009, the FXAA conducted a national survey of 113 FX families in Australia – the first ever. The total number of offspring in the sample was 289. This survey replicated a survey done in the US in 2008. The data were entered online and collated at Research Triangle International (RTI), North Carolina. From this survey we are able to extract the NSW sub-sample and examine the education responses.

For the purposes of this submission a telephone survey was conducted with nine families that belong to the FXAA, in February 2010, to gauge their current issues in relation to educational service provision in NSW.

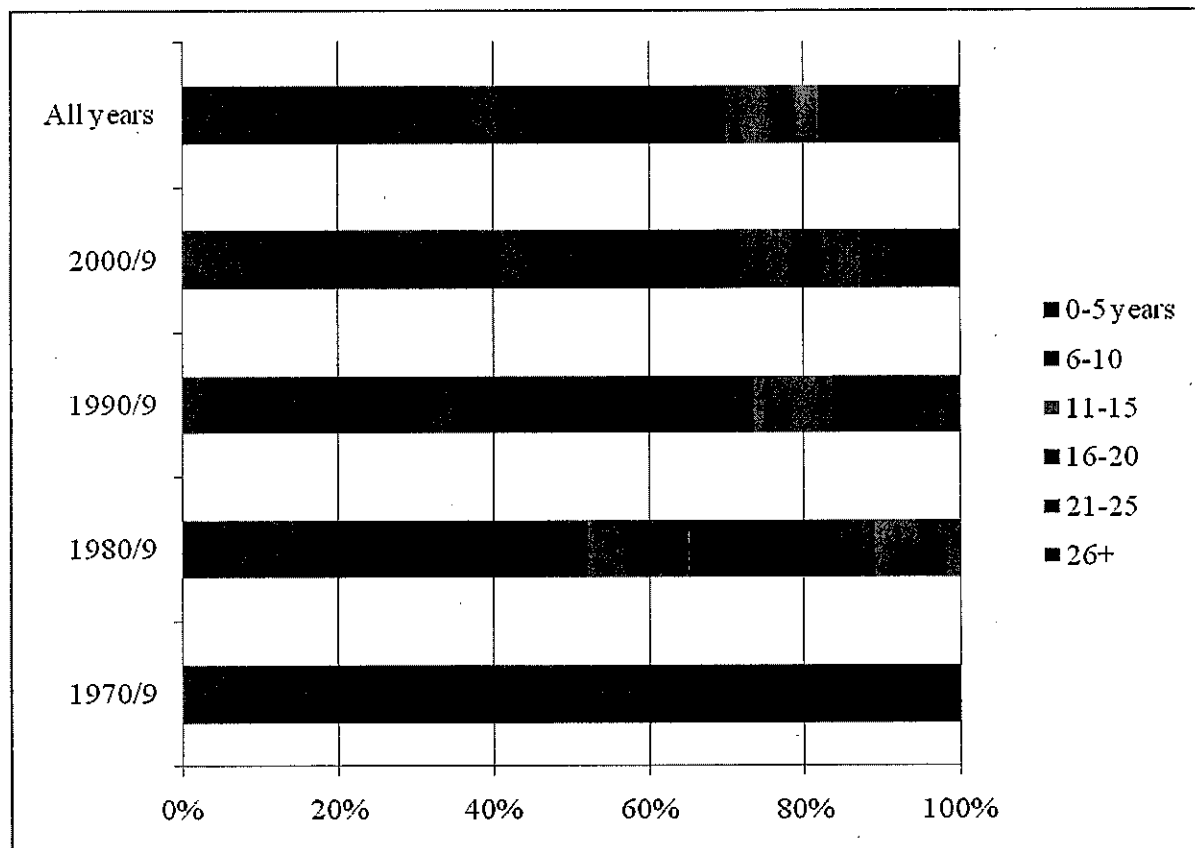
G. Issues for schooling

The following comments apply in particular to TOR 1, 2, 4, 5 and 6.

1. late or no diagnosis (TOR 1)

The Australian FX survey (2009) found that age at diagnosis varied markedly in the last decade. Whereas 60% of our sample had been diagnosed by age 5, almost 30% were diagnosed between 6 and 15 years old. This has serious implications as it means that the explanation for difficulties at school may not be available to teachers and parents. Children who are undiagnosed may not have access to early intervention programs or special assistance.

Figure 6: Year tested for FXS and age of child



Source: FXAA, Australian FX survey, 2009.

Many of our members have experienced extreme distress for both themselves and their child/ren because of the lack of an early diagnosis and the inability of teachers to identify common FX traits. Case study 1 lived in NSW with his parents. One of his grandparent wrote:

‘The definitive diagnosis was not achieved until Tim was four, following the correct diagnosis of the son of a first cousin in another state. Although Tim took part in early intervention classes, there is no doubt that his development would have been greater had the family known about his fragile X diagnosis. Special educators now agree that there is a definite learning style associated with fragile X, and Tim would have benefited from this knowledge. In addition, his parents and the whole extended family suffered greatly’.

The family subsequently left Australia to live in North America, where they felt the educational service provision for children with FXDs was much better.

Our national survey found two out of nine NSW children whose diagnosis of FXS was not revealed to the school and teachers. The question is why did the parents choose not to advise the school of the diagnosis? Perhaps they felt the child would be disadvantaged if a ‘label’ became attached to the child.

I certainly felt this when my child attended school in the 1980s. The ‘label’ and badly administered IQ tests became the school’s justification for trying to force me to take him out of regular school and place him in a special school. I was totally opposed to this and was able to argue against it. I had seen what segregation could do, in the case of my brother. Unfortunately other parents are not able to make this choice.

Recommendation 1: If the school system generally and teachers in particular were fully aware of FXDs they may be able to identify children and recommend earlier diagnosis and intervention.

2. Lack of knowledge of schools and teachers about how to teach children with FXDs (TOR 1 & 4)

Many of our members complain about the lack of knowledge of the school system in NSW as to how to teach their child/ren with FXD. Parents feel that educational choices are difficult to make and this is the cause of considerable tension and distress in families.

In the early 1980s, I pioneered mainstreaming for my son with 165 FX repeats — in the face of extreme opposition from the Principal of his primary school. My brother was sent to a special school, Crowle Home Meadowbank in the 1960s, and was subsequently institutionalised for almost 50 years. As it turns out, he is only a pre-mutation FX carrier.

With the aid of a NSW Education Dept ‘Integration’ Grant I was able to travel to the US, Canada and the UK to research mainstreaming of children with intellectual disabilities. This resulted in a report to the NSW Government and more widespread use of mainstreaming as an educational option.

The respondents in our national survey reported on eight children currently attending school in NSW: six were in regular public schools (mainly in special classes), one was in a state special school and one attended another type of school. Of the eight, only two spent 100% of their time in a regular classroom, two spent 1-20% and four spent no time at all in a regular classroom.

Our February 2010 telephone survey revealed that parents might be divided on the best option for the education of their child. Some expect better guidance from schools than they are currently getting.

Case study 2:

'The parents of a 10 year old boy were divided but the mainstream 'won'. The teachers are inadequately educated in FXS, not equipped to deal with attention behaviour ... they find him disruptive in class (of 30)'.

She/he goes on to say...

'Mainstream is not the way to go especially for primary. The school is now saying he may not be able to attend'.

Some felt that their school was doing well with their child, in spite of the following types of comments: 'education/knowledge FXS inadequate to begin with, aided by parents', 'tested positive to FXS – testing the stepping stone, system requires a name (label), direction of the school was then great'.

One interviewee said about support for her nine year old son in a mainstream school:

'Fabulous – special aide – 5 days a week – all but last 1 and a half hours per day. ... the aide is fantastic – attends additional courses on own free will , Looks into additional teaching aids and communicates daily with parents.

Main problem is that the Headmistress does not want him there – nor the school counsellor'.

Another parent has a child in a mainstream school and is provided with an aide four hours per day – from 10 am to 2 pm. Before and after these hours:

'He is integrated into the class routine. He is made to feel and look as the rest of the class – is given some worksheets which he can just colour in if he like'.

'The Principal is very aware. He is on top of it and has a great approach. He was a special school Principal before.

Others were dissatisfied: 'no support, do their best, in some areas it is like a babysitting group, parents are educating staff'; 'all disabilities put together, inadequate classroom, no special needs teacher, were discriminated against, not included in special events'. Three pre-mutation males and females did not have a written plan – partly because the school did not know about their situation.

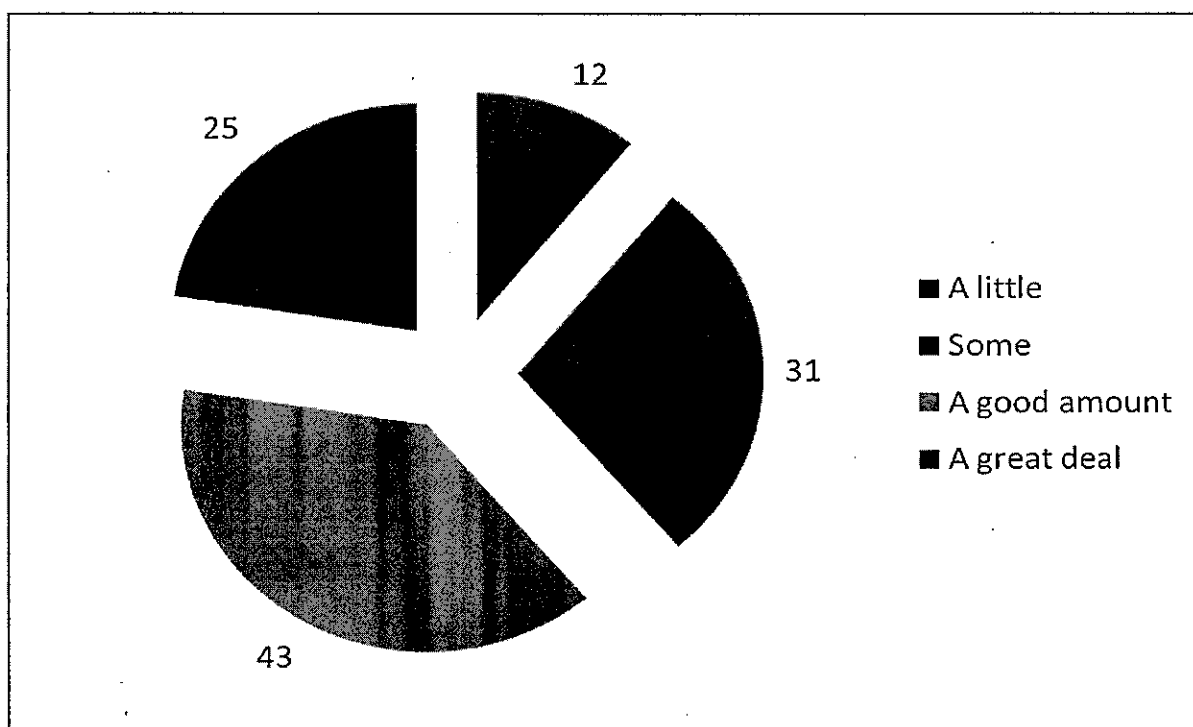
The situation seems to be that it is very school or teacher specific. There is no blanket knowledge or awareness of FXDs in NSW schools – though knowledge about the syndrome has been around since 1969.

Out national survey found that for children in regular schools, seven out of 11 respondents in NSW said that the regular education teacher did not understand or support the child 'at all' or 'only a little'. Only three said they did it 'very well'. On the other hand, 16 out of 17 special education teachers were reported as understanding and supporting the child 'somewhat' or 'very well'.

Overall, parents felt that staff in teachers and principals in schools were not adequately educated about FXDs and they often had to do the educating of teachers themselves. 'Parent involvement is high', said one. Another said they 'forward on the FXAA newsletter, etc'. 'More knowledge of autism' was another comment.

This places a lot of the onus on parents to be the purveyors of information about FXDs. The national FX survey found that parents have varying levels of knowledge on how to help their child with FX learn new skills. More than half had a good amount of knowledge or more but 39% had only some or little knowledge.

Figure 7: How much do you know about how to help your child with FXS learn new skills? (numbers)



Source: Australian FX survey, 2009

Recommendation 2: Education about FXDs should be mandatory for all teachers and principals so that they are knowledgeable about how these children best learn. The kits that are already available should be placed in all schools. The NSW Education Dept should take the lead on this.

Recommendation 3: Selection between mainstream and special education placement should not just be left to parents alone or based on faulty advice by school principal/teachers.

Recommendation 4: Mainstream schools should be adequately resourced to properly integrate children with FXDs.

3. FXS Children lagging behind (TOR 5)

Partly because of the above factors, FXS children may not achieve their full educational and social potential. Eight parents of children with the full mutation in NSW agreed that their child's education goals were 'challenging and appropriate' but when asked how much progress had been made in the past year toward meeting these goals, the following picture emerged: one said 'a lot', four said 'some' and three said 'not much'.

For full mutation NSW children only, the following results were received in the Australian FX survey. The majority of children appear in the first column in all four skill set areas. This is a serious concern in terms of their future employability and general ability to live an independent and fulfilling life. Yet we know that if they are taught in appropriate ways, FX children can master reading and their ability to learn about the world around them is often exemplary.

Table 2: Skills levels for full mutation FXS school children in NSW, 2009

Skill set	Substantially below grade level	Slightly below grade level	At grade level	Total
Reading	6		1	7
Writing	5	2		7
Science	6		1	7
Maths	7			7

Source: Australian FX survey, 2009

Curricula are often inappropriate for FXS children. They will rarely be able to do mathematics and time should be spent on the basic skills of handling money, shopping, telling the time, etc. Their school is much better spent in other activities.

The ABC's *Four Corners Program* on 15 February canvassed the inadequacy of the Australian education system for many children with disabilities. Parents who had the option were leaving and going to the UK where the facilities were far superior. One school, St Margaret's, had five teachers, aides, support workers, occupational therapists to each classroom of 6 children. This is all at no cost to parents.

Margaret Thatcher introduced legislation, which stated that each child was to have a 'statement of needs' and local authorities were obliged to provide this, no matter what the cost. Other legislation has been put in place to ensure this is done. This model and that of parts of the USA, especially California, show Australia to be lagging far behind when it comes to the educational needs and rights of children with disabilities.

FXS children do not need expensive physical care or special infrastructure, on the whole, but they do need specially trained teachers and aides who can present material that is appropriate and in the ways that we know they will learn. This requires individual plans.

Recommendation 5: That the difficulties facing FX learners be counteracted by the use of appropriate curriculum and learning materials that are already available in both Australia and overseas.

Recommendation 6: That overseas laws and policies be examined for possible replication in Australia — to help overcome the deficits in our current education system in NSW.

4. Adequacy of professional support (TOR 6)

Support from professionals is far from adequate, with most parents receiving little or nothing. School counsellors and school doctors, the front liners, should be trained on FXS so that they do not make inappropriate comments such as 'this child is never going to amount to much'. This comment was recently made to one of our parents. I was told by my son's school doctor that 'I would have to accept that he would never work'. I walked out on her and refused to take this comment. With a lot of effort and hard work, he now holds a job in a metal factory.

Many parents ring the FXAA in despair. In 2001, the association started up FX children's clinics at Westmead Hospital, funded by the association and free to members. They have met an urgent need and continue to be booked out. The problem is that families with newly diagnosed children take some time to find out about these – and some never do. If services were provided by schools they would be much more accessible to all.

The clinics provide one-off advice – rather than the ongoing advice that is needed on an annual basis. The FXAA, as a predominantly parent group, should not have to organise and fund these clinics. They should be the responsibility of governments in a social democracy.

Recommendation 7: The amount of student and family access to professional support and services in NSW needs to be examined and expanded to meet the needs of all children with disabilities.

H. Conclusion

The FXAA is frequently contacted by parents in relation to the education of their children. Lack of awareness of FXD is a general problem in the community at large but lack of knowledge in the school system is hampering our children severely and jeopardising their futures.

The situation in some schools does not seem to have improved much from the 1980s, when my son was at school. Knowledge and information is available about FXDs now but it does not seem to have made its way into many schools. This is in spite of the FXAA sending booklets into many schools in 2006.

We would welcome the opportunity to provide further information or case studies to this Inquiry to highlight our concerns.

List of Recommendations

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Recommendation 2: Education about FXDs should be mandatory for all teachers and principals so that they are knowledgeable about how these children best learn. The kits that are already available should be placed in all schools. The NSW Education Dept should take the lead on this.

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Reference

Hagerman, P. 2008 'The Fragile X Prevalence paradox', Downloaded from <http://jmg.bmj.com/cgi/content/abstract/jmg.2008.059055v1>, Accessed on 18 February 2010.