

Educational Provision and family support needs for children with fragile X Syndrome: Parent and Teacher survey

Colin Reilly. creilly@youngpilepsy.org.uk

Research Department, Young Epilepsy, UK.

Background

This parent and teacher survey focussed on aspects of educational provision, social functioning and family support needs for children with four genetic syndromes including fragile X syndrome and was carried out in the UK and Ireland in 2011. The lead researcher, Colin Reilly would like to thank all parents and teachers of children with fragile X syndrome who took part.

This is one of the largest studies to date to feature the views of parents and teachers of children with fragile X syndrome in relation to educational provision. The other syndromes were Prader-Willi Syndrome, Williams Syndrome and Velo-Cardio-Facial Syndrome (VCFS, also known as 22qdeletion syndrome). This report primarily focuses on the views of parents and teachers of children with fragile X syndrome with respect to educational provision and family support needs, but the other syndromes are referenced on occasion to provide contrast.

Methodology

Parent and teacher surveys were developed in collaboration with parent syndrome support groups in the UK and Ireland. In total, 381 parents (115 parents of children with fragile X syndrome (94 male and 21 female children)) and 204 teachers (59 teachers of children with fragile X syndrome (46 male and 13 female)) returned surveys. In the fragile X syndrome group, 101 of the parent responses were from the UK and 14 from Ireland while in the teacher group 49 teachers were from the UK and 10 from Ireland.

The survey had six sections focussing on: child, family and teacher demographics, medical conditions, educational provision, adjustment at home and school, Autism Spectrum Disorder (ASD) and parent support needs.

Main Findings

Demographics

Teacher

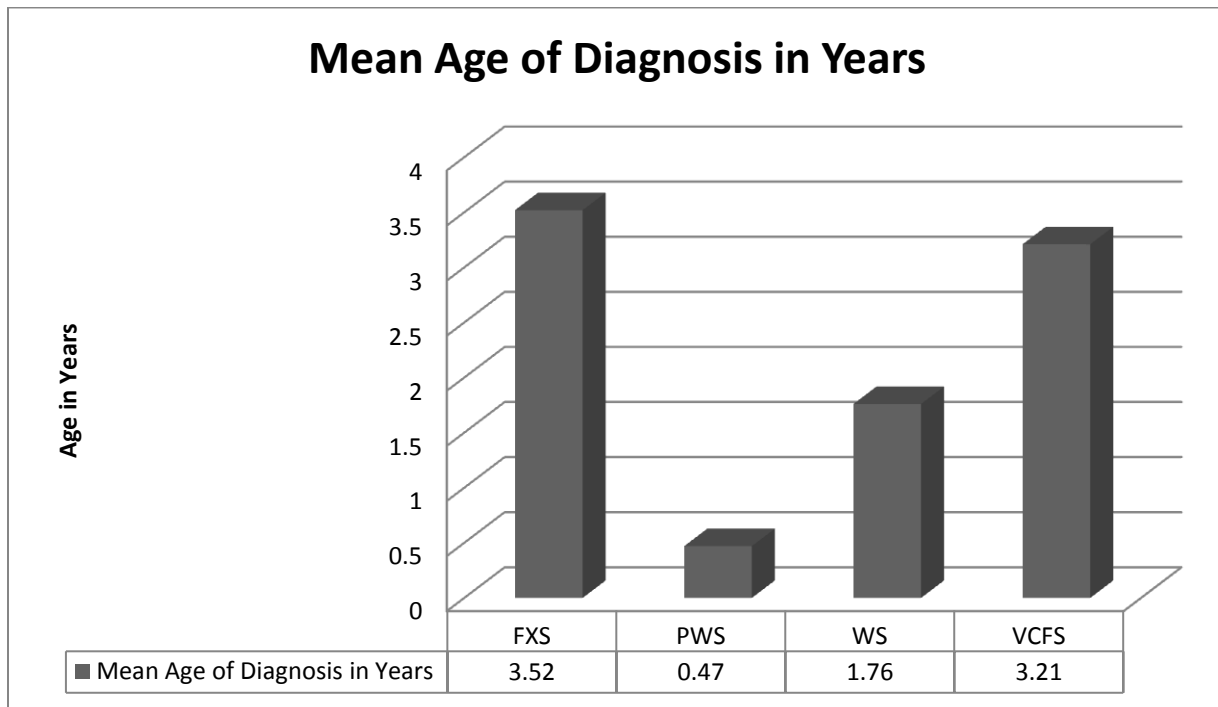
In the fragile X syndrome group 41 of the 59 respondents to the teacher survey were class teachers while the other respondents included SENCOS and learning support assistants. The respondents to the teacher survey in the fragile X group had worked on average 13 years in special educational needs and 1.7 years with the child whom they responded about. More teachers of children with fragile X syndrome (29%) reported receiving input on fragile X syndrome in initial or subsequent professional training compared with the other three syndrome groups (all less than 10%).

Child and Family

The average age for the children with fragile X syndrome in the parent survey was 11.58 years and in the teacher survey 11.19 years. The average number of children in the fragile X families in the parent survey was 2.36 children (range 1-5 children). The average number of children in the fragile X group was lower than in the other syndrome groups. In the 115 families affected by fragile X syndrome, 69% (n=79) of families had one child affected by fragile X syndrome, 28% (n=32) had two affected children, 3% (n=3) had three affected children and 1% (n=1) had five affected children.

Parents were asked to indicate the age at which their child was diagnosed with the syndrome. The average age of diagnosis in the four syndromes is illustrated in Figure 1.

Figure 1: Average Age of Diagnosis in Each of the Syndromes



FXS= Fragile X Syndrome, PWS= Prader-Willi Syndrome, WS= Williams Syndrome, VCFS= Velo-Cardio-Facial Syndrome

The average age of diagnosis was highest in fragile X syndrome (3.52 years). Females and males with fragile X syndrome did not differ significantly with respect to age of diagnosis.

Neurodevelopment and Medical Conditions, Cognition and Communication

Neurodevelopmental Conditions

Parents and teachers were asked if the child had been diagnosed with a neurodevelopmental (i.e. Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder) or mental health condition. The responses of parents of children with fragile X are shown in table 1:

Table 1: Percentage Receiving Professional Diagnoses of ASD, ADHD and Mental Health Condition: Parents’ Reports

	ASD		ADHD		Mental Health	
	Male	Female	Male	Female	Male	Female
Fragile X syndrome (n=111)	40 (44%)	3 (14%)	20 (22%)	5 (24%)	5 (5%)	0 (0%)

The percentage of children diagnosed with ASD and ADHD was higher in the fragile X syndrome group compared with the other syndrome groups. In the fragile X syndrome group, the mean age of diagnosis of ASD was 5.82 years and ADHD was 5.09 years. These ages were both lower than the other syndrome groups. Professional diagnoses of ASD, ADHD and mental health conditions reported by respondents in the teacher survey are illustrated in table 2:

Table 2: Percentage Receiving Professional Diagnoses of ASD, ADHD and Mental Health Condition by Gender- Teachers' Reports

Syndrome Name	ASD		ADHD		Mental Health	
	Male	Female	Male	Female	Male	Female
Fragile X syndrome(n=56)	11 (26%)	2 (15%)	4 (9%)	1 (8%)	0 (0%)	1 (8%)

In the teacher sample, the highest rate of ASD and ADHD diagnoses was reported in the fragile X syndrome group.

Table 3 shows medications prescribed for behavioural and psychiatric reasons based on parent report in fragile X.

Table 3: Medications Prescribed for Psychiatric or Behavioural Reasons in fragile X syndrome(n=111)

Medication Type	
Any Medication	19%
Methylphenidate	14%
Atomoxetine	4%
Dextroamphetamine	3%
Risperidone	7%
Sertraline	0%
Citalopram	0%
Fluoxetine	1%
Melatonin	9%
Other	2%

19% of children with fragile X had been prescribed drugs for behavioural and/or psychiatric reasons and there was an even split between males (19%) and females (19%). The percentage in the fragile X group was higher than the other syndrome groups possibly reflecting the high levels of symptoms of ADHD in the syndrome.

Medical Conditions

Parents were also asked if their child ever had a range of medical conditions and results are shown in table 4:

Table 4: Medical conditions reported by Parents of Children with Fragile X Syndrome

	Male		Female		Total	
	Past	Present	Past	Present	Past	Present
Epilepsy (n=108) Male = 89 Female = 19	10	7	0	0	10	7
Visual Difficulties(n=108) Male = 89 Female = 19	4	13	1	3	5	16
Hearing Difficulties (n=110) Male = 89 Female = 21	18	4	1	3	19	7
Cardiac Difficulties (n=109) Male = 89 Female = 20	3	4	0	1	3	5
Cleft Difficulties (n=110) Male = 90 Female = 90	8	3	1	0	9	3
Obesity (n=109) Male =89 Female = 20	3	8	0	3	3	11
Scoliosis (n=89) Male=74 Female =15	0	2	0	0	0	2
Sleep Aponea (n=88) Male=73 Female= 15	2	0	0	0	2	0

n= number of parents who answered about the specific condition.

Epilepsy and hearing difficulties were the most commonly reported difficulties. However, none of the females in the sample had epilepsy.

Cognitive Functioning and Communication

Respondents in the parent and teacher samples were asked to indicate the child's level of cognitive functioning based on categories from ICD-10 (World Health Organisation, 1992) and DSM-IV (American Psychiatric Association, 1994). Parent and teacher responses are shown in table 5:

Table 5: Parent and Teacher reported Cognitive Ability in Fragile X syndrome

Reported Level of Cognitive Functioning	Parent (n=114)	Teacher (n=55)
Non ID (IQ70+)	8%	7%
Mild-Moderate ID(IQ35-69)	31%	38%
Severe-Profound ID (IQ 34 or less)	19%	31%
'Don't Know'	42%	24%

ID=Intellectual Disability

The large number of 'Don't Know' responses indicates that many parents and teachers were not able to categorise the child's level of cognitive functioning according to the specified categories listed in the survey. This may be because their child has not undergone a psychological assessment which has included an assessment of global cognitive functioning. In general there appeared to be a higher frequency of children functioning in the Severe-Profound range of intellectual disability in the fragile X syndrome group compared with the other syndrome groups.

Receptive Communication

Respondents in both samples were also asked to indicate the child's level of receptive communication by ticking one option only and results are shown in table 6:

Table 6: Parent and Teacher Reports of Receptive Communication in Fragile X syndrome

Receptive Communication Ability	Teachers (n=58)	Parents (n=115)
Does not usually respond or understands some words only (Lowest Level of Receptive Communication)	9 (16%)	19 (17%)
Can follow instructions and/or can get objects reliably	20 (34%)	37 (32%)
Understands a sequence of commands and/or understands instructions involving decisions (Highest Level of Receptive Communication)	29 (50%)	59 (51%)

In the category representing the lowest level of receptive communication the highest percentage was in the fragile X syndrome group in the parent and teacher samples.

Expressive Communication

Respondents in both samples were asked to indicate how the child communicated and were given 12 possible options. Respondents were allowed to tick more than one option. Responses are shown in table 7:

Table 7: Reported Types of Expressive Communication in Parent and Teacher Samples

Level of Expressive Communication	Parent	Teacher
Does not communicate regularly with others	9 (8%)	2(3%)
Pulls people by the hand	28 (24%)	5(9%)
Gets objects to show needs	11 (10%)	5(9%)
Points to objects	26 (23%)	11(19%)
Exchanges Pictures	21(18%)	9(16%)
Sign Language	23 (20%)	8(14%)
Assistive Technology	4 (4%)	2(3%)
Writing/Typing	13 (12%)	5(9%)
Speech Sounds	34(30%)	11(19%)
Shouting/Screaming	28(24%)	6(10%)
Meaningful Speech	80(70%)	44(76%)
Other Communication	6(5%)	5(9%)

In the parent sample, the fragile X syndrome group had higher frequencies in categories which represent lower levels of expressive communication.

Educational Provision

School Placement

Respondents in both samples were asked to indicate what type of school placement the child with fragile X syndrome was currently attending and responses are shown in table 8:

Table 8: Types of School Placement for Children in the Parent and Teacher Sample.

School Placement	Parent (n=115)	Teacher (n=59)
Mainstream Class in Primary	21%	15%
Mainstream Class in Secondary	4%	3%
Special Class in Primary	9%	12%
Special Class in Secondary	7%	5%
Class in Special School	44%	51%
Special Class in Special School	11%	7%
Special Residential School	3%	2%
Spilt placement*	2%	3%
Other	0%	2%

Approximately one-fifth of students with fragile X syndrome were attending a mainstream class in primary school provision in the parent sample. Nearly half the children with fragile X syndrome were attending a class in special school in the parent sample. In the teacher sample, 15% of students with fragile X syndrome were attending a mainstream class in primary school whilst just over a half of all students with fragile X syndrome were attending a special school.

The school placement choices in both teacher and parent samples were then collapsed into two categories – ‘Mainstream’ and ‘Specialised’. The ‘Mainstream’ category was for students who attended mainstream primary or secondary school but did not include special classes in such settings. The ‘Specialised’ designation was for all other types of educational placement. In the parent sample 29(25%) students with fragile X were attending ‘mainstream’ provision and 86(75%) ‘specialised’ provision. In the teacher sample the breakdown was 11 (19%) in mainstream and 48(81%) in ‘specialised’ provision. In the parent and teacher samples, the fragile X syndrome group had the lowest percentage of children attending mainstream schooling compared with the other syndromes. This is likely to reflect the lower levels of cognitive functioning associated with fragile X syndrome compared with the other syndrome groups. In the parent sample, the children were divided into age categories in order to evaluate the impact of age on school placement and the results of this categorisation are shown in table 9:

Table 9: School Placement in Fragile X Syndrome According to Age Category

4-9years		10-13years		14-19 years	
Mainstream	Specialised	Mainstream	Specialised	Mainstream	Specialised
39%	61%	22%	78%	9%	91%

More children with fragile X were attending specialised settings at the older age group. This was also the case in the other syndromes and probably reflects the increasing academic demands as children move through the school system. In the parent sample, the children were also divided by gender to see the impact of this variable on school placement and the results of this categorisation are shown in table 10:

Table 10: School Placement according to Gender in Fragile X: Parent Sample

Male		Female	
Mainstream	Specialised	Mainstream	Specialised
16%	84%	67%	33%

In relation to gender, there is a clear pattern of a higher percentage of females in mainstream settings and males in specialised settings, probably reflecting that in fragile X syndrome females are usually less severely affected than males.

Knowledge of the Child's Condition among School Staff

Parents were asked if they had informed the head teacher/school principal at their child's school of their child's diagnosis. Only 2 of 105 parents of children with fragile X syndrome said they had not informed the child's head teacher/school principal. Parents were also asked about the reaction of school staff if they did inform them of their child's diagnosis. 85 of 92 (92%) who responded said it was 'positive', 3 said staff were 'not interested' and 4 said they got a 'negative reaction'. Parents were asked about the willingness of school staff to 'make every effort' to cater for their children's needs. 80 of 115 (70%) who responded said school were 'very willing' and 35 (30%) said 'willing'. No parents said that staff were 'unwilling'. In general, parents of children with fragile X reported positive responses from staff at their child's school.

Respondents in the parent sample were also asked if they had discussed their child's condition with the current class teacher or SENCO/resource teacher. Respondents in the teacher sample were asked to indicate whether or not they discussed the child's condition with the child's parents before they started working with the child and results are in table 11:

Table 11: Number of Parents and Teachers who Discussed Fragile X Syndrome

Parent		Teacher	
Yes	No	Yes	No
100(89%)	13(11%)	32(54%)	27(46%)

Nearly 90% of parents had discussed the child's condition with a staff member at the child's school. The percentage is lower in the teacher sample due to fact that current class teacher may not have discussed fragile X but a previous teacher may have done so.

Respondents in the parent sample who did discuss their child's condition with the child's teacher/SENCO were asked if they thought that the teacher/SENCO knew anything about fragile X syndrome. Results are shown separately for mainstream and specialised settings in table 12:

Table 12: Parental Opinion of Teacher/SENCO's Alleged Knowledge of Fragile X

Mainstream		Specialised	
Yes did know	No did not know	Yes did know	No did not know
17(61%)	11(39%)	49(68%)	23(32%)

There was, a higher level of reported knowledge in specialised as opposed to mainstream schools^[b1]^[CR2]. As well as parent's views about teacher/SENCO knowledge of the child's condition when child started school, parents were also asked to indicate whether they agreed that current school staff were knowledgeable about their child's condition. 56% agreed that staff were knowledgeable about fragile X, 16% indicated 'don't know' and 28% disagreed that staff were knowledgeable about fragile X.

Respondents to the teacher survey were asked to indicate how knowledgeable they felt about fragile X and results are displayed with respect to teachers in specialised and mainstream settings in table 13:

Table 13: Teacher Views on Their Knowledge of Fragile X Syndrome in Mainstream and Specialised Settings

Mainstream		Specialised	
Very Knowledgeable/ Knowledgeable	Limited/No Knowledge	Very Knowledgeable/ Knowledgeable	Limited/No Knowledge
5(45%)	6(55%)	14(30%)	33(70%)

There was a higher level of reported knowledge in mainstream settings. It would appear that delete while? thereare still a good number of teachers who have a limited knowledge of fragile X and this may have implications for how affected children are taught and supported.

Respondents in the teacher sample were asked what information sources they accessed in order to find out about fragile X syndrome. Respondents were allowed to select more than one response and results are shown in table 14:

Table 14: Information Sources Accessed by Teachers

Information Source	(n=53)
Internet	42(79%)
Child's family	25(47%)
Teaching Colleagues	24(45%)
Books	24(45%)
Support Group	5(9%)
Other	9(17%)

The information sources most commonly accessed were the child's family and the Internet. Teachers who sought more information were asked to indicate which information source was best and responses are illustrated in table 15:

Table 15: Teacher Views on Most Useful Information Source about Fragile X Syndrome

Information Source	(n=49)
Internet	43%
Child's Family	29%
Books	10%
Teaching Colleagues	10%
Other	8%
Support Group	0%

The Internet was identified as the most useful source of information. In the other syndromes groups the child's family was selected most often as the best source of information. Teachers were then asked if they were aware of support groups for fragile X syndrome. The majority (62%) of teachers reported not being aware of support groups for children with fragile X syndrome.

Teaching Approaches

Parents and teachers were asked about the key approaches/strategies to adopt when teaching children affected by fragile X syndrome based on what they had researched or been told. This was an open question and respondents were provided with space to write their responses. The responses were analysed by two raters who assigned codes. The codes reflected specific teaching approaches. In the parent sample, the 16 codes mentioned most frequently are shown in table 16. The codes not shown in the table were mentioned by less than 5% of parents.

Table 16: Strategies/Teaching Approaches:Parents of Children with Fragile X

Strategy /Teaching Approach	Rater1	Rater2
Structure/Routine	30%	25%
Side-On Teaching	29%	29%
Visual Materials	25%	26%
Environment	21%	23%
Rewards	19%	19%
Simple Instructions	14%	11%
Short Task	16%	17%
Patience	11%	11%
Small Group Teaching	11%	13%
Repetition/Memory	8%	8%
One-to-One Teaching	9%	11%
Minimise Negative Emotions	7%	9%
Experiential Learning	5%	7%
Individualised Approach	6%	4%
Other Approach	13%	11%

The strategies most often reported in the parent sample were the need for 'Structure/Routine' and need for 'side-on teaching'. 'Side-on Teaching' was mentioned by nearly one-third of the parents of children with fragile X syndrome and was not referred to by parents of children with the other three syndromes with the exception of one parent of a child with Prader-Willi syndrome.

In the teacher sample, the codes most frequently mentioned by teachers are shown in table 17.

Table 17: Strategies/Teaching Approaches:Teachers of Children with Fragile X

Code	R1	R2
Structure /Routine	41%	39%
Visual Materials/Approach	32%	34%
Simple Instructions	27%	25%
Rewards	20%	20%
Experiential Learning	19%	20%
One-to-One Teaching	17%	17%
Short Tasks	17%	17%
Social Skill Development	17%	15%
Individualised Approach	17%	15%
Patience	12%	15%
Environment	15%	15%
Minimise Negative Emotions	10%	12%
Repetition/Memory	9%	9%
Other	17%	17%

The strategy spontaneously mentioned most often by teachers was the need for 'Structure/Routine'. The 'Side-on Teaching' code was mentioned by only 5% of teachers of children with fragile X syndrome whereas it had been mentioned by 29% of parents of children with the syndrome. The need to develop social skills was mentioned by one in seven respondents in the teacher sample, in comparison with the parent sample where it was rarely mentioned

Respondents in the parent and teacher samples were asked to specify the teaching arrangement in which they felt the child with fragile X syndrome learned best. Options offered included; 'one-to-one with adult', 'small group with adult', and 'whole class'. The majority of parents (62%) and teachers (56%) chose the 'one-to-one' arrangement. The 'small group with adult' option was chosen by 33% of parents and 39% of teachers and 2% of parents and 0% of teachers chose the 'whole class' option.

Parents and teachers were asked to indicate the range of teaching approaches/strategies used in school with the children. In the parent sample, the option of 'I am not aware' was offered as it was felt parents may not be aware of all the approaches used in the classroom. The 'I am not aware' option has been excluded from table 18 which displays the frequency with which teaching approaches were used in both samples:

Table 18: Reported use of Teaching Approaches by Parents (P) and Teachers (T) with Children with Fragile X

Approach	Parent	Teacher
Information Technology	92%	97%
Rewards	85%	85%
Home-School Diary	82%	93%
Life Skills	79%	88%
Visual Aids	79%	81%
Visual Schedule	71%	70%
Social Skill Training	70%	92%
Side-On Teaching	63%	76%
Circle Time	61%	80%
Whole/Sight Word	59%	73%
Individual Behaviour Plan	66%	53%
Social Stories	55%	53%
Role Plays	48%	56%
Calm Area	58%	63%
Individual Workstation	55%	41%

Add nP and nT sample sizes as note beneath Table 19? [b3]

Table 18 shows that the approach most frequently endorsed in both parent and teacher samples was use of information technology. The next most frequently used approaches/strategies in both samples were the use of rewards, home-school diary, life and social skill training, use of visual aids/schedules, side-on-teaching and circle time, all reported by more than 60% of respondents in both samples.

Reading

Respondents in both samples were asked what approach was most effective with regard to helping the child recognise words. Parent and teacher views are illustrated in table 19:

Table 19: Most Effective Approach to Word Reading According to Parents and Teachers of children with Fragile X Syndrome

Syndrome	Phonics Based Approach		Sight Words		Other Approaches*	
	Parent	Teacher	Parent	Teacher	Parent	Teacher
FXS (n ^P =91 n ^T =51)	21%	29%	73%	57%	7%	14%

n^P=number in parent sample, n^T=number in teacher sample. *Other Approach included combinations of approaches (e.g., sight and phonics)

The children who reportedly could not recognise words are excluded from table 19. The sight word approach was used most often in both the parent and teacher samples. The phonics based approach to reading was used most frequently in the other three syndrome groups in the parent sample.

Respondents in both samples were then asked to rate the child's reading comprehension ability in comparison with their word reading ability. Responses are illustrated in table 20:

Table 20: Parent and Teacher Views on Child's Level of Reading Comprehension in Comparison with Word Reading Ability

	Reading Comprehension is:		
	Above Level of Word Reading	Is at Same Level as Word Reading	Is Below Level of Word Reading
Parents (n=80)	41%	24%	35%
Teachers (n=44)	25%	36%	39%

In the fragile X syndrome group more parents reported that their child's level of reading comprehension was above their level of word reading ability than below. The opposite pattern was evident in the other syndromes.

Best Teaching Approaches According to Teacher

Teachers were asked to indicate their views on the most effective teaching approaches to use when supporting the children. This question was different from that reported on in Table 17. The focus on table 17 was on what teachers had researched whereas the focus here was on their experiences of working with the children. Respondents were

provided with space to write their responses and the responses were analysed by two raters. The teaching approaches most frequently mentioned are shown in table 21. The 15 codes not shown in the table were mentioned by 5% or less of teachers.

Table 21: Most Effective Teaching Approaches Based on Teacher Experiences with Children who have Fragile X Syndrome

Teaching Approach	R1	R2
Routine and Structure	32%	34%
Individualised	22%	22%
Experiential Learning	24%	24%
Visual Materials	25%	24%
Patience	17%	20%
Repetition and Memory	15%	15%
Rewards/Reinforcer	10%	10%
Small Group Teaching/Support	14%	15%
Quiet Uncluttered Environment	10%	12%
Instructions	9%	7%
Negative Emotions	7%	7%
Social Skills	7%	10%
Short Tasks/Lesson	5%	5%
Other	12%	10%

R1=Rater 1 R2= Rater 2

The teaching approach spontaneously mentioned most often by teachers was the need for routine and structure and this was mentioned by one-third of all teachers.

Educational Achievement

Perceived Educational Strengths

Parents and teachers were asked to indicate areas of school functioning in which the child displayed a strength. Parent and teacher responses are summarised in Table 22.

Table 22: Perceptions of Areas of School Functioning where Child with Fragile X Displays Strengths

Area of School Functioning	Parent n=114	Teacher n=59
Computers/IT	75%	52%
Music	52%	22%
Physical Education	33%	25%
Reading	32%	39%
Playing with Peers	16%	17%
Science	12%	8%
Spelling	11%	8%
Mathematics	6%	12%
Handwriting	5%	9%

Computers/IT was most often identified as strength by parents and teachers. Respondents in both samples were also asked to indicate curriculum areas where the child experienced greatest difficulty. They had to select at least one option but could select more than one if they wished. The responses of parents and teachers for each area of school functioning are illustrated in table 23:

Table 23: Perceptions of Areas of School Functioning where Child with fragile X Displays a Need

Curriculum Area	Parent n=114	Teacher n=59
Mathematics	83%	51%
Handwriting	75%	61%
Spelling	67%	46%
Reading	51%	37%
Playing with Peers	39%	29%
Science	35%	22%
Physical Education	20%	25%
Music	12%	14%
Computers/ IT	7%	7%

Handwriting and mathematics were areas most often selected as difficulties.

Educational Supports, Relationships and Future Provision

Respondents in both parent and teacher samples (UK only) were asked whether or not the child had a statement of special educational needs (SEN) and responses are illustrated in table 24:

Table 24: Provision of Statement of Special Educational Needs (SEN)

Syndrome	Parent	Teacher
Fragile X Syndrome	90(90%)	44(90%)

In the parent and teacher samples, 90% of respondents reported that the child had a statement of special educational needs. In the parent sample, the level of provision of statements of special educational needs was broken down according to age and this is summarised in table 25:

Table 25: Provision of Statement of SEN According to Age in Parent Sample

Age in Years	(n=98)	
	Yes	No
4-9	91%	9%
10-13	86%	14%

14-19	93%	7%
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Both Irish and UK respondents in the parent and teacher samples were asked to indicate if the child had an Individual Educational Plan (IEP). 111(98%) of parents reported that the child with fragile X had an IEP whilst the figure for teachers was 55(93%). Respondents in both samples were asked about who was involved in IEP development and results are shown in Table 26:

Table 26:Personnel Involved in IEP Process for children with fragile X

Participant	Parent n=112	Teacher n=57
Class Teacher	93%	91%
Parent or Guardian	73%	68%
Speech Language Therapist	43%	49%
LSA/SNA*	37%	49%
SENCO	37%	N/A
Educational Psychologist	30%	23%
Specialist Teacher	22%	33%
Occupational Therapist	21%	14%
Physiotherapist	8%	N/A
Other	6%	11%

N/A= not applicable as not offered as an option in teacher survey.

*LSA/SNA= Learning support assistant/Special needs assistant

According to both the parents and teachers, the professional with the highest rate of participation in the IEP process was the class teacher (93% in parent sample and 91% in teacher sample). Respondents in both samples were asked what subjects/areas of the curriculum were included in the child's IEP and parent and teacher responses are illustrated in table 27:

Table 27: Subjects/Curriculum Areas Included in IEP According to Parents and Teachers

Subject/Curriculum Area	Parent (n=105)	Teacher (n=53)
Maths	74%	74%
Social Skills	72%	83%
Reading	69%	66%
Communication Skills	67%	68%
Independence Skills	68%	62%
Writing	60%	40%
Behaviour	52%	45%
Fine Motor Skills	46%	51%
Gross Motor Skills	42%	43%
Playing with Peers	38%	42%
Computers/IT	32%	19%

Spelling	31%	23%
Music/Art	26%	11%
Other	6%	11%

The areas most often included in IEPs in the parent and teacher sample were social skills, maths, reading, communication and independence skills.

Teacher Views on Educational Provision, Supports and Training

Teachers were asked to indicate if they think they are given enough resources to teach the child with fragile X syndrome. 67% of teachers disagreed that teachers are given enough resources. Teachers were also asked to indicate if they felt the needs of children with fragile X syndrome are of a similar nature to children with intellectual disability due to other causes. 80% of teachers agreed that the needs of children with fragile X syndrome are of a similar nature to children with intellectual disability due to other causes.

Teachers were then asked whether they thought children with fragile X syndrome have very complex needs and require very specific supports. 70% of the teachers who responded agreed that children with fragile X syndrome have very complex needs. Teachers were subsequently asked to indicate whether or not they felt that children with fragile X syndrome will struggle to reach their potential in mainstream educational settings. 75% agreed that they would struggle and 25% disagreed. Respondents in the teacher sample were also asked to indicate the type of additional training in relation to fragile X syndrome they might benefit from, and their responses are shown in Table 28:

Table 28: Teacher Views on Areas Where They Would Like Additional Training

Training Need	(n=59)
Training on behavioural aspects of fragile X syndrome	(53%)
Training on cognitive aspects of fragile X syndrome	(63%)
Training on teaching strategies of fragile X syndrome	(46%)
Other Training on fragile X syndrome	(10%)

Home-School Relationships

Parents were asked if they felt that staff at their child's school listen to their concerns. 98% of parents agreed that staff listen to their concerns. Respondents in the parent sample were also asked if they had difficulty understanding the language used in reports and at meetings by school staff and 93% of respondents indicated that they had no difficulty. Respondents in the parent sample were subsequently asked if their child's school communicates with them when their child does well at school and 93% of parents agreed that school does communicate. With regard to home-school relationships, 93% of parents reported that they had an 'excellent' relationship with staff at the child's school. Furthermore, 94% of parents agreed that their child's teacher had an 'excellent' relationship with the child. For children with an LSA/SNA, 90% of parents

agreed that the LSA/SNA has an ‘excellent’ relationship with the child. Parents were also asked about the willingness of the teacher to adapt the classroom and the curriculum in order to include the child and 90% agreed that teachers were ‘willing’.

School-Based Behavioural Issues

Respondents in the teacher sample were asked to indicate if they felt the child displays significant verbal or physical aggression and responses are summarised in table 29:

Table 29: Teacher’s Views on Whether the Child Displays Significant Verbal Aggression

Type of Aggression	Regularly /Occasionally	Never
Verbal	42%	58%
Physical Aggression	31%	69%

Respondents in the parent sample were asked whether their child’s teacher can usually identify the cause of, and respond effectively with concerning behaviour displayed by the child. Responses are illustrated in table 7.30:

Table 30: Teacher’s Ability to Identify the Cause of and Deal Effectively with Concerning Behaviour: Parent Views(n=112)

Disagree	Don’t Know	Agree
11%	8%	81%

The majority of parents agreed that teachers can usually find the cause of, and deal effectively with incidents of concerning behaviour displayed by the child.

Inclusion/Participation in School

Parents were asked about their child’s participation and inclusion in school. Parents were firstly asked whether their child’s teacher sets up opportunities for the child to interact with children of a similar age at school. The majority of parents (85%) agreed that their child’s teacher sets up opportunities for their child to interact with similarly aged children. Parents were also asked whether the child is included in most classroom activities and, in the total sample, 92% of parents agreed that child is included. Parents were then asked whether their child has a good network of friends at school and outside of school and results are shown in table 31:

Table 31: Parent Report of Whether Child Has a Good Network of Friends at School

	Disagree	Don’t Know	Agree
At School	21%	10%	69%

Outside of School	78%	0%	22%
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The fragile X group had the highest percentage of parents who disagreed that the child had a good number of friends out of school.

Child's Current Educational Provision

Parents were asked whether they thought their child was happy at their current school placement. Parents of children with fragile X syndrome (96%) most frequently indicated that their child was happy at school. Respondents in both samples were asked whether they felt the child was progressing as well as he/she could at school and responses are illustrated in table 32:

Table 32: Respondents Views on Whether the Child Is Progressing as well as he/she Could at School

Disagree		Agree	
Parent	Teacher	Parent	Teacher
15(13%)	6(11%)	98(87%)	51(90%)

In both samples the vast majority of parents and teachers agreed that the child with fragile X syndrome was progressing as well as they could. Parents were also asked whether they thought the child's school was meeting their needs in three areas. In the area of academic needs 85% reported that they felt their child's needs were being adequately met. With regard to socialisation needs 78% of parents reported that their child's needs were being met and 79% of parents also reported that their child's needs were being met with respect to life skill needs.

Respondents in the parent sample were also asked if the UK/Irish education system has met the needs of the child. 65% agreed that the UK/Irish education system has met the needs of the child with Fragile X while 35% disagreed. Parents were given a list of educational settings and asked to indicate the ones which they thought would best meet their child's needs and responses are shown in table 33:

Table 33: Parent Views: Educational Setting that would Best Meet the Child's Needs

Type of Educational Setting	FXS (n=114)
Class in special school	45(40%)
Special class/unit in special school	19(17%)
Mainstream class in primary	15(13%)
Special class/unit in primary	13(11%)
Special class/unit in secondary	9(8%)
Special residential school	5(4%)
Mainstream class in secondary	4(4%)
Other	2(2%)

Split Placement*	2(2%)
Home tuition/schooling	0(0%)

*Split placement was not given as an option but was mentioned by 2 parents

Parents most often chose a class in a special school or a special class/unit in a special school. The categories were recoded into 'mainstream' (mainstream class in primary and secondary) and 'specialised' (all other categories). shouldn't this be 17% (19) of parents chose a mainstream setting and shouldn't this be 80% (91) [b4]a specialised setting with respect to the most suitable school setting for meeting child's needs.

Perceptions of Changes in Educational Provision that Would Benefit the Child

Respondents in both samples were asked to indicate changes to the child's current educational provision which they felt would help the child most and respondents were given 16 options. Responses are shown in table 34:

Table 34: Areas parents and teachers of children with fragile X would like increased resources.

Increase in Resources for	Parent n=112	Teacher n=59
Independence Skills	51%	27%
Social Skills	47%	32%
One-to-one time with teacher	46%	42%
Hygiene/care	47%	9%
Handwriting/Fine Motor Skill	46%	25%
Communication	41%	31%
Mathematics	38%	24%
Reading	34%	15%
Gross Motor Skills	30%	20%
Computers	27%	12%
Spelling	27%	9%
LSA/SNA	26%	10%
Small pupil-teach ratio	24%	25%
Supporting Behaviour	23%	15%
Music/Art	21%	5%
Other	5%	15%

Views on Knowledge of Health and Educational Professionals

Respondents in the parent and teacher sample were asked to indicate the range of health and educational professionals who had worked with the child and responses are shown in Table 35.

Table 35: Health and Educational Professionals that had Worked with the Child

Professional	Parent(n=109)	Teacher (n=56)
Speech Language Therapist	97%	82%
Paediatrician	94%	29%
Educational Psychologist	94%	63%
Occupational Therapist	83%	46%
Social Worker	64%	20%
Physiotherapist	62%	18%
Clinical Psychologist	61%	16%
Psychiatrist	43%	5%

The percentages of respondents indicating if the various professionals had worked with the child are much lower in the teacher sample, probably as a result of teachers not always being aware if professionals had worked with the child. Parents were asked to rate the level of knowledge of fragile X syndrome of the professional who had worked with their child and were given the options 'Good/Some Knowledge', or 'Limited/No Knowledge' and responses are shown in table 36:

Table 36: Perceived Knowledge of Professionals According to Parents

Professional	Good/Some	Limited/None
Paediatrician	68%	32%
Psychiatrist	59%	41%
Educational Psychologist	55%	45%
Clinical Psychologist	52%	48%
Speech and Language Therapist	51%	49%
Occupational Therapist	47%	53%
Physiotherapist	34%	66%
Social Worker	26%	74%

The highest level of perceived knowledge (i.e. highest rating of 'Some/Good Knowledge') across the four syndrome groups was for paediatricians.

Respondents in the teacher sample were asked to indicate what professional supports they felt the child could benefit from an increase in. Responses are summarised in table 37:

Table 37: Additional Professional Supports Needed: Teacher Views

Additional Support	n=57
Speech and Language Therapist	49%

Occupational Therapist	42%
Educational Psychologist	23%
Physiotherapist	9%
Social Worker	9%
Clinical Psychologist	9%
Psychiatrist	2%
Paediatrician	4%
Other	12%

With regard to additional professional support, teachers most often expressed a desire for increased speech and language therapy input followed by occupational therapy input and support from educational psychologists.

Autism Spectrum Disorder (ASD)

Respondents in the parent and teacher sample were asked if professionals who work with the child ever mentioned that the child displays features of Autism Spectrum Disorder (ASD). Responses of parents and teachers of children with fragile X are displayed in table 38:

Table 38: Professional Mention of Features of Autism Spectrum Disorder (ASD)

Parents		Teachers		
Yes	No	Yes	No	I am not aware
79(69%)	35(31%)	22(38%)	20(35%)	16(28%)

Note: The 'I am not aware' category was offered in the teacher but not the parent sample.

Parents and teachers in the fragile X syndrome group more frequently reported that professionals mentioned that the child displayed features of ASD compared with the other syndromes. Teachers were also asked to indicate if they thought that the child displays significant features of ASD. 61% of teachers indicated that they thought the child did display significant features of Autism Spectrum Disorder (ASD). Respondents in both samples were then asked if the child had been assessed for ASD. Teachers were offered the 'I am not aware' category. Responses in both samples are displayed in table 39:

Table 39: Assessments for Autism Spectrum Disorder (ASD)

Parent		Teacher	
Yes	No	Yes	No
52(46%)	60(54%)	24(42%)	33(58%)

In both parent and teacher samples, the syndrome where the highest percentage of children had been assessed for ASD was fragile X (46% in parent sample and 42% in teacher sample). Teachers were asked whether they thought that resources developed for teaching children with ASD are also useful for children with fragile X syndrome. 96% of teachers agreed that teaching resources developed for children with ASD are also

useful for teaching children with fragile X syndrome. Respondents in the teacher sample were also asked to indicate if they agreed that they often used resources designed for children with ASD with the child with fragile X they taught and 85% agreed that they did.

The next section focussed on the children with fragile X who had been diagnosed with ASD (44% of boys and 14% of girls in this study). The first question in the subsection focussed on whether the respondent considered ASD or fragile X as the child’s most important diagnosis. 22% of parents and 56% of teachers of children with fragile X syndrome indicated that ASD was the child’s most important diagnosis. Respondents were then asked whether staff who work with the child at school view him/her as primarily having ASD as opposed to fragile X syndrome. In the parent sample, 53% of respondents agreed that school staff view the child’s primary diagnosis as ASD while in the teacher sample 60% of teachers agreed. Respondents in both samples were subsequently asked whether health and educational professionals who work with the child at school view him/her as primarily having ASD as opposed to fragile X syndrome. In the parent sample 49% disagreed that health and educational professionals viewed the child’s primary diagnosis as ASD while in the teacher sample 56% disagreed that that health and educational professionals viewed the child’s primary diagnosis as ASD.

Teachers and parents were also asked if they agreed that there is more information available for children with ASD than for children with fragile X. 96% of parents and 90% of teachers agreed that there was more information for children with ASD compared with fragile X. In the parent survey the final question asked concerned whether parents find support groups for children with ASD more useful than support groups for children with fragile X syndrome. The majority (79%) of parents disagreed that support groups for children with ASD are more useful.

The impact of fragile X syndrome on the family

Parents of children with fragile X syndrome were asked to indicate whether or not they endorsed (respond by ticking yes/no) items in four main areas: “restrictions” (on parent/family activities), challenges (arising from having a child with the specific neurogenetic syndrome), future concerns (in relation to affected child), and positive aspects (of parenting a child with fragile X syndrome).

The frequency with which the parents reported restrictions on family/parent activities due to the presence of fragile X syndrome is displayed in Table 40:

Table 40: Restrictions on family/parent activities reported by parents of children with fragile X syndrome

Restriction	
Going Shopping	62%
Taking Holidays/Vacations	46%
Taking Public Transport	40%
Other Restrictions	28%

The restriction on family/parent activities endorsed most often by parents was going shopping.

The frequency with which the parents endorsed challenges is displayed in Table 41.

Table 41: Parent reported challenges associated with raising a child with Fragile X syndrome.

Challenging Aspect	
Child's difficulties with social skills	77%
Child has a learning difficulty	71%
Child's anxiety	62%
Child's communication difficulties	59%
Child's obsessions	50%
Child being different	43%
Child has a genetic condition	43%
Child displays physical aggression	41%
Child's lack of progress at school	32%
Sleep difficulties	30%
Child engages in destructive behaviour	28%
Child's excessive activity levels	28%
Child displays verbal aggression	24%
Child's difficulty with diet	23%
Family's non-acceptance	19%
Child's medical difficulties	17%
Child's excessive sociability	16%
Other Challenge	9%
Sibling's non-acceptance	9%
Spouse's non-acceptance	9%
No challenging aspects	1%

Only 1% of participants did not endorse at least one challenging aspect. The aspects endorsed most often were "child's difficulties with social skills" and "child has a learning difficulty".

The frequency with which the parents endorsed positive aspects is displayed in Table 42.

Table 42 : Parent reported positive aspects of raising a child with fragile X

Aspect	
Joy/happiness brought by child	78%
Changed outlook on life	78%
Makes us more tolerant	72%
Child's sense of humour	74%
Makes us more patient	64%
Makes us more compassionate	63%

Opportunity to learn and develop	47%
Makes us closer as a family	48%
Positive Impact on siblings	30%
Friendship with other parents	30%
Provides company for parents	20%
Makes us more spiritual	17%
Other Positive	4%
No Positive Aspects	5%

Only 5% of the parents did not endorse at least one positive aspect. The positive aspects endorsed most often were “joy/happiness brought by child,” “changed outlook on life, “makes us more tolerant” and “child’s sense of humour”.

The frequency with which the parents endorsed future concerns about the child is displayed in Table 43:

Table 43: Parent reported future concerns about the child with fragile X syndrome

Future Concern	
Capacity for Independent Living	85%
Future care when parents gone	85%
General Happiness Concerns	77%
Employment Concerns	70%
Mental Health Concerns	57%
General Health Concerns	37%
Career option Concerns	49%
Marriage Prospect Concerns	42%
Sitting Public/State Examinations [#]	24%
Other Concerns	10%
No Future Concerns	3%

[#]Formal exams taken during or at end of secondary education

The items most often endorsed by parents were ‘Capacity for Independent Living’ and ‘Future concerns when parents are gone’.

Adjustment at Home and School

Parents were asked if they felt their child was aware that they had fragile X syndrome. In total 34 children (30%) (22 of the males (24%) and 12 females (57%)) were reportedly aware that they had the syndrome. This was significantly lower than the other three syndromes. Parents were also asked about the child’s relationships with their siblings and were given a number of options to choose from. 58% of parents said relationships between the child with fragile X syndrome and their siblings were ‘positive or very positive’, 21% chose ‘variable’, 1% said ‘very negative’ and 19% indicated that this question was not applicable to them.

Parents were also asked about their child's participation in sporting or other recreational clubs. Club membership for the children with fragile X is shown in Table 44:

Table 44: Membership of clubs in children with fragile X

Gender	Mainstream	Special Needs	Special and Mainstream	Not a member of any club
Male	15 (16%)	39(42%)	4(4%)	35 (38%)
Female	10(48%)	1(5%)	0(0%)	10(48%)

Bullying

Parents were asked whether they felt that their child was bullied more than other children and responses are in Table 45:

Table 45: Bullying experienced by children with fragile X syndrome

Gender	Yes	No	Unsure
Male	24(27%)	65 (72%)	1(1%)
Female	8 (38%)	13(62%)	0(0%)

The fragile X group had the lowest level of reported bullying of the four syndromes. Parents were also asked about frequency of bullying and responses are shown in Table 46:

Table 46: Frequency of Bullying directed towards children with fragile X

Gender	Never	Not Very Often	Often	Very Often
Male	32 (42%)	36(47%)	8(11%)	0(0%)
Female	3 (18%)	6(35%)	7(41%)	1(6%)

Parents were also asked to specific types of bullying their child had experienced if they had been bullied:

Table 47:Type of Bullying directed towards children with fragile X

Gender	Unwanted verbal behaviours	Unwanted physical behaviours	Unwanted verbal and physical behaviours	Other Bullying
Male	20(56%)	6(17%)	9(25%)	1(3%)
Female	7(58%)	0(0%)	5(42%)	0(0%)

The majority of children had been in receipt of unwanted verbal behaviours.

Parental Needs

The parent support needs questionnaire contained a total of 73 items. Each item was based on a four point scale (1 greatest support need, 4 no support needed). Lower scores indicate a higher level of need. The average score for each item for parents of children with fragile X syndrome are in Table 48:

Table 48: Ranking of parental needs according to parents of children with fragile X syndrome

Rank	Support Need	Average Score
1	To get support finding out about future educational options for my child	1.94
2	To understand about future services my child might receive	1.95
3	To understand future needs of my child	1.97
4	To help my child understand and use money	2.00
5	To understand how to teach my child	2.04
6	To access social opportunities for my child	2.08
7	To understand about how to give? children with fragile X help	2.09
8	To understand how children with ID/developmental delay develop	2.14
9	To understand learning strengths of fragile X	2.14
10	To locate an appropriate school place	2.16
11	To help my child with concentration and maintaining attention	2.24
12	To help my child read	2.26
13	To help my child tell the time	2.30
14	To help my child recognize numbers and count objects	2.30
15	To help manage my child's anxiety	2.31
16	To manage my child's behaviour	2.33
17	To help my child communicate	2.34
18	To help my child spell	2.37
19	To understand behavioural profile of children with fragile X	2.41
20	To find more time for myself	2.45
21	To access activities for my child during school holidays	2.45
22	To locate a professional knowledgeable about fragile X	2.51
23	To access appropriate therapies for my child	2.52
24	To help my child understand what he/she reads	2.57
25	To access speech and language therapy	2.57
26	To understand genetics of fragile X	2.57
27	To know what to do when my child engages in aggressive behaviour	2.58
28	To locate a dentist who understands my child's needs	2.60
29	To implement recommendations made by professionals	2.60
30	To locate babysitters	2.64
31	To phone another parent and discuss fragile X	2.69
32	To access occupational therapy	2.70
33	To chat online to other parents who have a child with fragile X	2.71

34	To meet and talk with other parents of child with with fragile X	2.72
35	To get care for child when parent attending appointments	2.73
36	To pay for therapy childcare or other services	2.75
37	To get information about a support group for my child	2.76
38	To get and pay for special equipment or learning resources for my child	2.77
39	To know what to do when my child engages in self-injurious behaviour	2.81
40	To understand financial entitlements	2.82
41	To access respite for my child	2.83
42	To get time to take my child to appointments with professionals	2.83
43	To find out about other families with a child who has fragile X	2.85
44	To locate a doctor who understands what my child needs	2.86
45	To access a psychologist for my child	2.90
46	To help my family support each other during difficult times	2.90
47	To plan for and attend meetings in my child's school	2.93
48	To explain my child's condition to other children	2.96
49	To find reading material about families who have a child with special needs	2.96
50	To locate after school care for child	2.96
51	To plan and go on holiday with my child	2.97
52	To decide on and do family recreational activities	2.97
53	To talk with someone in my family about concerns	3.00
54	To discuss problems and reach solutions with family	3.01
55	To pay for babysitting for my child	3.01
56	To understand professional reports and school reports	3.02
57	To leave the house and do the shopping	3.02
58	To find time to interact with my child	3.02
59	To respond when friends and neighbours ask questions about my child	3.03
60	To play with my child	3.09
61	To help my child eat a healthy diet	3.10
62	To access friends to talk to	3.10
63	To accept my child's disability	3.11
64	To pay for toys my child needs	3.14
65	To help my spouse accept my child's condition	3.14
66	To get a job for myself	3.18
67	To access a psychiatrist for my child	3.19
68	To explain fragile X to my child's siblings	3.20
69	To adapt home to support my child	3.23
70	To help my child get a good night's sleep	3.28
71	To decide who will do chores	3.30
72	To explain fragile X to parents or spouse's parents	3.32
73	To meet transport costs for bringing my child to therapy	3.35

The three needs endorsed most often by parents of children with fragile X all referred to the child's future options/needs.

Summary/Discussion

This study was one of the largest to examine parent and teacher views of educational ~~provision and~~ provision and parental views on impact on family functioning in families with children with fragile X. The findings reveal a number of areas which warrant further comment and may have implications for future research and practice.

Sample Characteristics

The gender ratio of children with fragile X syndrome is usually reported as 2:1 whereas in this sample it is approximately 4:1. Although it is not altogether clear why the gender ratio in this study is skewed in such a manner, it is likely that any surveys of parents of children with fragile X syndrome are biased, in that samples are more likely to include parents of children who are more severely affected. More severely affected children are more likely to be diagnosed, and diagnosed at an earlier age, than those who are less severely affected. As some females are less severely affected, parents may not access support via parent support groups. However, there is a risk that the lower level of female representation in surveys may lead to an underestimation of their needs, and representative studies focussing exclusively on females may be necessary so that the extent and nature of their needs are fully understood. Such studies will require significant efforts to identify all females affected by the syndrome so that the full range of need in this group can accurately be described.

Age of Diagnosis

The highest average age of diagnosis among the four syndrome groups was for the fragile X syndrome group at three and a half years. In fragile X the lack of associated medical problems and no obvious signs at birth means children are likely to be referred for genetic investigation for developmental problems which may only appear in the ~~second—~~ second or third year of life. Early diagnosis is likely to bring greater understanding for families and may aid future educational and therapeutic ~~interventions.~~ There interventions. There is thus a need to continue to increase awareness of syndrome presentation among medical professionals to ensure children with fragile X syndrome are identified as early as possible.

Teacher Training and Knowledge

Even though more teachers of children with fragile X had received training in fragile X than teachers in the other three syndrome groups, only 29% had received formal input and this is concerning. This lack of training is likely to have significant implications on teachers' views on the importance of the child's syndrome to education planning and subsequent classroom practices. If teachers have not received any input on fragile X syndrome, it is more likely that they will not feel that the child's syndrome is important with respect to educational planning. Half of all teachers indicated that they would like further training on the syndrome, indicating that many feel they lack the necessary knowledge and skills to meet the children's needs.

There may be a role for syndrome support groups —engaging_____in information dissemination work to ensure teachers have quality information focussing on areas relevant to educational practices. The provision of an education support worker who might visit schools to advise teachers might be beneficial. It may also be useful for the syndrome groups to collaborate and explore the possibility of delivering a training module on educational aspects of genetic syndromes online, as this can ensure that teachers get the most up to date information in a way that is likely to be most efficient for them.

Diagnosis of Comorbid Neurodevelopmental and Mental Health Conditions

Although children with fragile X were more likely to be diagnosed with ASD and ADHD compared with the other syndrome groups, it is still important that children with fragile X are screened and considered for these disorders as a diagnosis of ASD and ADHD may help in terms of access to services and treatments. In the current study, only 5% of parents and 2% of teachers of children with fragile X syndrome reported that the child had ever been diagnosed with a mental health condition. This is in contrast to research studies which suggest high rates of anxiety disorder in children with fragile X syndrome—Colin reference be given here with list at end of report of a/some published papers which report high rates of anxiety disorder in children with fragile X?. The low rates of diagnosis of mental health difficulties in fragile X reported in this survey suggests that children are not getting diagnosed with these conditions despite the research findings. There is a need to further explore reasons why children with fragile X do not receive these diagnoses. The lack of recognition of mental health conditions is likely to have significant ~~impact on~~impact on the quality of life of the children and their families. If the conditions are not recognised it is unlikely that they will be treated effectively and thus the symptoms may continue to be impairing for significant periods of time.

Use of Medication for Psychiatric Behavioural Reasons

The use of medication for psychiatric and behavioural reasons was highest in the fragile X syndrome group, with just under 20% of the children reportedly taking medication. In the fragile X syndrome group the two most commonly used medications were methylphenidate (Ritalin or Concerta) and Risperidone. A previous survey of the use of medication in fragile X syndrome in the US reported that 91% of males and 81% of females were taking medication for behaviour or psychiatric ~~symptoms.~~symptoms. It may be that in the UK there is a lack of belief in the efficacy of psychopharmacology in genetic syndromes and there may be significant differences in prescribing practices in the UK and Ireland compared with the US. Exploring attitudes among parents and health professionals in the UK may help add to an understanding of when medication is useful in fragile X for behavioural and psychiatric reasons.

Teaching Approaches Based on what Parents and Teachers had Researched

The current study suggests that the syndromes do differ with respect to the use of a number of teaching approaches deemed to be important based on what parents and teachers have researched. The use of ‘side-on teaching’ was mentioned primarily by parents of fragile X syndrome and not the other syndromes. Some approaches

~~mentioned~~mentioned in guidelines for children with fragile X were rarely mentioned by parents and teachers. The need to avoid direct questioning in children with fragile X syndrome and the relative strength in simultaneous ~~processing~~processing has been suggested by a number of ~~authors.~~authors. However, these were rarely referred to by parents or teachers in this study. It would appear that parents and teachers are not often aware of the more specific syndrome specific guidelines which reflect more subtle aspects of a syndrome's cognitive and behavioural profile. There may thus be a need for awareness raising on the more specific aspects of the learning and behavioural profile in fragile X.

Teacher Views on Best Teaching Approaches and importance of child's syndrome

The need for 'side on teaching', an approach specifically recommended for fragile X syndrome was not mentioned at all by teachers when asked what works best. This is somewhat surprising given the emphasis on this in published guidelines. ~~Colin [CR5] – could titles of these published guidelines be referenced here and listed at end of report? –~~ Therefore, there is some evidence that what is emphasised in published guidelines for the syndromes is not always reflected in actual practice. There are a number of possible reasons for this, including the possibility that some of the guidelines are not useful or at least not useful with all of the children with the syndrome. Another possibility is the teachers are not using the most effective approaches and should be adhering more closely to the published guidelines.

Only 20% of teachers of children with fragile X syndrome thought that children's needs were different or distinct from other children with intellectual disability. The fact that the majority of teachers feel that the needs of the children are similar to the needs of others with intellectual disability might indicate that teachers do not see a consideration of fragile X as important in educational planning. The lack of intervention studies to assess different approaches means there is no clear evidence to guide practice and as a result some students may be benefiting from efficacious approaches whereas other may not be benefiting from less useful approaches. There is a need for more studies of educational interventions in fragile X to identify most efficacious strategies and approaches.

Impact on the Family of Fragile X Syndrome

Fragile_X syndrome clearly has very significant impact on family functioning. The most often mentioned ~~restrictions~~ were going shopping and taking holidays. The most often mentioned ~~challenges~~ included ~~difficulties~~ with social skills and learning issues. In terms of future concerns, capacity for independent living and future care when parents are gone, were most often mentioned. On the parent support ~~checklist,~~ the checklist, the needs most often ~~endorsed~~ referred to future options/needs highlighting that ~~parents need~~ parents need support and information around ~~transitions~~ and future provision. Psychosocial, psycho-educational and emotional supports need to be

targeted at all family members given the impact of fragile X syndrome on parents, siblings and the wider family.

The fact that 95% of parents reported at least one positive aspect emphasises the importance of genetic counsellors providing information on potential positive aspects of the syndrome and providing a balanced view of the impact of the syndrome on family functioning.

Relevant Resources [CR6] ~~(please take away as you see fit)~~ [CR7]

~~Colin – could you add a reference list including the published paper(s) reporting anxiety in children with fragile X and teaching guidelines that I asked for in the summary section?~~

~~Amongst the guidelines were you thinking of the Fragile X Society's booklet 'Introductory Guide to Educational Needs and how they can be met' and the book 'Educating Children with Fragile X Syndrome: a Multi-Professional View' edited by Dr Denise Dew Hughes?~~

Anxiety

- Cordeiro, L., Ballinger, E., Hagerman, R. & Hessel, D. (2011). Clinical assessment of DSM-IV anxiety disorders in fragile X syndrome: prevalence and characterisation. *Journal of Neurodevelopmental Disorders*, 3, 57-67.

Education

- Braden, M. (2000a). *Curriculum guide for individuals with fragile X syndrome*. Colorado: Author.
- Braden, M. (2000b). *Fragile: Handle with care. More about fragile X syndrome - adolescents and adults*. Dillon, CO: Spectra Publishing Co.
- Dew Hughes (Ed.) (2004) *Educating children with fragile X syndrome*. London: Routledge Falmer
- Stackhouse, T. & Scharfenaker, S. (2006). Hyperarousal and fragile X syndrome. *National Fragile X Foundation Quarterly*, 24, 28-29.
- Spiridigliozzi, G., Lachiewicz, A.M., MacMurdo, C.S., Vizoso, A.D., O'Donnell, C.M., McConkie-Rosell, A. et al. (1994). *Educating boys with fragile X syndrome. A guide for parents and professionals*. Durham, NC: Duke University Medical Center.

Published papers based on this study:

- [Reilly, C., Senior, J. & Murtagh, L. \(2015\). The impact on the family of four neurogenetic syndromes: A comparative study of parental views". *Journal of Genetic Counselling*, 24, 851-61.](#)
- [Reilly, C., Senior, J. & Murtagh, L. \(2015\). 'Behavioural phenotypes in the classroom: a qualitative study of parental and teacher knowledge of classroom guidelines and teacher views on best practices'. *Journal of Research on Special Educational Needs* DOI: 10.1111/1471-3802.12097.](#)
- [Reilly, C., Senior, J. & Murtagh, L. \(2015\). ASD, ADHD, mental health conditions and psychopharmacology in neurogenetic syndromes: parent survey, *Journal of Intellectual Disability Research*, 59: 307-318.](#)
- [Reilly C., Senior J, Murtagh L. \(2015\). A comparative study of educational provision for children with neurogenetic syndromes: parent and teacher survey. *Journal of Intellectual Disability Research*, 59, 1094-1107](#)

:

~~A comparative study of educational provision for children with neurogenetic syndromes: parent and teacher survey. *Journal of Intellectual Disability Research* 2015~~

~~Behavioural phenotypes in the classroom: a qualitative study of parental and teacher knowledge of classroom guidelines and teacher views on best practices. *Journal of Research in Special Educational Research* 2015~~

~~The impact on the family of four neurogenetic syndromes: A comparative study of parental views. *Journal of Genetic Counselling* 2015~~