

Behavioural phenotypes in the classroom: a qualitative study of parental and teacher knowledge of classroom guidelines and teacher views on best practices

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Research suggests that genetic syndromes associated with intellectual disability often have specific cognitive and behavioural profiles. It has been suggested that educational approaches need to reflect these profiles. Parents (n = 381) and teachers (n = 204) of children with one of four syndromes, fragile X syndrome, Prader–Willi syndrome, Williams syndrome and velo-cardio-facial syndrome were surveyed. Syndromes were compared with respect to what parents and teachers had researched or been told with respect to appropriate educational approaches. Parent and teacher reports were subsequently compared with actual published guidelines on the syndromes. Teachers were also surveyed on what they felt were successful approaches based on actual experiences of teaching the children. Parent and teacher reports of efficacious strategies for supporting their children based on what they had been researched or been told differed across syndromes as might be anticipated. However, differences between parents and teachers and between parent/teacher reports and the published guidelines suggest that parent and teacher knowledge of guidelines is deficient and/or that parents and teachers are accessing knowledge elsewhere. With respect to teaching practices, there were much less differences between the syndromes than in the published guidelines indicating that differences between syndromes in guidelines may not be as evident in practice.

Introduction

In the context of genetic syndromes associated with special educational needs, behavioural phenotypes can be defined as involving the ‘heightened probability or likelihood that people with a given syndrome will exhibit certain behavioural and developmental sequelae relative to those without the syndrome’ (Dykens, 1995, p. 523). There is now considerable evidence to support the view that a number

of genetic syndromes have well-established behavioural phenotypes (Masters-Glidden and Schoolcraft, 2007) that differ markedly across several domains, including academic skills, communication skills, visual-spatial skills, social skills and emotional functioning. It has been claimed that understanding the behavioural phenotype associated with a genetic syndrome is vital in order to select appropriate educational remediation strategies for children with that syndrome (Campbell, Daly and Toal et al., 2009).

For those who argue that aetiology or syndrome is important with respect to educational planning (e.g., Hodapp and Dykens, 2001), it is hypothesised that knowledge of genetic aetiology may aid early identification of syndrome-specific cognitive and behavioural profiles. By utilising these profiles, it is proposed that teachers can develop more targeted and effective interventions (Hodapp and Fidler, 1999). The view that the syndrome a child has is important with respect to educational planning is not universally accepted. Hallahan and Kauffman (2000) argue that the focus of educational programmes should vary according to the degree of the student’s intellectual disability. Abbeduto and Keller-Bell (2002) describe calls for curricula for individual syndromes as reflecting ‘insularity’ and advocate the importance of recognising that common problems exist across syndromes.

Clinic-based research focusing on behavioural phenotypes often includes conclusions about the findings/results helping identify possible school and home-based intervention strategies (e.g., Pérez-García, Granero and Gallastegui et al., 2011). Based on syndrome-specific data, recommendations now exist for syndrome-specific interventions for the classroom, employment and everyday living, all with the aim of optimising autonomy, competence and inclusion (e.g., Dykens and Hodapp, 1997; Dykens, Hodapp and Finucane, 2000; Hodapp and Fidler, 1999). However, none of the recommendations have been systematically evaluated (Dykens and Hodapp, 2001), and it is not clear how useful

knowledge of a particular behavioural phenotype is in classroom settings. It has also been asserted that special educators have largely ignored calls to tailor interventions to cognitive or behavioural profiles associated with specific syndromes (Hodapp and Dykens, 2009).

This study involves children who are affected by one of four genetic syndromes associated with intellectual disability and/or special educational needs. The syndromes were chosen based on their population prevalence, the fact they are all associated with special educational needs, and all have had guidelines published on classroom-based interventions. The four genetic syndromes are fragile X syndrome (FXS), Prader–Willi syndrome (PWS), velo-cardio-facial syndrome (VCFS; also known as 22q11.2 deletion syndrome) and Williams syndrome (WS). All four syndromes are caused by abnormalities in gene or chromosomal structure and can be identified via genetic testing. Guidelines for classroom-based interventions (i.e., teaching strategies/approaches and environmental accommodations) exist for the four syndromes. These guidelines are largely based on the opinions of experts in the field, and few surveys or intervention studies to evaluate views on the applicability, or test the validity of the guidelines, have been carried out.

The educational systems in the UK and Ireland are broadly similar. Formal education starts 1 year earlier (at 4 years) in the UK than Ireland (5 years), and children tend to enter the secondary tier of the education system a year earlier in the UK (at 11 years). Secondary education is usually complete between 16 and 18 years in both countries. Supports for children with the genetic syndromes under consideration are not organised/allocated according to the child's syndrome in either country, but are dependent on the presence of additional learning and neurodevelopmental difficulties.

The primary aim of this study was to ascertain what parents and teachers of children with the four syndromes had

researched or been told with respect to classroom-based interventions for their child. Parent and teacher reports are compared across the syndromes to see if significant differences exist between the syndromes, but also to see if differences existed between what parents and teachers reported and the content of actual guidelines. A further aim was to compare the syndromes with respect to teacher views of efficacious approaches based on experiences of teaching the children.

Methods

Recruitment and participants

This research was part of the larger EPGEN (Education and Psychosocial aspects of Genetic Syndromes) parent and teacher survey focusing on aspects of educational provision and psychosocial needs of children with four genetic syndromes carried out in the UK and Ireland in 2011 (see Reilly, Senior and Murtagh, 2014, for more details). This survey was devised in collaboration with support groups for the syndromes in the UK and Ireland. The syndrome support groups were identified via web-based searches and also via liaison with health professionals knowledgeable about the syndromes in both countries. Each of the four syndrome support groups had one main support group in the UK and one in Ireland. The groups are registered charities and/or affiliated with umbrella international support groups for the syndromes. All syndrome support groups with the exception of the Williams syndrome support group in Ireland agreed to take part. Participants were parents and teachers of school-aged children (4–19 years) with one of the four syndromes and were recruited via member databases of the support groups.

Parents were sent a research pack including the survey and information letter, and were asked to pass on a research pack to their child's head teacher, who was asked to pass the survey and information letter to the child's teacher. The number of surveys distributed, and number of complete responses, within each syndrome is displayed in Table 1.

Table 1: Survey distribution and response rate in EPGEN survey

Syndrome	Parental surveys distributed	Parental surveys returned	Teacher surveys distributed	Teacher surveys returned	Parent–teacher matches
Fragile X	359	115 (32%) (M94:F21)	359	59 (16%) (M46:F13)	42
Prader–Willi	326	110 (34%) (M59:F51)	326	58 (18%) (M37:F21)	38
VCFS	264	76 (29%) (M42:F33)*	264	42 (16%) (M18:F24)	21
Williams	259	80 (31%) (M40:F40)	260	45 (17%) (M20:F25)	29
Total	1209	381 (32%)	1209	204 (17%)	130

*Gender not recorded for one child. M, male; F, female; EPGEN, Education and Psychosocial aspects of Genetic Syndromes.

The response rate in the total sample was 32% (range across syndromes 29–34%) for parents and 17% (range 16–18%) for teachers. The teacher response rate was lower than the parent response rate for all support groups. It is not clear how many parents did not pass on the teacher survey to the child's head teacher/school principal or how many head teachers did not pass on the surveys to the child's teacher. One indication of how many surveys may have been passed on by parents to teachers is the number of matched pairs (i.e., parents and teacher surveys with same code indicating that parents and teachers responded about the same child). The number of matched pairs ($n = 130$) indicates 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 and 62% were male. In 89% ($n = 339$) of cases, the respondent to the parent survey was the mother. Respondents to the teacher survey included class teacher (68%), resource/specialist teacher (10%), subject teacher (3%) and other (e.g., supporting paraprofessional, co-ordinator/director of special educational needs department) (19%).

Procedure and measures

Parents and teachers were asked about classroom interventions (i.e., teaching strategies/approaches and environmental accommodations) to adopt when teaching children affected by the syndrome based on what they had researched or been told. This was an open question and respondents were provided with space to record their responses. Teachers were also asked to indicate their views on the most effective classroom interventions to use when supporting the children based on their experience with the child.

Recommendations for classroom interventions for children with the four syndromes from the US and UK were reviewed by the first author based on published guidelines for each syndrome. The main resources with regard to recommendations for intervention in FXS were Braden (2000a, 2000b, 2002, 2004), Dew-Hughes (2004), Picker and Sudhalter (2011), Powell (2004), Scharfenaker, O'Connor and Stackhouse et al. (2002), Spiridigliozzi, Lachiewicz and MacMurdo et al. (1994), and the National Fragile X Foundation (2004). With regard to PWS, guidelines or ideas for intervention in the areas of education and behaviour have been published by the Chedd, Levine and Wharton (2006), Prader-Willi Association United Kingdom (2002, 2004, 2006), Whitman and Jackson (2006), Reilly (2009), and Waters (1999). The two main sources of recommendations for educational interventions in WS are Semel and Rosner (2003), and Udwin, Yule and Howlin (2007). The main publication in VCFS is a book edited by Cutler-Landsman (2007). There is also a short fact sheet published by the MaxAppeal! (2011) support group, which includes references to school-based interventions.

Analysis

A 'thematic analysis' approach was adopted with respect to the three open questions. Thematic analysis is a method for identifying and subsequently analysing and reporting patterns or themes with data (Boyatzis, 1998). The process of thematic analysis began with two of the researchers (an educational psychologist and a clinical psychologist) familiarising themselves with the data generated from the open questions. Both researchers read the responses to the open questions from the surveys and reread them after they were transferred to a word processor file. All the data were read through in its entirety by both researchers. At this stage, both researchers took notes to hint at possible codes. The next phase of analysis involved the generating of initial codes (Braun and Clarke, 2006). This involves the production of initial codes from the data that appear interesting, and refer to the most basic segment of the raw data or information that can be assessed in a meaningful way regarding the phenomenon (Boyatzis, 1998). The two researchers coded 80 randomly chosen responses (20 of each syndrome) in order to generate codes for each of the three open questions. Coding was performed manually using numerical codes to identify potential patterns. The two researchers then met to decide on final codes and themes.

For the first question, it was agreed that there should be 30 codes. The next stage involves sorting out the different codes into potential themes and collating all the relevant codes within the identified themes (Braun and Clarke, 2006). It was agreed to organise the 30 codes into six themes and one 'other' theme. The codes and themes can be found in the appendices (Appendix A). For the teacher questions, a similar pattern was followed. For the first teacher question, 34 codes were generated, which were organised into eight themes (Appendix B). It was hoped to use the same codes for parents and teachers, but this was not possible, although the majority of the codes were the same. For the second open question in the teacher survey, 29 codes were generated and organised into eight themes (Appendix C). The data were then blindly rated by both researchers using the generated codes and themes for each of the three questions. The subsequent ratings were entered into IBM SPSS version 21.0 (Armonk, NY, USA), and chi-square (or Fisher's exact test where appropriate) analyses were undertaken to see if significant differences existed between the syndrome groups. Inter-rater reliability using the kappa statistic for the codes and the themes was also calculated for the three open questions.

Recommendations for teaching children with the four syndromes from the US and UK were reviewed based on published guidelines for each syndrome. A teaching approach/strategy mentioned by 10% or more of parents and teachers based on what they had researched was searched for in the published guidelines by the first author. If the first author felt an approach/strategy was present, this was marked as present/absent.

Ethics

The study was granted ethical approval by the Human Research Ethics Committee at University College Dublin and the ethical approval covered the UK and Ireland. The purpose and nature of the research were outlined in information letters that were sent to all potential participating parents and teachers.

Results

Parent views on key interventions based on what they had researched

The 11 codes mentioned most frequently by parents are shown in Table 2. The 19 codes not shown in the table were mentioned by less than 10% of parents according to both raters.

The median kappa value for inter-rater agreement was 0.925 based on the 30 codes, indicating a good level of agreement between both raters. Significant differences between the syndrome groups were found for six of the codes in Table 2. The need for structure or routine was spontaneously mentioned most frequently by parents in the PWS group and least often in the VCFS and WS groups. The need to use visual materials was reported most often by the parents of children with FXS and least often by the parents of children with WS. In contrast, the need for repetition or use of memory strategies was mentioned most often by parents of children with WS and least often by parents of children with FXS. The requirement for 'patience' was mentioned by approximately one quarter of parents of children with PWS and only by one in ten parents in the other syndrome groups. The benefits of using environmental accommodations (e.g., preferential seating,

minimal distractions) in the school were mentioned most often by parents of children with FXS and least often by parents of children with VCFS and PWS. The necessity to 'minimise negative emotions' (e.g., reduce fears and anxieties, avoid confrontation) was mentioned most often by parents of children with PWS and least by parent of children with VCFS.

As well as the strategies shown in Table 2, significant differences were also found based on the codings of both raters for the 'music' code (mentioned most often by parents of children with WS), 'whole word reading', (mentioned most often in FXS) and use of 'humour' (mentioned most often in PWS). Significant differences between the syndromes were also found for the need to 'accommodate tiredness' (mentioned most frequently in WS), the need for 'side-on teaching' (mentioned by nearly one third of the parents of children with FXS but not in other three syndromes) and the need to manage the child's diet (referred to by 22% of parents of children with PWS but not by any other parents).

The 30 codes used in the parent sample were organised into seven themes (Appendix A). Significant differences between the syndromes emerged for three of the themes. The 'staff interaction' theme was mentioned most often by parents of children with PWS and least often by parents of children with VCFS ($R1 P < 0.05$; $R2 P < 0.05$). The 'environment' theme was mentioned most often by parents of children with FXS and parents of children with PWS and least often by parents of children with VCFS ($R1 P < 0.001$) ($R2 P < 0.001$). The 'physical health/diet' theme was mentioned most frequently by parents of children with PWS ($R1 P < 0.001$; $R2 P < 0.001$).

Table 2: Key teaching strategies based on what they had researched or been told: parent views

Strategy (teaching approach)	FXS		PWS		WS		VCFS		Total	Total
	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)
R1 = rater 1										
R2 = rater 2										
Structure/routine*	30	25	38	38	6	6	4	5	22	20
Simple instructions	14	11	23	25	16	20	17	20	18	19
Rewards	19	19	23	22	14	13	13	11	18	17
Visual materials**	25	26	15	17	9	9	15	16	17	18
Repetition/memory***	8	8	13	14	25	25	21	22	16	16
Patience**	11	11	24	25	15	15	11	9	15	16
One-to-one teaching	9	11	15	18	23	23	13	13	14	16
Short task	16	17	13	12	20	18	8	7	14	13
Environmental accommodations***	21	23	5	6	15	15	5	5	12	13
Small group teaching	11	13	6	5	14	15	8	8	10	10
Minimise negative emotions***	7	9	14	16	4	6	3	5	8	10

Notes: FXS, fragile X syndrome; PWS, Prader-Willi syndrome; WS, Williams syndrome; VCFS, velo-cardio-facial syndrome. * $P < 0.001$, ** $P < 0.05$, *** $P < 0.01$. Where R1 or R2 is indicated, significant differences between the syndromes were only noted on this rater's codings or there was a different level of significance found between the two raters.

Table 3: Key teaching strategies based on what they had researched or been told: teacher views

Code	FXS		PWS		WS		VCFS		Total	Total
	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)
R1 = rater 1										
R2 = rater 2										
Structure /Routine***	41	39	48	50	40	40	12	12	37	37
Simple Instructions	27	25	29	36	31	27	27	27	29	29
Visual Materials/Approach	32	34	24	24	20	20	20	22	25	26
Rewards	20	20	26	24	20	24	12	12	20	21
Individualised Approach	17	15	12	19	22	24	24	22	18	20
Experiential Learning	19	20	12	10	24	26	10	10	16	17
Short Tasks	17	17	17	17	22	27	5	2	16	16
R2**										
Repetition/Memory R1** R2***	9	9	7	7	27	29	22	22	15	15
One-to-One Teaching	17	17	12	12	13	16	12	17	14	15
Social Skill Development	17	15	9	10	13	16	17	20	14	15
Patience	12	15	9	14	9	11	12	12	10	13
Environment**	15	15	9	9	20	20	0	0	11	11
Minimise Negative Emotions	10	12	9	10	9	13	9	10	9	11

Notes: FXS, fragile X syndrome; PWS, Prader–Willi syndrome; WS, Williams syndrome; VCFS, velo-cardio-facial syndrome. * $P < 0.001$, ** $P < 0.05$, *** $P < 0.01$. Where R1 or R2 indicated means that significant differences between the syndromes were only noted on this rater's codings or there was a different level of significance found between the two raters.

Teacher views on key interventions based on what they had researched

The codes most frequently mentioned by teachers are shown in Table 3. The 20 codes not shown in the table were referred by less than 10% of teachers according to both raters.

The median kappa value for inter-rater agreement was 0.912 based on the 34 codes. Significant differences between the syndrome groups were found for a fewer number of codes than the parent sample. The need for structure and routine was mentioned most often by teachers of children with PWS and least often by teachers of children with VCFS. The need for short tasks was referred to most frequently by teachers of WS and least often by teachers of children with VCFS. The use of repetition and memory strategies was brought up most by teachers of children with WS and least in the PWS group. The benefits of using environmental accommodations were most frequently alluded to by teachers of children with WS and were not mentioned at all by teachers of children with VCFS. As well as the strategies shown in Table 3, significant differences were also found based on both raters' codings for the need to use music (mentioned most often in WS), the requirement to manage the child's diet (mentioned most often in PWS), the benefit of supporting the child's handwriting (referred to most often in WS), and the need to accommodate tiredness and manage the child's behaviour (both mentioned most frequently in the PWS

group). The 34 codes used in the teacher sample were organised into eight themes (Appendix B). The two themes where differences emerged were the 'environment' theme (mentioned by more than half of respondents in the FXS, PWS and WS groups, but only by one in six of respondents in the VCFS group) and diet theme mentioned most often in the PWS group.

Comparison between guidelines for interventions and parent and teachers' reports of what they had researched

Table 4 illustrates the responses of parents and teachers to an open question on efficacious approaches for teaching the children based on what they had researched or been told, and compares this with what is contained in actual published guidelines.

Although there was a good level of agreement between teachers, parents and guidelines for some approaches and strategies, there was less agreement for other approaches. There were a number of areas where discrepancies existed between what parents and teachers reported they had researched or been told and what is in the actual guidelines. For example, the need for structure and routine is in published guidelines for WS and VCFS but was mentioned by few parents of children with the syndromes. The need to use visual materials was mentioned by teachers of children with WS but it is not in the actual guidelines. The need to manage the environment in PWS is mentioned in guidelines but not by teachers or parents.

Table 4: Teaching strategies mentioned by 10%† or more of parents (P) and teachers (T) based on what they had researched versus actual published guidelines (PG)

Strategy/Approach	FXS			PWS			WS			VCFS		
	P	T	PG	P	T	PG	P	T	PG	P	T	PG
Structure/routine	*	*	*	*	*	*		*	*		*	*
Simple instructions	*	*	*	*	*	*	*	*	*	*	*	*
Rewards	*	*	*	*	*	*	*	*	*	*	*	*
Visual materials	*	*	*	*	*	*		*		*	*	*
Repetition/memory				*		*	*	*		*	*	*
Patience	*	*		*	*		*	*	*	*	*	
One-to-one teaching	*	*		*	*	*	*	*		*	*	*
Short task	*	*	*	*	*	*	*	*	*			*
Environment	*	*	*			*	*	*	*	*		*
Small group teaching	*						*					*
Individualised approach		*	*	*	*	*	*	*	*		*	
Minimise negative emotions		*	*	*				*	*			
Side-on teaching	*		*									
Experiential learning		*	*		*	*	*	*	*		*	*
Diet				*	*							
Music							*	*	*			
Simultaneous learning			*			*						

Notes: FXS, fragile X syndrome; PWS, Prader–Willi syndrome; WS, Williams syndrome; VCFS, velo-cardio-facial syndrome. †10% based on an average of Rater 1 and Rater 2, * indicates that the strategy/approach is included.

Most effective interventions according to teachers

Teachers were asked to indicate their views on the most effective interventions to use when supporting the children. The teaching approaches most frequently mentioned are shown in Table 5. The codes not shown in the table were mentioned by less than 10% of teachers according to both raters.

The median kappa value for inter-rater agreement was 0.886 based on the 29 codes. Significant differences between the syndromes were found for only two approaches in Table 5. The need for routine and structure was mentioned most often by teachers of children with PWS and least often by teachers of children with VCFS. The only other teaching approach in Table 5 where a significant difference between the syndrome groups was found was for the use of rewards or reinforcement (most often by teachers of children with PWS and least often by teachers of children with WS), and the difference was only found for one of the raters. As well as the teaching approaches shown in Table 5, significant differences were also found based on both raters' codings for the use of music in the curriculum (mentioned most often by teachers of children with WS) and behaviour management (mentioned most often in PWS group). The 29 codes used were organised into eight themes (refer to Appendix C). Significant differences between the syndromes were not found for any of the themes.

Discussion

This study provides, for the first time, information on parental and teacher knowledge of published guidelines for classroom interventions in four of the most common genetic syndromes, which have associated special educational needs and compares this with actual published guidelines. The study is also the largest study to date to sample the views of teachers regarding efficacious interventions for children affected by the syndromes.

Parent and teacher views on key interventions based on what they had researched versus published guidelines

In the study, parents and teachers were asked about efficacious approaches for supporting the children based on what they had researched or been told. It was noticeable that the responses of parents and teachers of children with VCFS tended to be shorter than parents and teachers in the other syndrome groups. This indicates the possibility that teachers and parents of children with this syndrome are less aware of the content of published guidelines on educational approaches for the syndrome. There are some approaches that emerged as important for parents and teachers that are not listed as being important or at least emphasised in current syndrome guidelines. For example, the need for repetition and use of memory techniques to accommodate memory deficits was mentioned by 25% of parents and nearly 30% of teachers of children with WS

Table 5: Most effective teaching approaches based on teacher experiences

Teaching approach	FXS		PWS		WS		VCFS		Total	
	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)	R1 (%)	R2 (%)
Structure/routine (R1***) (R2***)	32	34	47	48	36	36	12	12	33	34
Individualised	22	22	22	24	20	18	31	19	24	23
Visual materials	25	24	14	16	16	16	12	12	17	17
Experiential learning	24	24	7	7	18	18	14	14	16	16
Patience	17	20	16	16	11	11	14	14	15	16
Repetition and memory	15	15	9	9	16	16	21	21	15	15
Rewards/reinforcer (R2***)	10	10	22	28	7	4	12	12	13	14
Small group teaching/support	14	15	7	7	20	20	14	14	13	14
Instructions	9	7	14	17	13	13	12	10	12	12
Other	12	10	14	14	14	11	14	5	10	10
Short tasks/lesson	5	5	14	12	7	9	12	14	9	10
Social skills	7	10	5	9	2	9	17	17	7	11

Notes: FXS, fragile X syndrome; PWS, Prader–Willi syndrome; WS, Williams syndrome; VCFS, velo-cardio-facial syndrome. *** $P < 0.01$. Where R1 or R2 is indicated means that significant differences between the syndromes were only noted on this rater's codings or there was a different level of significance found between the two raters.

but that has not been emphasised greatly in publications on the syndrome. The need for patience when supporting children was emphasised by teachers and parents in all of the syndromes but is emphasised only in published guidelines for WS.

Parents and teachers may be accessing other sources of information outside of the published guidelines when answering this question. There are also interventions emphasised in published guidelines but which were not emphasised by parents or teachers. For example, the need to avoid direct questioning in children with FXS has been suggested in a number of publications (e.g., National Fragile X Foundation, 2004), but this was not mentioned by any of the parents or teachers. The need to capitalise on the relative strength in simultaneous processing in FXS and PWS has been mentioned by a number of authors in FXS (e.g., Braden, 2004) and PWS (e.g., Reilly, 2009) but was rarely referred to by parents or teachers in the current study.

Between-syndrome differences and commonalities across syndromes

Significant differences between the syndromes were noted in 13 areas in the parent sample and eight areas in the teacher sample. The fact that differences between the syndromes were found would be expected as the recommendations on the use of interventions do vary in the published guidelines.

Some of the approaches mentioned by parents and/or teachers can be seen to be approaching 'syndrome specificity', in that they were mentioned predominantly by parents and teachers of children in one syndrome group and are referred to in published guidelines in only one syndrome group. Examples of such syndrome-specific approaches include the need to manage the child's diet in PWS and emphasis on music in WS. The emphasis on dietary management in PWS reflects the propensity to overeat in the syndrome. The emphasis on use of music in WS classroom in the syndrome reflects the strong interest in music that the children with the syndrome often have. The value of using visual materials was reported most often by the parents of children with FXS and least often by the parents of children with WS. This probably reflects the strength in visual processing children with FXS are reported to have and the relative strength in auditory processing often reported in WS.

For other approaches, there is less 'syndrome specificity', but there are differences between the syndrome groups. For example, the need for structure and routine was mentioned more often by parents of children with FXS and PWS compared with parents of children with VCFS and WS, although it is mentioned in guidelines for all the groups. The need for repetition and use of memory strategies was mentioned more often by parents and teachers of children with VCFS and WS compared with parents of children with FXS or PWS, although it is mentioned in guidelines for PWS.

As well as differences between the syndromes, there were also differences between parents and teachers with regard to the emphasis on particular approaches. A stark example of this was in the case of WS where only 6% of parents spontaneously mentioned a need for structure and routine, whereas 40% of teachers mentioned this need. This need is referred to in guidelines for WS, suggesting that parents do not have as much knowledge of this recommendation compared with teachers.

As well as some syndrome-specific approaches, and approaches shared between two syndromes, there were some approaches that parents and teachers mentioned that did not differ between the syndromes and are referred to in guidelines for all four syndromes. These included the need to modify or use simple instructions with the child and the need to use rewards, and are likely to be useful for many children with special educational needs.

Teacher views on effective interventions based on classroom experiences

Teachers were also asked what they considered the most effective approaches in supporting the children based on their classroom experiences with the child. This is an important question that gives an idea of what works best with regard to actual classroom practices.

The most frequently mentioned strategy was the need for routine and structure. This was mentioned by nearly half of teachers of children with PWS, 40% of teachers of children with FXS, 40% of teachers of children with WS but only 12% of teachers of children with VCFS. This need for structure and predictability is emphasised in published recommendations for all of the syndromes, including VCFS (e.g., Braden, 2000a, 2000b; Cutler-Landsman, 2007; Semel and Rosner, 2003; Whitman and Jackson, 2006). This suggests that teachers of children with VCFS are either not aware of the utility of this approach or do not think it is useful. Other effective teaching approaches where significant differences were noted were use of music (most often mentioned by teachers of WS), and behaviour management (most often referred to by teachers of children with PWS), which can be seen to reflect the behavioural phenotype associated with these syndromes.

Significant differences between the syndromes were not found with respect to all other teaching approaches/strategies, suggesting that in most cases successful interventions are shared across syndromes. Interestingly, significant differences did not emerge in areas where one might have expected to have observed differences between the syndromes, such as the need for dietary management and to accommodate tiredness in PWS. This suggests that teachers do not see the need for syndrome-specific approaches in most areas but also suggests that useful approaches are shared across syndromes. More differences

between the syndromes with respect to effective approaches were noted based on teachers' research compared with their actual practice. Differences based on their research included the need for short tasks, the need for environmental accommodations, the need to support handwriting and the need to accommodate tiredness. The need for 'side-on teaching', an approach specifically recommended for FXS, was not mentioned at all by teachers when asked what works best. This indicates that although there is some agreement between the published guidelines and teacher experiences with regard to the emphasis on particular approaches in particular syndromes, there are areas where teacher experiences suggest that the needs of the children do not differ as much as might be expected based on published guidelines.

Limitations

A number of limitations need to be borne in mind when interpreting the results of the current study. The teacher response rate in the study was particularly low due to the sampling method employed. The sample was drawn from syndrome support groups and may not be representative of the total population affected by the syndromes. Making clear comparisons between what teachers and parents spontaneously mentioned and the content of published guidelines is not always easy as the guidelines themselves tend to mention a wide range of possible approaches that could be useful. Furthermore, the guidelines are not as clear with regard to whether an approach is suitable for all children with the syndrome or only children who conform to the behavioural phenotype proposed for that syndrome.

Implications for future research and practice

Although the intervention strategies/approaches parents and teachers spontaneously reported were sometimes in line with previous publications, they deviated from published guidelines in other cases. It may be that parents and teachers were drawing on sources other than published guidelines when answering this question (e.g., colleagues, other parents). Another factor may be that their experiences with the child may have influenced their responses. Parents and teachers appeared particularly aware of approaches focusing on classroom environment issues and the need for structure/routine but referred less often to approaches in subject areas such as mathematics and reading, which are included in published guidelines. Teacher views of efficacious approaches based on their experiences of working with the children suggest that most successful teaching approaches and strategies are shared across syndromes, but between-syndrome differences do exist. There is also evidence that what is emphasised in published guidelines for the syndromes is not always reflected in actual teaching practices. 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 others may not be benefiting

from less useful approaches. There is, thus, a need for more studies on effective teaching approaches for children with the syndromes. Studies to identify the most efficacious approaches to word reading, reading comprehension, numeracy and behaviour management in each of the syndromes would seem to be particularly important.

More differences emerged between the syndromes with respect to parental and teacher knowledge of published guidelines in comparison with teacher reports of classroom experiences with the children. Despite this, there were intervention approaches reported on by teachers based on their experiences, where the syndromes did differ. This suggests that syndromes do matter with regard to educational planning and that at least some teachers adjust practices based on the child's syndrome. As Einfeld (2005) suggests, educators cannot be expected to be aware of the behavioural phenotypes of all syndromes, but being aware how different syndromes can impact on learning and behaviour may allow teachers to seek out further advice and support, including accessing resources such as the published guidelines for the syndromes.

Conclusion

The findings of this research suggest that aetiology is considered in some instances with respect to educational planning, and there are some aspects of behavioural phenotypes that are relatively well known. Many teachers of children with the syndromes appear to be employing similar

strategies regardless of the child's syndrome in most areas of the curriculum. There are intervention approaches emphasised in published guidelines that seem relatively unknown to teachers and parents. Getting the classroom environment right for all children regardless of aetiology would appear to be a key starting point for teachers. However, considering the child's syndrome and its associated learning and behavioural profile should also be a consideration in educational planning.

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Appendix A: Parent codes organised into themes

Codes	Theme	Codes	Theme
Environment	Environment	Individual approach	General teaching approaches
Quiet area/calm area		Visual learning materials and approach	
Predictable structure and routine		ASD approach	
Short task/lesson		Experiential learning	
Prompting to stay on task	Staff interaction	Music	Teaching arrangements
Jokes and humour		Technology	
Instructions to child		Sensory activities	
Patience		Repetition and memory	
Minimise negative emotions	Specific subject/ curriculum areas	Rewards/sanction system	Physical health/diet
Side-on teaching avoid eye contact		Simultaneous (non-sequential)	
Whole word reading		Small group teaching/support	
Phonics approach to reading		One-to-one teaching support	
Social stories		Diet/food control	
Maths strategies		Consider tiredness-fatigue	
Handwriting		Other	Other

Appendix B: Teacher question 1 codes organised into themes

Codes	Theme	Codes	Theme
Quiet uncluttered environment	Environment	Experiential/functional learning	
Short task/lesson		Music	
Predictable structure and routine		Technology	
Quiet area/calm area		Sensory activities/sensory environment	
Jokes and humour	Staff interaction	Repetition	
Instructions to child		Rewards/sanction system	
Patience		Simultaneous (non-sequential) learning	
Minimise negative emotions		Modelling	
Side-on teaching avoid eye contact		Visual learning materials and approach	
Get eye contact		Handwriting approach	
Behaviour management		One-to-one teaching support	Teaching
Whole word reading	Specific subject/ curriculum areas	Small group teaching/support	arrangements
Phonetic or auditory approach		Diet/food control	Physical health/diet
Social skills development		Consider tiredness-fatigue	
Teach language of maths		Home school collaboration	External
Individual approach/differentiation	General teaching approach	Professional/specialist support	collaboration
ASD approach		Other	Other

Appendix C: Teacher question 2 organised into themes

Codes	Theme	Codes	Theme
Quiet uncluttered environment	Environment	Technology	General teaching approach
Quiet area/calm area		Sensory activities/sensory environment	
Predictable structure and routine		Repetition and memory	
Short task/lesson		Reward/reinforcer	
Jokes and humour	Staff interaction	Modelling	
Instructions to child		Promote responsibility	
Patience		Experiential/functional learning	
Minimise negative emotions		ASD approach	
Side-on teaching avoid eye contact		Visual learning materials and approach	
Get eye contact		One-to-one teaching support	Teaching arrangements
Behaviour management		Small group teaching/support	
Whole word reading	Specific subject/ curriculum areas	Diet/food control	Physical health/diet
Social skills development		External collaboration	Home school collaboration
Individual approach/differentiation	General teaching approach	Professional/specialist support	
Music		Other	Other

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