BRIEF REPORT: Strengths and Challenges of Children with a Developmental Disability: A Qualitative Analysis of Parent Perceptions

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Abstract

This study examines the perceptions of parents of children aged 3 to 19 with developmental disabilities (including autism spectrum disorder) on their child's strengths and challenges. Qualitative secondary analysis of a sample of 141 parents' responses was conducted on the data collected through a survey developed as part of the Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) project. The top three meta-themes for strengths were personality characteristics, social personality characteristics, and skills. With respect to challenges, meta-themes related to cognitive communication skills deficits, adaptive skill deficits, and behaviour problems were most common. The findings suggest that parents perceive their children as having positive personalities and characteristics beyond stereotypical assumptions.

Literature from the 1990s to the 2000s has emphasized the negative impact children with a developmental disability (DD) have on parents and family in terms of mental and physical health difficulties and marital/couple strain (Donenberg & Baker, 1993; Gerstein, Crnic, Blacher, & Baker, 2009; Gupta & Singhal, 2004; Hayes & Watson, 2013; Myers, Mackintosh & Goin-Kochel, 2009). However, over the last decade the focus of research has gradually changed to include the positive experiences of parents in the process of raising a child with DD.

Some of the variables commonly found to be related to positive experiences of parents and families include stronger marriage, strengthened family ties, and enhanced self-esteem (Green, 2007; Gupta & Singhal, 2004; Hastings, Allen, McDermott, & Still, 2002; Myers et al., 2009). A benefit that was frequently mentioned in the literature is personal growth, in the form of higher self-esteem and higher tolerance for others, which parents associated with caring for their child with DD (Green, 2007; Gupta & Singhal, 2004).

Some research focuses on parents' perceptions of their children's future, and the influence their perceptions could have on their interaction with their child (Kasari & Sigman, 1997; Lehmann & Roberto, 1996). Relatively fewer studies have focused on the child's strengths as they are perceived by their parents. One study qualitatively examined how children with autism were viewed by their parents and other people (Neely-Barnes, Hall, Roberts, & Graff, 2011). The purpose of this study is to fill the gap in this area by reporting on the perceptions of a large sample of parents on their children's strengths and challenges.

Method

The project received Ethics Approval from York University, and informed consent was obtained from all participants.

Participants

The study used secondary analysis of data collected through a survey developed as part of the Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) project (Perry & Weiss, 2009).

The sample consists of 141 parents of children (100 boys and 41 girls) with DD, ranging in age from 3 to 19 years. Of these, 57 children had been diagnosed with a DD while 84 were diagnosed with an autism spectrum disorder (ASD).

Measures

As part of the survey, parents responded to two open-ended questions: (1) "What are your child's greatest strengths?," and (2) "What are your child's greatest challenges or problems?" Space was provided for three responses to each of the questions.

Data Analysis

The analysis included both quantitative and qualitative techniques. The qualitative analysis involved a thematic content analysis of parents' responses to the questions regarding strengths and challenges. Thematic analysis was conducted by the authors collaboratively until saturation was reached, which occurred after 91 participants for both strengths and challenges.

To establish inter-rater reliability, participants 92 to 141 were coded independently by the first two authors. A high inter-rater reliability was noted with 88% agreement of the pre-established themes for strengths and 90% for challenges. When any disagreements presented themselves, the two authors discussed the most suitable theme that represented the response given and arrived at a consensus.

Each participant's responses were coded for the presence or absence of each theme in order to get the percentage of participants who reported particular themes.

Results

Strengths

A total of 34 themes emerged based on parents' comments on their child's strengths. These were further grouped into five meta-themes based on conceptual similarities: (1) Personality Characteristics, (2) Social Personality Characteristics, (3) Cognitive Functioning, (4) Behavioural Coping Mechanisms, and (5) Skills. Figure 1 depicts the percentage of parents that reported each of these meta-themes.

As seen in Figure 1, over 60% of parents reported *Personality Characteristics* as strengths of their child. This meta-theme was the most common, and included ten sub-themes (Table 1). Among these, being loving/caring/affectionate (28%; *"Loving and caring towards family and his animals"*), happy (24%; *"is generally very happy"*), and active/strong/healthy (13%; *"Physical fitness level"*) were most frequently mentioned by parents.
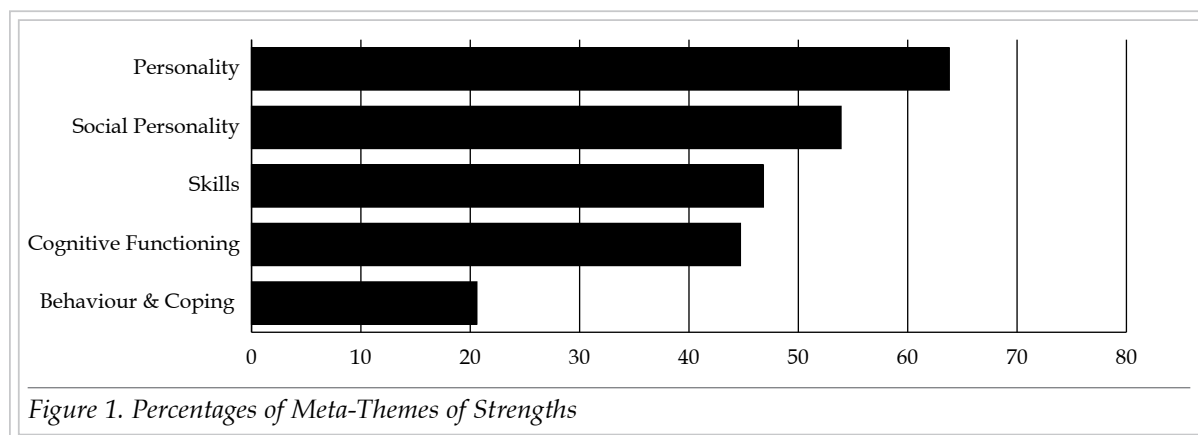

Figure 1. Percentages of Meta-Themes of Strengths

Table 1. Sub-themes for Strengths

Themes	Percentage (%)
ST1. Personality Characteristics	
1.1 Loving/Caring/Affectionate	27.7
1.2 Happy	24.1
1.3 Courageous	1.4
1.4 Curious	5.0
1.5 Patient	1.4
1.6 Independent	2.1
1.7 Cautious	0.7
1.8 Honest	0.7
1.9 Artistic/Creative	5.7
1.10 Active/Strong/Healthy	12.8
ST2. Social Personality Characteristics	
2.1 Sense of Humour	12.1
2.2 Helpful	7.1
2.3 Playful	4.3
2.4 Likeable/Charming	18.4
2.5 Sociable/Friendly	26.2
2.6 Creative/Imaginary Play	2.1
ST3. Cognitive Functioning	
3.1 Motivation	15.6
3.2 Focus/Attention	4.3
3.3 Memory	7.1
3.4 Intelligent/Smart	5.7
3.5 Problem-Solving	2.8
3.6 Savant Skills	5.7
3.7 Academic	12.8
ST4. Behavioural Characteristics/Coping Mechanisms	
4.1 Responds to Structure	3.5
4.2 Organizational Skills	0.7
4.3 Compliant/Well-Behaved/Cooperative	7.1
4.4 Adaptable/Flexible/Resilience	7.1
4.5 Responds to Reinforcement	3.5
ST5. Skills	
5.1 Recreational Skills/Hobbies	19.9
5.2 Self-Help Skills	5.0
5.3 Visual/Spatial	7.8
5.4 Speech/Communication	9.2
5.5 Physical/Motor	2.8
5.6 Navigating Technology	12.8

Social Personality Characteristics were the next highest reported meta-theme for perceived strengths with over half of the parents reporting this theme. This meta-theme included six sub-themes that were based on descriptions of the child's personality in social settings (Table 1). Examples of some of the social personality characteristics parents reported includes being playful, sociable, likable, and a sweet child. Their child being sociable/friendly

was the most commonly reported (26%; *"makes friends easy"*), followed by likeable/charming (18%; *"very endearing personality-people are drawn to her"*) and sense of humour (12%; *"sense of humour"*).

There were six sub-themes under the meta-theme of *Skills* whereby a little less than 50% of parents reported particular types of skills as a strength of their child. Parents were said to have reported a skill if they mentioned the child's enjoyments and abilities. Some of the sub-themes that were placed under the theme of skills were recreational/hobbies (20%; *"he loves the outdoors"*), navigating technology (13%; *"can use a computer and ipad on his own "*) and speech/communication (9%; *"high functioning speech"*).

There were seven sub-themes under the meta-theme of *Cognitive Functioning*. When parents reported this theme, they were describing the strengths of their child that related to cognitive abilities. The most common of the descriptions that were categorized under the theme of cognitive functioning included motivation (16%; *"if he wants to do something badly enough, he'll figure out a way!"*) and academic ability (13%; *"good literacy skills"*).

There were five sub-themes under the meta-theme of *Behavioural Characteristics/Coping Mechanisms*. When parents reported this theme, they were describing how well their child does in diverse situations. The two most commonly reported sub-themes were compliant/well-behaved/cooperative (7%; *"he is very co-operative"*) and adaptable/flexible/resilient (7%; *"has no problems with change, very adaptable"*).

Challenges

The seven meta-themes for challenges consisted of behaviour problems, adaptive skill deficits, cognitive communication skills deficits, restricted/repetitive behaviour, anxiety/sensory, attention difficulties, and other medical issues (refer to Figure 2).

The meta-theme of *Cognitive Communication Skills Deficit* was the highest reported meta-theme for challenges, with 62% of parents reporting a challenge in this category. There were seven sub-themes under cognitive communication skills deficit (Table 2). The top three sub-themes in this category were: communication (40%; *"not being able to communicate wants and needs"*); cognitive (17%; *"no cause and effect knowledge"*), and academic (10%; *"learning especially reading and math skills"*).

Adaptive Skill Deficits were the second highest reported meta-theme for challenges, with 50% parents reporting these. Parents who reported adaptive skill deficits described a variety of skills necessary to function in everyday life, for instance self-help skills. There were five sub-themes under adaptive skill deficits that contained responses such as gross motor skills. Social interests and skills (28%; *"has no interest in having or making friends"*); and self-help skills (14%; *"she requires full personal care for eating and toileting"*) were the most frequently mentioned by parents.

The meta-theme of *Behaviour Problem* was made up of nine sub-themes. Behaviour problems were reported by 50% of parents. When parents reported this theme, they were describing the
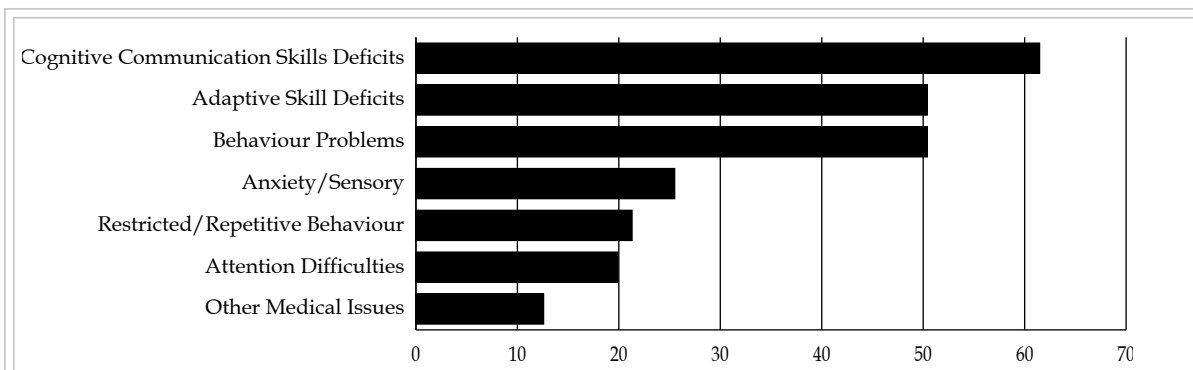

Figure 2. Percentages of Meta-Themes of Challenges

challenges of their child in relation to external behaviours directed at self or others. The three most frequent sub-themes here were: safety/ flight concerns (17%; *"lack of safety awareness"*) and inappropriate social interactions (11%; *"learning socially acceptable behaviours (hugging, etc. too*

much), reverts to Pokemon attacks when he is stressed, lashing out").

Twenty-five percent of parents reported *Anxiety/ Sensory* issues as a challenge of their child. There were four sub-themes included under anxiety/

Table 2. Sub-themes for Challenges

Themes	Percentage (%)
CT1. Behaviour Problems	
1.1 Aggression	6.4
1.2 Self-Injurious Behaviours	5.0
1.3 Anger Outbursts	5.0
1.4 Non-Compliant/Stubborn	9.9
1.5 Destruction of Property	2.1
1.6 Arguing	1.4
1.7 Safety/Flight Concerns	17.0
1.8 Other Behaviour Issues	8.5
1.9 Inappropriate Social Interactions	11.3
CT2. Adaptive Skill Deficits	
2.1 Self-Help Skills	14.2
2.2 Life Skills	6.4
2.3 Social Interests and Skills	27.7
2.4 Gross Motor	4.3
2.5 Fine Motor	5.0
CT3. Cognitive Communication Skills Deficit	
3.1 Communication	39.7
3.2 Academic	9.9
3.3 Cognitive	17.0
3.4 Social Cognition	7.8
CT4. Restricted/Repetitive Behaviour	
4.1 Rigidity/Routine	12.8
4.2 Repetitive Behaviour	5.0
4.3 Narrow Interests/ Lack of Motivation	5.0
CT5. Anxiety/Sensory	
5.1 Anxiety General	10.6
5.2 Anxiety Sensory	2.1
5.3 Sensory General	7.8
5.4 Frustration/Emotion Regulation/Patience	7.1
CT6. Attention Difficulties	
6.1 Hyperactivity/Impulsivity/Fidgety	7.8
6.2 Inattention/Poor Attention Span	14.2
CT7. Other Medical Issues	
7.1 Seizures	2.1
7.2 Sleep Problems	2.1
7.3 Food Sensitivities	1.4
7.4 Lethargic/ Tired/ Low Energy	2.1
7.5 Other Issues	5.7

sensory that related to difficulties children faced that led to feelings of anxiety or sensory over-stimulation. The two most frequent sub-themes were: anxiety general (10%; *"anxiety-related behaviours"*) and sensory general (8%; *"wants everything to go in mouth"*).

The meta-theme of *Restricted/Repetitive Behavior* was reported by 21% of parents. Parents who reported restricted/repetitive behaviour as a challenge of their child referred to their child as becoming stuck in routines and often engaging in repetitive behaviours such as rocking. The three sub-themes placed under this meta-theme include rigidity/routine, repetitive behaviour, and narrow interests/lack of motivation. Of the parents who reported restricted/repetitive behaviour, their child being rigid was most commonly reported (13%; *"inability to handle change and transitions"*).

The meta-theme of *Attention Difficulties*, reported by 20% of parents, incorporates responses which center on the child's challenges related to attention and impulsivity. There were two sub-themes under this meta-theme, of which inattention/poor attention span was most common (14%; *"has difficulty regulating attention and focus"*).

The final meta-theme for challenges was *Other Medical Issues*, aside from a DD or ASD diagnosis, with a frequency of 13%. Responses that were a part of this theme included any additional medical issues such as sleeping problems or food sensitivities of the child. Of the parents who reported this theme, other medical issues like weight gain and acid reflux were most commonly reported (6%; *"she has a chronic runny nose that makes her very uncomfortable"*).

Discussion

The aim of this study was to examine parents' perceptions of the strengths and challenges of their child with DD. The results indicate that parents do report a lot of strengths for their children in spite of the child's disability and challenges. Overall, the three most frequently reported meta-themes of the child's strengths include personality characteristics, social personality characteristics, and skills. For challenges, the top three reported meta-themes of the seven were cognitive communication skill deficits, behaviour problems, and adaptive skill deficits.

Interestingly, most parents reported strengths that related to the child's personality or inherent nature (he is loving, sociable, and so on) as opposed to challenges that more often related to the child's behaviour (e.g., she has tantrums, he can't communicate), which are often associated with negative outcomes experienced by parents (Hayes & Watson, 2013; Myers et al., 2009). Clearly these behaviour problems and skills deficits do not preclude parents' perceptions of endearing and positive qualities existing simultaneously. As there are no similar studies in the literature to compare our results to, it is difficult to say whether this pattern of results replicates or differs from other research about parents' perceptions of children's strengths and challenges. However, it does parallel the finding in the parent outcome literature that parents' negative impacts or outcomes, such as depression and stress, do not preclude the existence of positive outcomes such as enhanced personal growth.

The study does not come without a set of limitations. The representativeness of the sample cannot be ascertained and the proportion of children with ASD may have influenced the results. In addition, there was limited space for parents to write their responses. Three lines were provided for both strengths and challenges, so this may have constrained parents' responses to three brief items. It is possible they would have responded differently with an open-ended question and larger space. They may have had more than three strengths or challenges and only wrote the first three items that came to mind.

There are a number of strengths of the study to keep in mind, as well. First, it is a large sample (especially for qualitative research) that does incorporate participants from all over Canada. Second, the inter-rater reliability was high for both strengths and challenges. High inter-rater reliability provides validity and credibility to the themes that were created and the responses that fit into particular themes.

In future research, it would be interesting to compare mothers' and fathers' perceptions of their children's strengths and challenges as most of the responses used in the present study were from mothers. A future study could also compare parents' perceptions of children with a

DD with those from parents of typically developing children. It would also be interesting for future researchers to pose the same types of questions to the teachers of these children.

In conclusion, the study provides important information, not only to researchers, but also to clinicians working with families and to parents themselves. The findings show that a child with a DD is more than a set of challenges or skill deficits, as is often assumed. The study suggests that parents perceive their children as having interesting and positive personalities and characteristics exceeding stereotypical expectations and assumptions.

Acknowledgements

Key Messages From This Article

People with disabilities: You deserve to be recognized for all of your strengths. Strengths could be things about your personality (like being friendly) or things you are good at (like using the computer).

Professionals: Helping people with disabilities and their families means recognizing that there are both benefits and burdens in raising a child with a disability. It is also important to acknowledge and encourage parents' perceptions of their children's strengths.

Policymakers: Policy development should include a strengths-based approach that fosters a positive outlook on children with a disability and their families to create and promote acceptance.

References

Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology, 21*(2), 179–198. Retrieved from http://link.springer.com.ezproxy.library.yorku.ca/article/10.1007/BF00911315

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981–997.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150–163.

Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal, 15*(1), 22–35. Retrieved from http://209.190.218.30/NS_positive_perceptions.pdf

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(3), 269–275.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(3), 629–642.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders, 27*(1), 39–57. Retrieved from http://resolver.scholarsportal.info.ezproxy.library.yorku.ca/resolve/01623257/v27i0001/39_lpptiiycwa

Lehmann, J. P., & Roberto, K. A. (1996). Comparison of factors influencing mothers' perceptions about the future of their adolescent children with and without disabilities. *Mental Retardation, 34*(1), 27–38.

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affect their lives and their families' lives. *Research in Autism Spectrum Disorder, 3*(3), 670–684.

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*(3), 208–225.

Perry, A. & Weiss, J. (2009). *GO4KIDDS Extended Survey* (Unpublished survey), York University, Toronto, ON.