

Children with disabilities can also have positive effects and make unique contributions to families and family life.



Strength in Diversity

Positive Impacts of Children with Disabilities

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When it comes to exploring the experiences of families raising children with disabilities, studies tend to focus on the perceived *negative* impact of the disability on the family. These families are commonly viewed as “victims” who face excessive caregiving demands, emotional distress, physical and/or financial burdens and interpersonal difficulties, while the children are portrayed primarily as sources of stress and anguish. This tragedy dialogue supports an assumption that families with children with disabilities experience “chronic sorrow” and perpetuates the perception of disability as something to be avoided or eradicated.¹ These perceptions have a major influence

on today’s assumptions about – and reactions to – disability,² including how professionals respond to children with disabilities³ and how society views and responds to children at birth.⁴ Consequently, the general public tends to overlook many positive impacts and meaningful contributions that children with disabilities make within their families, communities and society in general.

In order to explore the positive impact disability can have within families, a qualitative, interview-based study was performed to add narrative depth to the research. All of the parents and children interviewed identified a variety of positive effects the children have

had on their families and contributions the children have made to family life. The most unsurprising discovery was the affirmation that a child with a disability can have some of the same positive effects on their families and make some of the same contributions as any other child. Highlighting these similarities is critical, given the tendency for children with disabilities to be distinguished from other children and viewed as less likely to affect their families in positive ways.⁵ Yet perhaps even more meaningful was the discovery that children with disabilities can also have positive effects and make *unique* contributions to families and family life.

Raising a child with a disability provides opportunities for personal growth

Parents in the study reported an ability to more readily recognize and appreciate the value, potential and strengths of a person with a disability as a result of their parenting experiences. Many described how their experiences left them with a greater acceptance of diversity, a stronger belief that there is an inherent and intrinsic value in people and a “more balanced appreciation for what people are about.”

One participant said her experience gave her a new perspective on how to help individuals she works with; she learned not to place limits on people or tell them what they can or cannot do, but instead help them strive for self-improvement. *Siblings* of children with a disability experienced attitudinal changes brought about by this family relationship. For these siblings, increased exposure to disability in their family environment made them more comfortable around *other* children with a disability, and they discovered a new-found enthusiasm for getting to know people with disabilities in general.

Children with a disability often exceeded expectations and did not necessarily comply with what is typical for their diagnoses, often being nothing close to the worst-case scenarios predicted by some doctors. As one participant stated, “I don’t know what my parents would have thought about people with disabilities before I came around, but I think it’s just... shown them that it really doesn’t mean that much... you can still be productive and still have goals and not really let anything stop you, as hard as that is sometimes.”

All of the parents in the study perceived themselves as having acquired new or enhanced positive character attributes as a result of raising a child with a disability. Attribute changes included family members learning to open their hearts and to be more loving, warm, caring, creative, balanced, gentle, calm, outgoing, responsible, independent and less selfish.

The positive attribute change most commonly reported by parents of a child with a disability was



Parents expressed pride in, or were impressed by, their children’s knowledge or creativity, their sense of right and wrong, their methods for overcoming fears, their ability to put their minds to something and take a chance, and for being their own advocates.

that they became more tolerant and accepting. As family members learned to be more accepting of diversity and of people’s behaviours, they cultivated a greater respect for other families of children with disabilities and experienced more compassion toward people in general.

Several parents commented that their child made them an overall “better person,” “better parent” or made other family members “better people.” Some of these effects carried over into the workplace: one participant perceived himself as a “better person at work” because of the understanding his son has given him about autism. This understanding has enabled him to relate to staff and other people in a different way; he supports his colleagues by helping them understand and interpret the behaviour of a co-worker who also has autism.

Parents experience pride, joy and strengthened relationships

All parents in the study reported positive emotions their children have fostered in them. A sense of pride was the most common. One parent recognized that some of the things that evoke a sense of pride “may not be the same as what other people [her son’s age] are doing,” yet she maintained she had numerous reasons to be proud. Parents expressed pride in, or were impressed by, their children’s knowledge or creativity, their sense of right and wrong, their methods for overcoming fears, their ability to put their minds to something and take a chance, and for being their own advocates. Additionally, all 10 children reported the positive emotions they also felt they evoked in family members – more than half believing they made their family proud.

One mother insisted she derives more excitement from the little things in life than many other people

and that she “celebrate[s] things that other people don’t even think about celebrating” because of her daughter. Another explained her pride in her daughter as follows: “Disability-wise, I’m very proud of her because she hasn’t let her disability control her life. She’s got multiple disabilities... And she doesn’t let that slow her down... It would be too easy to say, ‘Oh, I can’t do this’ and give up... She’s always willing to push the limits and do the best that she can.”

Many parents talked about having met people, gained friendships and made new connections thanks to their child. While any child can expand a family’s social network, certain examples were attributed to the family’s particular circumstances. For one couple, connecting themselves to other families through the creation of a support network for parents with similar experiences has been valuable, as they have been able to offer support to other parents who have approached them for advice and guidance.

Despite one parent noting that having a child with a disability may make some families “fall apart,” many parents perceived that their child *strengthened* their marriage or made the parents and/or family stronger. Two of the parents felt they had become better at communicating and sharing with their spouse thanks to their child. The father in this couple talked about the difficulty he and his wife experienced when their son was first diagnosed and described the role each played in helping the other get through the “tough parts.” Their experience, he explained, has made him and his wife “more free to talk about things and feelings,” thus improving their communication.

A few parents mentioned how their child added a fresh perspective and/or insight to the family. One father commented on the value of his son’s insight and identified this as something he appreciates most about him: “His insight into things is so different than anybody else. He thinks differently than we do... and I love hearing his insight. He adds such a dimension to our house... I just can’t imagine not having that dimension in our home. It’s... such a core of who we are in this house. He’s so amazing.”

Referring to his natural gifts when it comes to writing and composing music, one of the children insisted that having autism has given him the ability to be hyperfocused and successful with music. He concluded, “I think the music is a positive impact. It can impact everyone else, too, if they hear it.”

When asked how she makes a difference in her family, another one of the children replied, “I suppose it would be a little less lively without me. There wouldn’t be as many interesting dinner conversations.” She also referred to “the whole yin and yang thing” and how she counterbalances the mellowness in her family.

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Families learn from their unique experiences and seek to share their knowledge

Before concluding the interviews, all participants were asked what they would like other people to understand about them, their family and/or their experience. Parents shared that their experiences are “not all rosy” – that there have been “challenges,” “struggles,” “obstacles” and “tough times.” Yet parents did not necessarily hold the child responsible for any negative aspects of their experience. One parent admitted that her struggles adjusting to her child’s disability had less to do with the child than with other people’s preconceptions and the parents’ own feelings regarding what their experience would be like. She explained, “There was no question, that period of time where you struggle with it – a bit of a denial thing. Well, you almost grieve, but you come to the conclusion that those feelings are more about you, and what you thought, or what other people might be thinking.”

Other parents agreed that any anger, stress, anxiety and/or crises they may have experienced resulted from having to deal with the ignorance of other people and a general lack of societal understanding rather than from the child. One mother requested that people reconsider their use – or misuse – of certain labels, explaining that, while people with intellectual disabilities are often labelled as hindered in some way, “the hindrance is very often on the so-called ‘normal’ people for lack of understanding them.”

These findings coincided with those from an earlier study in which parents suggested that the sorrow they experienced originated largely from having to deal with recurring messages of negativity and hopelessness from other people, such as professionals, the health system, other family members and friends.⁶ This suggests a source of stress and negativity *outside* the child and that a family’s perceptions about their child may be determined, at least in part, by the surrounding cultural beliefs about disability.⁷ Therefore, if society holds negative attitudes toward disability and the surrounding cultural perceptions are largely negative, negativity can be transmitted to the family – to parents’ views of, and beliefs about, their children and to their parenting.⁸

The parents in the study also wished to dispel negative assumptions others might associate with their child and place any negativity in context of the bigger picture. Some described their experience “as a gift instead of a burden,” and insisted it is not a source of anything negative to have a child with a disability in the family, emphasizing that they are not sorry for the way their child has changed their lives. While acknowledging the stress, hard work and commitment required to raise a child with a disability, other parents commented on the unfortunate nature of other people not realizing



Focusing on the children’s positive impacts and contributions may serve to control the meaning and level of stress associated with the experience.

how rewarding the experience can be. One father reframed his experience raising his son in the following way: “You want a catastrophe? You want tragedy? You know what, let me pick up a paper and show you about somebody who died in a car accident. Let me show you about a young mother that was killed. Let me show you about the tsunami. Those are tragedies. This is a curveball. All you’ve got to do is learn how to hit curves and you’ll be fine... And it’s not easy, but you learn to grow with it.”

Among the most common requests from parents were that assumptions not be made based on disability and that people recognize each child’s ability and potential. Parents insisted that their children can give a lot to society and deserve respect and requested that people make an effort to learn from their children. Elaborating, one parent cautioned, “I was just thinking in terms of the impact of... people with Down syndrome on the world... We’ve been trying to basically eradicate this group of people by all the blood testing and stuff. It devalues the lives that they have. And they have something to offer... They’ve got something really special that we need to sit up and take note of because we could learn a lot from them.” When asked what they wanted to share with others, similarly powerful messages came from the children. One of the children wanted others to “understand that I have disabilities,



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but I'm not a worse person for it." Another child offered the following take-away message: "Lots of people have the perception that I'm kind of slow... I want them to know that I really do know a lot about the world and what's going on, and it hasn't stopped me - having cerebral palsy, being in a wheelchair - I'm *not* an unaware person. I have big ambitions and a bright future. I don't want them to feel sorry for me, because I think I'm going to have a really good and interesting and fun life!"

The positivity of embracing diversity goes beyond the family

Learning from families who view their circumstances in a positive light, making these perceptions more

readily available to the general public and coming to view the experience of raising a child with a disability as one that is not necessarily tragic - but rather enriching and rewarding - can have a variety of positive implications. These findings can provide medical professionals (particularly those involved in prenatal screening and diagnosis) with practical information to share with families when a diagnosis is given. These findings might also benefit other parents currently raising a child with a disability by encouraging them to focus more closely on what their child adds to their life.⁹

In presenting these findings, this study is not denying the existence of challenges and negative family experiences. Sharing these findings is also not suggesting that everything will automatically improve for families who struggle raising a child with a disability. Yet the belief is that appreciating the strengths and positives has potential for beneficial change.¹⁰ There is also evidence that focusing on the children's positive impacts and contributions may serve to control the meaning and level of stress associated with the experience.^{11, 12} This could be helpful in the adaptation process. If more families see their experiences in a positive light, perhaps they can assist in altering widespread perceptions of the impact of disability, provide support to new parents and relieve some of the fear and anxiety around the idea of raising a child with a disability. In doing so, the hope is that a more affirmative way of viewing disability could be promoted.♥

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¹ John Swain and Sally French, "Towards an Affirmation Model of Disability," *Disability & Society*, 15:4 (2000), accessed October 9, 2014, <http://bit.ly/1ycgl7r>.

² Jean Ann Summers, "Family Adjustment: Issues in Research on Families with Developmentally Disabled Children," in Vincent B. Van Hasselt, Phillip S. Strain and Michel Hersen (Eds.), *Handbook of Developmental and Physical Disabilities* (Elmsford, NY: Pergamon, 1988).

³ Shirley Kharasch Behr, *Underlying Dimensions of the Construct of Positive Contributions That Individuals with Developmental Disabilities Make to Their Families: A Factor Analytic Study* (unpublished doctoral dissertation), University of Kansas (1989).

⁴ Ibid.

⁵ John B. Fotheringham, Mora Skelton and Bernard Hoddinott, *The Retarded Child and His Family: The Effects of Home and Institution* (Toronto, ON: Institute for Studies in Education, 1971).

⁶ Tim Stainton and Hilde Besser, "The Positive Impact of Children with an Intellectual Disability on the Family," *Journal of Intellectual and Developmental Disability*, 23:1 (1998), accessed October 9, 2014, <http://bit.ly/1s01wQt>.

⁷ Diana Whitney and Amanda Trosten-Bloom, *The Power of Appreciative Inquiry: A Practical Guide to Positive Change* (San Francisco, CA: Berrett-Koehler Publishers, Inc., 2003).

⁸ Leonard I. Pearlin and Carmi Schooler, "The Structure of Coping," *Journal of Health and Social Behavior*, Vol. 19 (March 1978), accessed October 9, 2014, <http://bit.ly/1Ezxdqp>.

⁹ Penelope M. Kearney and Tim Griffin, "Between Joy and Sorrow: Being a Parent of a Child with Developmental Disability," *Journal of Advanced Nursing*, 34:5 (2001), accessed October 9, 2014, <http://bit.ly/1pVlh7l>.

¹⁰ Ashum Gupta and Nidhi Singhal, "Positive Perceptions in Parents of Children with Disabilities," *Asia Pacific Disability Rehabilitation Journal*, 15:1 (2004), accessed October 9, 2014, <http://bit.ly/ZSml0U>.

¹¹ Ibid.

¹² Lisa Woolfson, "Disabled Children, Parents and Society - A Need for Cognitive Reframing," *Proceedings of the British Psychological Society*, 11:1 (2003), accessed October 9, 2014, <http://bit.ly/1uGHSuW>.