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What do parents want?: an analysis of education-related comments made by parents of children with different genetic syndromes*

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*This study explored whether parents of children with three different genetic syndromes, Down syndrome (*n*=39), Prader-Willi syndrome (*n*=25), and Williams syndrome (*n*=26), express divergent desires for modifications in their child's current educational programming. A content analysis was performed on the parents' answers to an open-ended question about how to improve their child's current placement. The parents of children with Down syndrome spontaneously expressed a greater desire for changes or improvements in speech therapy and reading services, the parents of children with Prader-Willi syndrome expressed a desire for increases in adaptive physical education services, and the parents of children with Williams syndrome expressed a desire for increases and modifications to music services and aides in the classroom. Within-syndrome variation was also found in the specific sentiments and desires expressed. Implications for a syndrome-specific approach to special education programming are discussed.*

Over the past 10 years, researchers have increasingly realised that particular outcomes are more likely in different genetic disorders. We now know that individuals with certain genetic syndromes are predisposed to distinct developmental outcomes, expressing particular "behavioural phenotypes" (Dykens, 1995; Hodapp & Dykens, 1994). While

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research on behavioural phenotypes has increased exponentially over the past decade (Hodapp & Dykens, 2001), a new challenge has also emerged in determining how to apply these findings successfully and appropriately to the population of individuals with genetic syndromes and their families.

Based on syndrome-related cognitive-linguistic, personality, and maladaptive behaviour profiles, specific approaches have been proposed for educational, psychotherapeutic, and other interventions (Dykens & Hodapp, 1997; Fidler, Hodapp & Dykens, 2002; Hodapp & Fidler, 1999). Although some continue to support "non-categorical" programming, or educational interventions in which the child's aetiology is not taken into account (Forness & Kavale, 1994), it may be the case that targeting specific syndrome-related behaviours or profiles could be particularly helpful (Hodapp & Fidler, 1999). But in the only empirical study to date on the use of behavioural phenotype information in special education, Fidler et al. (2002) found that parents of children with Down syndrome, Williams syndrome, and Prader-Willi syndrome reported that their child's special education services were not currently targeted to aetiology-related cognitive-linguistic strengths and weaknesses.

Although syndrome-related educational programming is beginning to be discussed in the research community, parents may or may not desire such programming for their own children. Indeed, in general, most parents probably do not hold strong opinions on the larger issue of aetiology-related versus non-categorical programming. Yet these same parents do monitor their child's school progress and may attempt to dovetail their child's particular aetiology-related strengths and weaknesses to the types of programming the child receives. It may therefore be the case that parents of children with different syndromes spontaneously express divergent desires for different types of service, modification, and placement.

The reflections of parents of children with three different genetic syndromes associated with intellectual disabilities are analysed in this study. The first syndrome, Down syndrome, is the most common genetic (chromosomal) cause of intellectual disability, caused in almost all cases by a third chromosome 21. In addition to genetic and physical features, children with Down syndrome display linguistic weaknesses—particularly in grammar (Fowler, 1990), expressive language (Miller, 1999), and articulation (Kumin, 1994)—compared with their overall mental age. Conversely, these children show relative strengths in tasks that involve visuospatial as opposed to auditory processing (Hodapp, Leckman, Dykens, Sparrow, Zelinsky & Ort, 1992; Pueschel, Gallagher, Zartler & Pezzullo, 1987). Along these lines, researchers have argued for the language benefits of early sight reading in Down syndrome (Buckley, 1995; Miller & Leddy, 1999).

The second syndrome, Prader-Willi syndrome, is caused by missing genetic material from the chromosome 15 derived from the father (either a deletion on the paternally derived chromosome 15 or two chromosome 15s from the mother). Many children with Prader-Willi syndrome show extreme obsessions and compulsions (Dykens, Leckman & Cassidy, 1996) and overeating (hyperphagia) that, if left unchecked, results in life-threatening obesity (Dykens & Cassidy, 1996). In fact, the single most important factor related to early deaths in Prader-Willi syndrome is heart problems relating to obesity (Dykens, Goff, Hodapp & Davis, 1997).

The third disorder is Williams syndrome, caused by a micro-deletion on chromosome 7. Children with this syndrome generally show a characteristic "elfin-like" facial appearance, along with heart and other health problems (Pober & Dykens, 1996). The general cognitive-linguistic profile that emerges in Williams syndrome has been described

as one of "asymmetrical ability". Language in Williams syndrome has been described as "relatively spared" in comparison with other domains of cognition, while visuospatial processing seems to be particularly impaired (Bellugi, Lichtenberger, Jones, Lai & St. George, 2000). Although only small percentages of these children show language performance that is actually age appropriate (Mervis, Morris, Bertrand & Robinson, 1999), almost all children with Williams syndrome nevertheless show relative strengths in language, as well as in auditory processing and some areas of music (Lenhoff, 1998). Individuals with Williams syndrome also show socially disinhibited behaviour profiles (Dykens & Rosner, 1999; Jones et al., 2000), as well as high levels of anxieties and fears relative to other children with intellectual disabilities (Dykens, 2003). This social profile makes it difficult for individuals with Williams syndrome to create appropriate friendships, and to function independently in social and academic settings (Dykens & Rosner, 1999).

In this study, we asked the parents of children with Down syndrome, Prader-Willi syndrome, or Williams syndrome open-ended questions about how to improve their child's current educational programme. We then performed a content analysis of their answers in order to determine whether the parents' answers varied in systematic ways based on syndrome group. By syndrome, then, one might expect the following from the parents:

- Of children with Down syndrome: issues related to speech–language therapy and instruction in reading or other visual modalities;
- Of children with Prader-Willi syndrome: issues related to physical education or adapted physical education, in order to counteract the obesity and health-related issues in this population; and
- Of children with Williams syndrome: issues related to music- or language-oriented instruction, as well as increased numbers of classroom aides to help with anxieties and fears.

Method

Participants

The participants were the parents of three groups of 5–21 year old children and adolescents: 39 with Down syndrome, 25 with Prader-Willi syndrome, and 24 with Williams syndrome. The children in each of the three groups averaged 11–12 years of age, $F_{(2,84)} = 0.55$, ns, and most showed mild or moderate levels of intellectual disability, $\chi^2_{(2,n=88)} = 6.95$, ns. In each group, most children were either attending regular education classes full-time or part-time, with smaller percentages in special education classrooms, $\chi^2_{(2,n=83)} = 5.02$, ns. The mothers were the main respondents, and the mothers' and fathers' levels of education were generally high (most had completed college in each group). The families in this study were primarily middle class, and all of the children were currently living at home.

Procedures

The parents were recruited through local and national parent organisations of each of these three syndromes. Announcements were made at parent organisation events, and those interested filled out a form stating they would like to participate in research. Those

parents who volunteered were sent a battery of questionnaires, which they completed and then returned to the researchers via mail. The majority of parents expressing an interest in participating in the research study completed the questionnaires.

In addition to basic demographic information about themselves, their families and their children, the parents also completed questionnaires regarding their child's cognitive strengths and weaknesses, maladaptive behaviours, and their child's current educational placement.

Measures

Demographics questionnaire. The parents were asked about diagnostic information (when diagnosed and at which hospital), the child's level of intellectual impairment (borderline, mild, moderate, or severe intellectual disability), and information about the parents' age, education level, and ethnicity.

Open-ended education questionnaire. The parents were asked to complete a questionnaire with the following open-ended question: "If you could tailor your child's current educational programme to 'fit' your child more adequately, what changes would you make?". The parents were given a blank space on the questionnaire in which to write their response.

The answers were then analysed in accordance with Coffey and Atkinson's (1996) instructions for coding qualitative data. All parent responses were transcribed verbatim onto computer files and identifying information was removed. Prior to the analyses, potential syndrome-related themes were generated in terms of aetiology-related strengths and weaknesses as applied to educational programming.

Upon initial perusal of the transcripts, five aetiology-related themes were identified:

(1) Speech–language–communication therapy (spontaneously mentioned 17 times among the 88 total participants);
(2) Reading instruction (13 times from among 88 participants);
(3) Music services, classes, or instruction (14 times);
(4) Classroom aide services (27 times);
(5) Physical education or adaptive physical education (10 times).

All the themes were then coded as either present or absent in the spontaneous comments of each mother. Two coders, blind to the child syndrome group, independently coded all of the transcripts, and kappas were performed. Inter-rater reliability estimates ranged from 0.76 (for "classroom aide") to 0.95 (for "music"), with a median value of 0.82. Kappa values of 0.75 and above are considered evidence of "excellent" reliability (Cicchetti, 1984).

Education questionnaire. The parents were asked to describe their child's current educational placement, for example whether the child was currently fully included, partially mainstreamed, or in a special day class without mainstreaming. The parents also rated their satisfaction with the child's current placement on a five-point scale from very dissatisfied ($=1$) to very satisfied ($=5$), and whether they had considered changing placements.

The parents were also asked whether their children currently received any of the

following services: speech therapy, physical therapy, occupational therapy, extra reading, extra writing, extra mathematics, adaptive physical education, social skills training, psychological counselling, and one-on-one aide.

Results

Current placement and services

No differences were found in the educational placements of children in each of the three syndrome groups. Across all of the groups, most children were being educated in either fully or partially integrated settings, with between 25 and 40% of each group in special class placements. There were also no differences in satisfaction with current educational placement, $F_{(2,86)} = 1.13$, ns. The mean satisfaction rating for parents of children with Down syndrome was 3.64, for Prader-Willi syndrome the mean was 4.04, and for Williams syndrome the mean was 3.56. No differences were found in the degree to which parents wanted to change or modify their child's current educational placement, $\chi^2_{(2,n=86)} = 7.39$, ns. In terms of hourly services, individuals with Down syndrome received marginally more speech therapy than the children in the other two groups (Down syndrome: $X = 1.97$; Prader-Willi syndrome: $X = 1.29$, Williams syndrome: $X = 1.40$ hours/week, $F_{(2,76)} = 2.75$, $p < 0.07$), and individuals with Williams syndrome received marginally more occupational therapy (Down syndrome: $X = 0.63$; Prader-Willi syndrome: $X = 0.25$; Williams syndrome: $X = 1.00$ hours/week, $F_{(2,76)} = 2.90$, $p < 0.06$).

Parent satisfaction and desired change

Speech–language–communication therapy. Although no significant differences emerged in parent satisfaction with current educational placement overall, a content analysis uncovered divergent desires in programme modification based on the child's syndrome. For example, 33.3% of the parents of children with Down syndrome spontaneously mentioned that they wished for modifications or improvements in speech therapy services, compared with 8.0% of Prader-Willi syndrome parents and 4.2% of Williams syndrome parents, $\chi^2_{(2,n=88)} = 10.93$, $p < 0.005$.

The parents of children with Down syndrome focused on a wide variety of modifications within the topic of speech therapy. One parent wanted modification of current services in the direction of more one-on-one, stating that "[my child] is currently in large group speech therapy, I would prefer private sessions". Some parents wanted a focus on articulation in their children with Down syndrome. One parent described, "[the] focus would be on speech … his language is extremely limited and he is verbal but not understandable by outsiders unless they try hard to understand". Several parents wanted speech therapy pull-out services ("Speech—pull-out daily individualised"). One parent simply stated that, "I would like [child] to receive better quality speech therapy".

Reading and other visual modalities. Significantly more parents of children with Down syndrome (23.1%) also expressed a desire for more reading services for their children than the parents of children with Prader-Willi syndrome (4.0%), Fisher's exact $p < 0.05$. The parents of children with Down syndrome showed a range of responses with respect to reading. Some wanted more of an emphasis on overall reading instruction, with one parent expressing that they "… would like to have seen more individual help with reading—the potential is there, I think, but has not been worked

on enough". Another parent wanted their child simply to "learn how to read more". Others focused on particular reading and writing skills, hoping for "more emphasis on name writing and some sight word reading". One parent suggested a specific reading instruction approach they wanted to have implemented:

> [I] want [his] school to utilize Lindamood Bell reading techniques—they have some teachers skilled in this method that has been proven to improve children's academic performance. Lindamood Bell techniques in reading-lips.

Classroom aide. Half (50.0%) of the parents of children with Williams syndrome spontaneously mentioned wanting more classroom aide services for their child, compared with 17.9% of Down syndrome parents and 36% of Prader-Willi syndrome parents, $\chi^2_{(2,n=88)} = 7.32$, $p < 0.05$. The parents of children with Williams syndrome offered many different reasons for wanting modification in the aide-related services their child currently receives. Some noted that an aide would make it possible for their child to be mainstreamed and exposed to children in regular education classes. For example, one parent wrote that they "… would like to see more help with aides so she can stay in regular ed. Because she has made a few true friends". Another wrote that they would like "an aide for after school activities in High School, so he could feel part of the school". One Williams syndrome parent expressed dissatisfaction with the obtrusiveness of the aide currently in their child's classroom, stating "I think his aide does too much work for him". Some parents also expressed the need for an aide to help their child keep pace academically, with one parent writing: "As she is getting older school is moving on a faster pace, which makes it a challenge to keep her in the regular class". Another parent noted, "I would like her to be in a regular classroom with a part-time aide to work on academics".

Music services. The parents of children with Williams syndrome (25.0%) also more frequently expressed a desire for increased musical instruction for their children than the parents of children with Prader-Willi syndrome (4.0%), Fisher's exact, $p < 0.05$, two-tailed. The parents of children with Williams syndrome also expressed different desires with respect to music services for their children. One parent expressed that special education services underestimated their child's musical capabilities, stating "… we were told he wasn't capable of keeping up". One parent expressed the desire for instruction in a specific musical instrument ("Would like piano lessons"). Another parent wanted music to be incorporated into regular classroom instruction, hoping for "… [a] class with individualized learning strategies, such as visual learning with music".

Adaptive physical education. Significantly more parents of children with Prader-Willi syndrome (28.0%) expressed a desire for improvements and increases in adaptive physical education services than the parents of children with Down syndrome (5.1%), and Williams syndrome (8.3%), $\chi^2_{(2,\ n=88)} = 7.81$, $p < 0.05$. Again, a variety of modifications were mentioned by these parents in relation to their child's adaptive physical education. While some parents simply asked for more adaptive physical education, one parent wanted adaptive physical education teachers to be more sensitive to emotional issues. As one parent noted, "Ideally, the PE teacher would understand adaptive PE and make everyone feel welcome". Other parents wanted their children

to be more integrated with typically developing children during physical education, with one parent simply writing "adaptive PE and peers—not all special ed".

Discussion

This study explored whether parents spontaneously express syndrome-specific desires for modification of their child's current special education programming. The parents of children with Down syndrome, Prader-Willi syndrome, and Williams syndrome were asked an open-ended question regarding modifications to their child's current programme that would make the programme "better fit" their child's needs. A content analysis was then performed on their open-ended comments for the frequency of comments related to particular types of service.

Significant differences were found in the frequency with which various themes were raised by the parents of children with different genetic syndromes. The parents of children with Down syndrome, for example, more frequently expressed a desire for modifications and improvements in speech therapy services and reading instruction. The parents of children with Williams syndrome brought up the issues of music instruction and aides in the classroom to work with their child. The parents of children with Prader-Willi syndrome more frequently discussed issues relating to adaptive physical education services.

While some aspects of a syndrome's phenotype were reflected in parental education statements, others were not. For example, in Williams syndrome, the parents seemed to have been targeting certain aspects of the phenotype of their child's syndrome—musicality and social issues—but not others, like visuospatial processing deficits. In some cases, it could be that the parents were focusing on areas in which their child is likely to show greater success. Both the parents of children with Down syndrome and Williams syndrome discussed services for areas of relative strength (reading in Down syndrome, musicality in Williams syndrome). Another plausible explanation for this finding relates to the salience of the various syndrome characteristics. Areas of strength in music, or difficulties with hyperphagia and food-related issues, are likely to be more salient than difficult to observe visuospatial processing deficits. Similar findings relating to the salience of syndrome characteristics were found in a previous study where the parents were informed about the observable behavioural features of their child's syndrome, but not the more subtle learning-related issues (Fidler et al., 2002).

In addition, although the parents in each syndrome group tended to express similar themes in their open-ended comments, there were some interesting variations in the specific desires expressed. Some parents expressed a desire for more of a particular service, whereas others simply desired better quality services. Some parents mentioned issues relating to treatment of the child in a particular service setting, whether they expressed a desire for greater teacher sensitivity, or for a teacher not to underestimate their child's capabilities. Some parents also expressed concern about their child's integration into the larger, mainstream school environment. Yet amidst this variation in response, the parents of children in the three groups overall tended to bring up issues that were related to the educationally relevant features of their child's syndrome.

Another issue relates to the strength of these findings. Even when there were significant differences, half of the parents or fewer in a given syndrome group spontaneously mentioned the themes extracted. It may have been that some of the remaining parents in a given syndrome group simply did not feel that these were issues

for their children. However, this outcome may also have been observed because of the nature of the measure. Open-ended questions allow parents to be as detailed or terse as they wish. Because there was no structure to how the parents answered the question, some parents still may have felt similar to other parents but for various reasons did not mention that particular topic.

The findings of this study tie into a small but growing literature on the implications of behavioural phenotype research on special education practice (Hodapp & Fidler, 1999). A previous study showed that parents are aware of some features of their child's phenotype in Down syndrome, Williams syndrome, and Prader-Willi syndrome, but not other features (Fidler et al., 2002). Even when parents are less informed, the previous study also showed that parents are usually the only source of syndrome-related information in the educational setting in Williams syndrome and Prader-Willi syndrome. That study also showed that the parents of children with different syndromes differ in their opinions regarding the importance of genetic diagnosis for planning an educational programme.

The findings from this current study suggest that parents may support the tailoring of educational programming to meet the syndrome-specific needs of their child in terms of classroom instruction and services received. Although the parents were not directly asked whether they support a syndrome-specific approach to special education, their answers suggest that they conform to some degree to a syndrome-specific approach when it comes to their particular child. This parental support of aetiology-specific services and programming stands in contrast to other approaches in special education that have argued against categorising children according to particular conditions or syndromes (see Forness & Kavale, 1994).

Two limitations of this study should be noted. First, the participants in this study were recruited through parent groups, and may not reflect the larger populations of families of children with these three syndromes. Families connected to the nation-wide parent groups may be a uniquely informed subset of parents of children with this syndrome, and thus not representative of those parents who have not sought out the support of a parent group. In addition, the sample sizes were also relatively small for each syndrome group, and future studies should seek to replicate these findings with larger samples.

Although this study's findings cannot resolve the debate regarding best practices in special education, they do offer important information to researchers who struggle with questions regarding how to apply recent aetiology-related findings to educational practice. The efficacy of syndrome-related approaches in the classroom and in educational services has yet to be assessed. Still, this study suggests that such syndrome-related approaches ought to be explored; at the very least, parent desires conform to approaches that tailor instruction to the strengths and weaknesses associated with their child's genetic syndrome.

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