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A comparative study of educational provision for children with neurogenetic syndromes: parent and teacher survey

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Abstract

Background A number of neurogenetic syndromes have a high association with special educational needs including fragile X syndrome (FXS), Prader–Willi syndrome (PWS), Williams syndrome (WS) and Velo-Cardio-Facial syndrome (VCFS). There is a paucity of research on educational provision for children affected by these syndromes.

Method Parents (n = 381) and teachers (n = 204) of school-aged children with one of the four syndromes in the UK and Ireland were surveyed in a range of areas concerning the child's educational provision. Areas surveyed included school placement, views on the needs of children with the syndromes, desired changes to current provision and perceived teacher knowledge.

Results School placement in mainstream settings decreased with age in all of the syndromes. Males with the syndromes were more likely to be in specialised educational settings with the exception of WS. Teachers reported limited input on initial or subsequent training for all of the syndromes. The majority of teachers did not view the needs of children with syndromes as different from other children with intellectual disability (ID) although there were significant differences between the syndromes. Changes deemed necessary to provision by parents and teachers differed between the syndromes indicating the existence of perceptions of syndrome specific needs. The lowest perceived level of teacher knowledge was in the VCFS group.

Conclusion The majority of teachers of children with neurogenetic syndromes report limited knowledge of the syndromes, but also a lack of belief that the children's needs are different from the majority of children with ID. Differences between the syndromes in some areas of provision suggest that a child's syndrome does impact on educational provision in some areas.

Keywords educational provision, fragile X syndrome, Prader–Willi Syndrome, special educational needs, Velo-Cardio-Facial syndrome, Williams syndrome

Introduction

The term 'behavioural phenotype' is often used to denote the increased likelihood that individuals with a given syndrome will display certain behavioural and

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cognitive characteristics relative to those without the syndrome (Dykens 1995). There is some evidence of distinctive cognitive and behavioural profiles in a number of genetic syndromes associated with intellectual disability (ID) and/or special educational needs (Rosner et al. 2004). This has led to the view that educators need to be aware of the distinctive learning and behavioural profiles associated with the syndromes, so that educational programmes can be adapted to capitalise on learning strengths or intensively ameliorate needs (e.g. Dykens & Hodapp 2001; Campbell et al. 2009). Children with Prader–Willi syndrome (PWS) are more likely to display hyperphagia (excessive interest in food), and children with Williams syndrome (WS) more likely to display hypersociability (excessive sociability) compared to others without these syndromes. Based on syndrome-specific data, recommendations now exist for syndrome specific interventions for the classroom in a number of syndromes (e.g. Braden 2002; Dew-Hughes 2004; Chedd et al. 2006; Cutler-Landsman 2007). For example, it has been suggested that in WS there is a need to capitalise on the children's relative auditory/verbal strengths (Semel and Rosner 2003). However, none of the recommendations have been systematically evaluated (Dykens and Hodapp 2001).

Unlike Down syndrome, the most common neurogenetic syndrome associated with ID, there is lack of published research on aspects of educational provision for children with four of the most common neurogenetic conditions including fragile X syndrome (FXS), PWS, WS and Velo-Cardio-Facial syndrome (VCFS) (also known as 22q11.2 deletion syndrome). This lack of knowledge may hinder the development of an understanding of the impact of research on cognition and behaviour on classroom practices in these syndromes. It is argued that knowledge of genetic aetiology aids the early identification of syndrome-specific learning and behavioural profiles and allows teachers to develop more effective interventions (Hodapp and Fidler 1999). For example, focusing on auditory strengths in WS should lead to faster acquisition of reading than other approaches to reading such as visual approaches (Semel & Rosner 2003).

One way of establishing whether syndromes have unique needs is to compare syndromes with respect to aspects of educational provision. Comparative studies of educational provision that have been carried out in genetic syndromes have focussed on parental as opposed to teacher perceptions (Fidler et al. 2002; e.g. Hodapp et al. 1998; Fidler et al. 2003). Hodapp et al. (1998) reported that parents of children with PWS reported greater dissatisfaction with the current curricula and made more mention of 'Prader–Willi syndrome related' issues and concerns than parents of children with Down syndrome (Hodapp et al. 1998). In another study, parents of children with Down syndrome rated their children's syndrome as more important for educational purposes than parents of children with PWS or WS (Fidler et al. 2002). Fidler et al. (2003) reported that parents of children with WS more frequently indicated a desire for increased musical instruction and in-class support, whereas more parents of children with PWS expressed a desire for improvements in adaptive physical education services. These studies suggest that syndrome groups do differ with respect to parental perceptions of educational provision suggesting the need to consider a child's syndrome in educational planning.

FXS is the leading known cause of inherited ID (Greco et al. 2006) with a prevalence of 1 in 4000 for males and 1 in 8000 for females (Sherman 2002). It is caused by a CGG triplet repeat expansion on the X chromosome (Fu et al. 1991). There is a high association with Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and anxiety disorders (Reilly 2012). Cognitive functioning is typically in the moderate ID range for males (Hall 2009), while females are typically less severely affected. PWS is characterised by hyperphagia, a range of physical and behavioural characteristics and cognitive impairment typically in the mild ID range (Whittington & Holland 2004). The prevalence is estimated to be 1 in 8000 to 1 in 45 000 (Butler 1990; Cassidy 1997; Whittington & Holland 2004). PWS is caused by the absence of expression of one or more genes at the locus q11–q13 on chromosome 15 (Whittington & Holland 2004). WS is a condition associated with mild ID (Martens et al. 2008), a range of medical conditions (Morris 2005) and an increased risk for difficulties with attention, fears/phobias and social disinhibition (Jones et al. 2000; Leyfer et al. 2006). Estimated prevalence is 1 in 7,500 to 1 in 20,000 (Wang et al. 1997; Stromme et al. 2002). WS is caused by the deletion of approximately 20 genes on chromosome 7 (band 7q11.23). VCFS is associated with a range of

congenital and late-onset medical issues including congenital heart disease (Shprintzen 2005). Cognitive impairment is usually in the mild-borderline ID range (Green et al. 2009). There is an increased risk for difficulties with attention, anxiety and schizophrenia (Murphy et al. 1999; Feinstein et al. 2002). Estimated prevalence is 1 in 4000 (Goodship et al. 1998). VCFS is caused a microdeletion of chromosome 22 at band q11.2 (Scambler et al. 1992).

This research was part of a larger survey focussing on aspects of educational provision and psychosocial needs of children with neurogenetic syndromes carried out in the UK and Ireland in 2011 (Reilly et al. 2014). The primary aim of the current paper was to compare aspects of educational provision in the four neurogenetic syndromes. Specifically, we wanted to compare school placement (mainstream vs. specialised), teacher training needs and teacher views on the needs of the children with the specific syndrome. We also wanted to compare parent and teacher views on desired changes to educational provision and views on teacher knowledge of the syndromes.

Materials and methods

Recruitment and participants

No existing surveys were deemed suitable with respect to the aims of the current research so new surveys were developed for parents and teachers. This is the first time the surveys have been used and there are currently no psychometric data available. The parent and teacher survey was devised and piloted in consultation with the management/research committees of the relevant syndrome support groups in the UK and Ireland.

Participants were parents and teachers of children (4 to 19 years) with one of the four syndromes and were recruited via member databases of the support groups. An information letter, research pack and prepaid return envelope were sent to parents/guardians of children on the member databases of the support groups. Parents/guardians were asked to pass on a research pack to their child's head teacher who was asked to pass the survey to the child's teacher. The number of surveys distributed, and number of complete responses, within each syndrome is displayed in Table 1.

The response rate in the parent sample was 32% (range across syndromes 29–34%) and 17% (range 16%–18%) in the teacher sample. In 89% (n = 339) of cases the respondent to the parent survey was the child's mother. Respondents to the teacher survey included class teacher (68%), resource/specialist teacher (10%), subject teacher (3%) and 'other' (e.g. supporting paraprofessional, coordinator of special educational needs department) (19%). Teacher respondents had a mean of 17.76 years working in education, 13.41 years in special education and 1.44 years teaching/supporting the child. Statistically significant differences between the syndromes in terms of number of years working in education, special education or teaching/supporting the child were not found based on ANOVA analyses.

The number of matched pairs (i.e. parent and teacher surveys with the same code, indicating that parents and teachers responded about the same child) was 130, indicating that many of the teacher responses (64%) were based on a child about whom parents had also responded. Children whom participants reported on had a mean age of 11.12 years (parent sample) and 10.62 years (teacher sample). Significant differences between the syndromes in terms of child age were not found based on ANOVA analysis. There were significant differences between the syndromes based on gender in both samples (parent $X^2(3) = 28.27$, $p < .001$: teacher $X^2(3) = 17.82$, $p < .001$) likely reflecting the increased number of males with FXS.

Procedure and measures

Parent participants were asked to complete and return a 53-item survey and teachers a 40-item survey. Both parent and teacher surveys focussed on child demographics, medical/neurodevelopmental conditions, educational provision and family support needs. Parent and teacher questions relevant to the current paper are in Appendix 1 and 2. Parents and teachers were asked about the child's current school placement and choices were collapsed into two categories—'mainstream' and 'specialised'. The mainstream category was for students who attended a mainstream primary/secondary school but did not include special classes in such settings. The

Table 1 Survey distribution and response rate in EPGEN survey

Syndrome	Parental surveys distributed	Parental surveys returned and gender of child	Teacher surveys distributed	Teacher surveys returned and gender of child	Parent–teacher matches	Child: mean age
FXS	359	115 (32%) (M94:F21)	359	59 (16%) (M46:F13)	42	P11.58 T11.19
PWS	326	110 (34%) (M59:F51)	326	58 (18%) (M37:F21)	38	P11.20 T10.71
WS	259	80 (31%) (M40:F40)	260	45 (17%) (M20:F25)	29	P10.39 T11.33
VCFS	264	76 (29%) (M42:F33)*	264	42 (16%) (M18:F24)	21	P11.06 T9.52
Total	1209	381 (32%)	1209	204 (17%)	130	P11.12 T10.62

*Gender not recorded for one child, M = Male F = Female, P = Parent, T = Teacher, FXS = Fragile X Syndrome, PWS = Prader–Willi Syndrome, WS = Williams Syndrome, VCFS = Velo-Cardio-Facial Syndrome.

specialised designation was for all other types of educational placements. For children resident in the UK, parents and teachers asked about the provision of statements of special educational needs. In the UK a Statement of Special Educational Needs is a legal document that sets out a child's special educational needs as assessed by the Local Education Authority. The majority of children on the special educational needs register will not have a statement as it is reserved for children with the greatest level of need. Teachers were asked about input/training on the child's syndrome in initial and subsequent professional training.

Teachers were also asked whether they felt they would need further training on behavioural aspects of the syndromes or teaching strategies for the syndromes. Teachers were also asked four questions in relation to their views on educational provision for children with the syndrome. These questions were on a four point Likert scale and responses were subsequently recoded into two categories; 'Agree/Disagree'. Parents and teachers were asked about what changes to child's current educational provision would help the child and were given a range of options. Parents were asked if they agreed or disagreed that staff in their child's school are knowledgeable about their child's syndrome. Teachers were asked to indicate how knowledgeable they felt about the child's syndrome and were given four options.

Analysis

Logistic regression analysis was used to compare school placement and provision of statements of special educational needs. It was also used to compare teacher input on syndromes and teacher training needs, teacher views on the needs of children with neurogenetic syndromes and perceptions of teacher knowledge across the syndrome groups. FXS was used as the reference syndrome for these analyses except in the case of teacher training needs, as preliminary chi-square analyses suggested group differences which were not found when FXS was used as the reference syndrome. VCFS was subsequently used as the reference syndrome for this analysis. Odds Ratios (OR) were used to describe the strength of significant associations.

Chi-square analyses or Fisher Exact tests were carried out to compare the syndrome groups with respect to desired changes to child's educational provision, and to indicate the association of age and gender with school placement and provision of statements or special educational needs. Wilcoxon signed-rank test was used to compare parent and teacher responses in the matched sample (i.e. parent and teachers who were responding about the same child) with respect to desired changes to educational provision.

The study was granted ethical approval by the Human Research Ethics Committee at University College Dublin.

Results

Educational provision

Table 2 shows school placement and provision of statements of special educational needs. In the parent sample, children with FXS were less likely to be in mainstream school compared with PWS (OR 0.370 (95%CI 0.210–0.650); $p < 0.01$) and VCFS (OR 0.230 (95%CI 0.123–0.430); $p < 0.001$) but not WS. In the teacher sample, children with FXS were less likely to be in mainstream school compared with PWS (OR 0.246 (95%CI 0.0107–0.565); $p < 0.01$), WS (OR 0.331 (95%CI 0.136–0.805); $p < 0.05$) and VCFS (OR 0.081 (95%CI 0.031–0.210); $p < 0.001$). Children with FXS were more likely to have a statement compared with children with VCFS (OR 2.864 (95% CI 1.178–6.959); $p < 0.05$) but not the other syndrome groups in the parent sample. In the teacher sample significant differences were not noted between the syndromes.

In the parent sample, the children were divided into age categories in order to indicate school placement and provision of Statements according to age, and results of this categorisation are in Table 3.

There was a significant difference between the three age groups with respect to attendance at mainstream schooling ($X^2(1) = 44.82$; $p < 0.001$). The percentage of children attending mainstream schooling was lower in the oldest age category in all of the syndromes. With respect to provision of statements, there was a significant difference between the three age groups ($X^2(1) = 9.48$; $p < 0.05$) with lowest level of provision at the youngest age range.

In the parent sample, the children were also divided by gender to illustrate the association of this variable with school placement/Statements and the results of this categorisation are shown in Table 4.

In the total sample, significantly more males were attending specialised settings than females ($X^2(1) = 25.15$; $p < 0.001$). There was a pattern of a higher percentage of females in mainstream settings and males in specialised settings in all syndromes except WS. With respect to Statements the biggest difference

Table 2 School placement and Statement of Special Educational Needs in parent (P) and teacher (T) samples

	P	T	P	T	P	T	P	T	P	T
Provision	**FXS**		**PWS**		**WS**		**VCFS**		**Total**	
Mainstream	29(25%)	11(19%)	52(48%)	28(48%)	28(35%)	18(41%)	44(60%)	31(74%)	153(41%)	88(43%)
Specialised	86(75%)	48(81%)	57(52%)	30(52%)	52(65%)	26(59%)	30(41%)	11(26%)	225(60%)	115(57%)
Statement	90(90%)	44(90%)	90(90%)	44(90%)	74(93%)	44(98%)	44(76%)	20(74%)	298(88%)	152(89%)

P = Parent, T = Teacher FXS = Fragile X Syndrome, PWS = Prader–Willi Syndrome, WS = Williams Syndrome, VCFS = Velo-Cardio-Facial Syndrome.

Table 3 School placement and provision of statements according to age category in the parent sample

Age range	**4–9 years**			**10–13 years**			**14–19 years**		
Provision	**Main**	**Special**	**State**	**Main**	**Special**	**State**	**Main**	**Special**	**State.**
FXS (n = 115)*	39%	61%	91%	22%	78%	86%	9%	91%	93%
PWS (n = 109)*	69%	31%	82%	51%	49%	94%	11%	89%	96%
WS (n = 80)*	62%	38%	82%	22%	78%	100%	9%	91%	100%
VCFS (n = 74)*	65%	35%	74%	56%	44%	70%	54%	46%	100%

Main = Mainstream educational setting, Special = Specialised educational setting, State = Statement of Special Educational Needs.
*n value is lower for all of the syndromes for provision of statements.

Table 4 School placement according to gender in the parent sample

Gender			**Male**			**Female**
Provision	Mainstream	Specialised	Statement*	Mainstream	Specialised	Statement*
FXS (n = 115)	16%	84%	95%	67%	33%	66%
PWS (n = 109)	39%	61%	91%	58%	42%	89%
WS (n = 80)	35%	65%	90%	35%	65%	95%
VCFS (n = 74)	46%	54%	79%	75%	25%	71%

*n value is lower for all of the syndromes for provision of statements. FXS = Fragile X Syndrome, PWS=Prader–Willi Syndrome, WS = Williams Syndrome, VCFS = Velo-Cardio-Facial Syndrome.

between the syndromes was in the FXS group where more males than females had a statement. However, in the total sample there was not a significant difference between males and females.

Teacher input on syndromes and training needs

Teachers (n = 204) were asked if they had received input on the child's syndrome in initial/subsequent training. While 17 (29%) teachers of children with FXS received input, the percentage who received input in the other syndromes was lower (PWS 4 (7%), WS 1 (2%), VCFS 1 (3%)). Compared with FXS, teachers of children with PWS (OR 5.464 (95% CI 1.711–17.456); $p < 0.01$), WS (OR 17.810 (95% CI 2.268–139.821); $p < 0.01$) and VCFS (OR 15.786 (95%CI 2.005–124.269); $p < 0.01$) were significantly less likely to have received input. In relation to the need for training on teaching strategies, teachers of children with VCFS (60%) most frequently expressed a desire for training (FXS 46%, PWS 38% and WS 52%). The number of teachers in the VCFS group who wanted more training on teaching strategies was significantly greater compared to PWS (OR 2.406 (95%CI 1.067–5.426; $p < 0.05$)), but not the other groups. The need for training on behavioural aspects was expressed by the majority of teachers in all of the syndrome groups (FXS 53%, PWS 66% and WS 59% VCFS 53%), but was significantly less in VCFS compared with the PWS (OR 0.395 (95%CI 0.174–0.893); $p < 0.05$), but not the other groups.

Teacher views on needs of children with neurogenetic syndromes

The responses of teachers in relation to views on resources and needs of children with the syndromes are shown in Table 5.

Seventy-three percent of teachers disagreed that teachers are given adequate resources to teach children with the syndromes. There were no significant differences between the syndromes. Sixty-five percent of teachers agreed that the needs of children with the syndrome are of a similar nature to children with ID because of other causes. Teachers of children with FXS were significantly more likely to agree with this statement than teachers of children with PWS (OR 0.244 (95%CI 0.105–0.571); $p < 0.01$) or WS (OR 0.331 (95%CI 0.133–0.821; $p < 0.05$)), but not VCFS. Sixty-nine percent of teachers agreed that the children have very complex needs and need very specialised supports, and 71% agreed that children with the syndromes will struggle to reach their potential in mainstream educational settings. There were no significant differences between the groups for these two questions.

Desired changes to child's educational provision

Respondents in both samples were asked to indicate the changes to the child's current educational provision which would help the child most. Responses and are shown in Table 6.

Significant differences between the syndromes were found in four areas of provision in the parent sample. In the areas of handwriting/fine motor skills, hygiene/care skills and access to computers, parents of children with WS most often expressed a desire for an increase in resources. The need for a smaller pupil-teacher ratio was endorsed most often by parents of children with VCFS. A significant difference between the syndromes was found in four areas in the teacher sample. Teachers of children with FXS and WS most frequently expressed a need for increased resources in

Table 5 Teacher views on aspects of educational provision for children with neurogenetic syndromes

Item	FXS		PWS		WS		VCFS		Total	
	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree
Teachers are given adequate resources teach the child with syndrome (n = 190)	33%	67%	22%	78%	37%	63%	16%	84%	27%	73%
The needs of children with genetic syndromes are similar to children with intellectual disability because of other causes (n = 190)	80%	20%	50%	50%	58%	43%	70%	30%	65%	35%
Children with syndrome have very complex needs and require very specialised supports (n = 199)	70%	30%	76%	24%	70%	30%	55%	45%	69%	31%
Children with the syndrome will struggle to reach their potential in mainstream educational settings (n = 192)	70%	30%	79%	21%	67%	33%	67%	33%	71%	29%

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

Table 6 Views on changes in educational provision that would help the child most

	FXS		PWS		WS		VCFS		Total	
Increase in resources for	**P n = 112**	**T n = 59**	**P n = 109**	**T n = 58**	**P n = 76**	**T n = 45**	**P n = 75**	**T n = 42**	**P n = 372**	**T n = 204**
One-to-one time with teacher	46%	42%	42%	31%	41%	33%	47%	36%	44%	36%
Independence skills	51%	27%	34%	28%	46%	29%	43%	26%	43%	28%
Social skills	47%	32%	38%	29%	42%	24%	40%	17%	42%	27%
Handwriting/fine motor skill P**$\chi^2(3) = 8.38$	46%	25%	33%	26%	53%	22%	37%	21%	42%	24%
Hygiene/care P***$\chi^2(3) = 16.82$	47%	9%	28%	9%	55%	11%	37%	0%	41%	7%
Mathematics T**$\chi^2(3) = 7.86$	38%	24%	39%	19%	38%	4%	45%	24%	40%	18%
Communication T**$\chi^2(3) = 10.94$	41%	31%	30%	24%	28%	4%	31%	24%	33%	22%
Small pupil–teach ratio P**$\chi^2(3) = 10.37$	24%	25%	29%	35%	24%	36%	44%	50%	30%	35%
Reading	34%	15%	26%	17%	36%	7%	24%	14%	30%	14%
Gross motor skills	30%	20%	30%	17%	36%	11%	27%	7%	30%	15%
Computers P***$\chi^2(3) = 14.21$	27%	12%	18%	21%	41%	16%	19%	17%	26%	16%
Spelling	27%	9%	24%	9%	32%	2%	20%	14%	26%	8%
LSA/SNA T***$\chi^2(3) = 12.93$	26%	10%	17%	19%	21%	16%	33%	38%	24%	20%
Music/art T*F = 20.00	21%	5%	20%	7%	33%	31%	17%	2%	22%	11%
Supporting behaviour	23%	15%	28%	12%	18%	4%	15%	2%	22%	9%
Other	5%	15%	13%	9%	15%	11%	8%	14%	10%	12%

*$p < 0.001$ **$p < 0.05$ ***$p < .01$, F = Fisher's Exact Test was used. P = Parent Sample, T = Teacher Sample. LSA/SNA = Learning Support Assistant/Special Needs Assistant.

mathematics. In the area of music/art, teachers of children with WS most often endorsed a need for increased provision. With regard to resources to promote communication skills, teachers of children with FXS most often indicated a desire for an increase. Teachers of children with VCFS were most likely to seek additional support from a Learning Support Assistant (LSA)/Special Needs Assistant (SNA) (supporting paraprofessional). In the matched sample, significant differences were found between parents and teachers with respect to increased resources for mathematics ($z = -4.061$; $p < .001$), reading ($z = -2.777$; $p < .01$), spelling ($z = -3.212$; $p < .01$), social skills ($z = -2.562$; $p < .05$), gross motor skills ($z = -2.654$; $p < .01$), music/art ($z = -3.272$; $p < .001$), fine motor/handwriting ($z = -2.598$; $p < .01$), behaviour ($z = -3.182$; $p < .001$) and hygiene ($z = -5.515$; $p < .001$) based on Wilcoxon signed-rank test. In all these areas, the need for increased resources was most often expressed by parents.

Perceptions of teacher knowledge

Parents were asked if they agreed or disagreed with the statement that 'staff in their child's school are knowledgeable about their child's syndrome'. Fifty-five percent of parents of children with VCFS disagreed that school staff were knowledgeable about the child's syndrome, whereas in the other syndrome groups less than half of parents (FXS 28%, PWS 23% and WS 23%) disagreed. Compared with the FXS group, parents of children with VCFS (OR 0.237 95%CI 0.123–0.457; $p < 0.001$) were less likely to agree that staff were knowledgeable about their child's condition while there was not a significant difference between FXS and the other syndromes groups. Respondents to the teacher survey were asked to indicate how knowledgeable they felt about the child's syndrome and results are displayed in Table 7.

In the FXS and VCFS groups, there was a higher level of reported knowledge in mainstream settings although the majority in this setting still reported 'Limited/No Knowledge'. The opposite pattern was the case for the PWS and WS groups with greater number of respondents in specialised settings reporting that they were 'Very Knowledgeable/ Knowledgeable'. In the total teacher sample, 56% reported that they had 'Limited or No Knowledge'. The lowest level of knowledge was reported by teachers of children with VCFS and highest by teachers of children with PWS. Compared with teachers in the FXS group, teachers of children with PWS (OR 0.256 95%CI 0.119–0.554; $p < 0.01$) reported a significantly higher level of knowledge. There was no difference between the FXS group and the other syndrome groups.

Discussion

This study was the largest to date to examine aspects of educational provision for children affected by four of the most common genetic syndromes with associated special educational needs. While the overall response rate in the teacher sample was low, there have been no previous studies which had compared the views of teachers of children with different genetic syndromes on aspects of educational provision.

Children with FXS had the highest frequency of specialised school placement and children with VCFS the highest frequency of placement in mainstream settings. This likely reflects the differences in mean levels of cognitive impairment between the groups. In all of the syndromes, there were more children attending specialised educational settings in the oldest age category, likely reflecting the increasing demands of the curriculum with age and widening gaps between typically developing peers and the child with the syndromes. While over 90% of students with FXS, PWS and WS had a Statement of Special Educational Needs, only three quarters of students with VCFS had a statement. This lower level of provision might reflect a lower severity of special educational needs in VCFS. It is also possible that the children's learning and behavioural needs have not been adequately identified.

In the total sample, only 11% of teachers reported that they had received input on the child's genetic syndrome via initial or subsequent training. This lack of training is likely to have significant implications on teachers' views on the importance of the child's syndrome to education planning. If teachers have not received any input on the syndrome, they may not be aware of the cognitive and behavioural profiles associated with the syndrome or the published guidelines on classroom strategies. While 38% of

Table 7 Teacher views on their knowledge of child's syndrome in mainstream and specialised settings

	Mainstream		Specialised	
Syndrome	**Very knowledgeable/ knowledgeable**	**Limited/no knowledge**	**Very knowledgeable/ knowledgeable**	**Limited/no knowledge**
FXS	5(45%)	6(55%)	14(30%)	33(70%)
PWS	16(57%)	12(43%)	22(73%)	8(27%)
WS	5(28%)	13(72%)	12(46%)	14(54%)
VCFS	12(40%)	18(60%)	2(18%)	9(82%)

teachers of children with PWS indicated a need for training on teaching strategies, 60% of teachers of children with VCFS indicated that they would like further training. This higher need in VCFS might reflect the lower knowledge levels reported by teachers of children with VCFS in the current study and that published guidelines for the syndrome have only been available since 2007 (Cutler-Landsman 2007).

Nearly two thirds of teachers felt that the needs of children with the syndrome were similar to the needs of other children with ID suggesting that the majority of teachers do not see the child's aetiology as vital in educational planning. In the PWS group, 50% of teachers felt that the needs of children with this syndrome were similar to other children with ID, whereas the equivalent figure was 80% in the FXS group. This indicates that there may be differences between the syndromes with respect to the importance placed by teachers on the aetiology of the child's condition in relation to educational planning. With regard to attendance at mainstream schooling, 71% of teachers were of the view that the children with the syndrome would find it difficult to reach their potential in mainstream settings. Such a figure suggests that the children who currently attend mainstream may face challenges including teacher expectations that they will struggle to reach their potential.

There were significant differences between the syndromes with respect to areas where respondents felt that changes to educational provision were needed. In the parent sample, there were significant differences between the syndromes with regard to the desire for increased resources for handwriting/fine motor skills, computers and hygiene/care skills, all with the greatest need in WS. The desire for increased resources for handwriting/fine motor skills resources could be seen to reflect a previously noted need in this area in WS (e.g. Udwin et al. 2007), but the findings with respect to the other areas have not previously been described. The need for a smaller pupil-teacher ratio was expressed most often by parents of children with VCFS, possibly reflecting the higher percentage of children with VCFS attending mainstream educational settings. In the teacher sample, significant differences were found with respect to an increase in resources for mathematics, music/art, communication and paraprofessional allocation. With regard to mathematics, the greatest desire for an increase was in FXS and VCFS. Relative difficulties in mathematics have been noted in VCFS (e.g. Campbell & Swillen 2005) and FXS (e.g. Gibb 1996), but have also been noted in WS (e.g. Paterson et al. 2006). With regard to an increase in Music/Art resources, the highest frequency was in the WS group which is partly in line with expectations as music is seen as a relative strength in the syndrome (e.g. Lenhoff 1998). The difference between the syndromes with respect to increased resources for communication is likely to reflect a low need for an increase expressed by teachers of children with WS. Expressive communication has been identified as a relative strength in WS (Mervis & Klein-Tasman 2000). Teachers of children with VCFS expressed a need for an increase in paraprofessional allocation, possibly reflecting a higher level of placement in mainstream schooling, but also the reported difficulties the children have with attention and group learning (Cutler-Landsman 2007).

Less than a quarter of parents of children with VCFS felt that staff in their child's school were knowledgeable about their child's condition compared with more than 50% in the other

syndromes. Perceptions of lower levels of knowledge of VCFS echoes a US study which found that teachers demonstrated a lower awareness of VCFS compared with FXS (Lee et al. 2005). With respect to teacher views regarding their knowledge of the child's syndrome, 56% in the total sample indicated that they had 'little or no knowledge' of the child's syndrome. Two thirds of teachers of children with PWS indicated that they were knowledgeable whereas in the other syndrome groups only one third of teachers reported that they were knowledgeable. Teachers are not likely to adopt aetiology related approaches if they are not knowledgeable about the condition. It has been argued that it is crucial that teachers understand the nature and characteristics of specific syndromes (Lee et al. 2005) although many teaching techniques may be useful regardless of diagnosis (Starr et al. 2006).

Limitations

The teacher response rate was particularly low, and thus considerable caution is needed when interpreting results. The sample was a convenience sample in that all respondents were members of family support groups and may not be representative of the total population affected by the syndromes in the UK and Ireland. Questions about educational provision referred to one time point only and views on provision may change as the child progresses through school, so longitudinal work would be useful.

As there were no preexisting surveys deemed suitable for the study, the parent and teacher surveys were developed specifically for the current study. Although the surveys were developed in close collaboration with family support groups there is a lack of data on the validity or reliability of the surveys. Because of the sampling method employed it was not possible to verify genetic diagnosis. Information on the children's level of cognitive functioning was not available and would have been useful with respect to understanding aspects of educational provision.

Summary

Differences between the syndromes in some areas of educational provision suggest that a child's syndrome does impact on educational provision. The significant differences between the syndromes in relation to aspects of desired educational provision among both parents and teachers may influence educational planning, and lead to some syndrome specific approaches in classroom settings. However, the majority of teachers in the current study felt that the needs of children with genetic syndromes are similar to children with ID because of other causes, and this is concerning if one adopts the view that aetiology is important with respect to educational planning. Knowing that a child with WS should do better with a phonics approach to reading and boys with FXS are likely to better with visual approaches would appear useful. However, while there are published guidelines in the area of learning and behaviour for each of the four reviewed syndromes there is a limited amount of evidence of the efficacy of such approaches in school settings (Reilly 2012). There is thus a need for more intervention studies in educational settings for each of the syndromes to test approaches hypothesised to be useful.

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Appendix I: Parent questions

Type of schooling*

What type of school is your child currently attending?

Mainstream class in primary	❒	Home tuition/schooling	❒
Mainstream class in secondary	❒	Class in special school	❒
Special class/unit in primary	❒	Special class/unit in special school	❒
Special class/unit in secondary	❒	Special residential school	❒
Other	❒		

If 'Other' Please give details: _____

*Categories subsequently collapsed into 'mainstream' and 'specialised' categories.

Statement of special educational needs or co-ordinated support plan

Has child got a Statement of Special Educational Needs?

Yes ❒ No ❒

Desired changes to child's educational provision

Increased one-to-one time with a teacher	❒	Increased resources for Fine Motor Skills or Handwriting	❒
Increased resources for Mathematics	❒	Increased resources for Computers/IT	❒
Increased resources for Reading	❒	Increased resources for Communication Skills	❒
Increased resources for Spelling	❒	A smaller teacher–pupil ratio	❒
Increased resources for Social Skills	❒	Increased resources for supporting Positive Behaviour	❒
Increased resources for Gross Motor Skills (e.g. Physiotherapy or Physical exercise)	❒	Increased resources for Independence Skills	❒
Increased resources for Music/Art	❒	Increased resources for developing Personal Hygiene/Care Skills	❒
Increased resources for an LSA	❒	Other	❒

Appendix (Continued)

Perceptions of teacher knowledge

	Strongly disagree	Disagree	Agree	Strongly agree
School staff are knowledgeable about my child's syndrome	❒	❒	❒	❒

Appendix 2: Teacher questions

- Type of schooling*

What type of school is child currently attending?

Mainstream class in primary	❒	Home tuition/schooling	❒
Mainstream class in secondary	❒	Class in special school	❒
Special class/unit in primary	❒	Special class/unit in special school	❒
Special class/unit in secondary	❒	Special residential school	❒
Other	❒		

If 'Other' Please give details: _____

*Categories subsequently collapsed into 'mainstream' and 'specialised' categories.

Statement of special educational needs

Has child got a Statement of Special Educational Needs?

Yes ❒ No ❒

Teacher training

Did you receive any input on child's syndrome, in your initial training or via subsequent professional training:

Yes ❒ No ❒

What training would be most helpful to you as the child's teacher?

Training on behavioural aspects of child's syndrome	❒	Training on teaching strategies for children with named syndrome	❒

Teacher views on needs of children with neurogenetic syndromes

	Strongly disagree	Disagree	Agree	Strongly agree
Teachers are given enough supports/resources to teach children with VCFS*	❒	❒	❒	❒
The needs of children with VCFS are of a similar nature to children with intellectual disability because of other causes	❒	❒	❒	❒

Appendix (Continued)

	Strongly disagree	Disagree	Agree	Strongly agree
Children with VCFS have very complex needs and need very specialised supports	❒	❒	❒	❒
Most children with VCFS will struggle to reach their potential in mainstream educational settings	❒	❒	❒	❒

*VCFS was changed to FXS, PWS or PWS depending on the child's syndrome.

Desired changes to child's educational provision

Increased one-to-one time with a teacher	❒	Increased resources for fine Motor Skills or Handwriting	❒
Increased resources for Mathematics	❒	Increased resources for Computers/IT	❒
Increased resources for Reading	❒	Increased resources for Communication Skills	❒
Increased resources for Spelling	❒	A smaller teacher-pupil ratio	❒
Increased resources for Social Skills	❒	Increased resources for supporting Positive Behaviour	❒
Increased resources for Gross Motor Skills (e.g. Physiotherapy or Physical Exercise)	❒	Increased resources for Independence Skills	❒
Increased resources for Music/Art	❒	Increased resources for developing Personal Hygiene/Care Skills	❒
Increased resources for an LSA	❒	Other	❒

Perceptions of teacher knowledge

How do you feel in relation to your knowledge of 22q deletion syndrome now?

Very knowledgeable ❒	Knowledgeable ❒	Have limited knowledge ❒	Have little or no knowledge ❒