

BRIEF REPORT: Professional Support and Positive Gain for Mothers of Children with ASD

Abstract

Though raising a child with autism spectrum disorder (ASD) is often associated with stress, many parents report positive aspects as well. Access to professional supports may be related to positive gain, given that professional supports are related to decreased levels of stress. The purpose of this study was to investigate the relationship between professional support and positive gain for mothers of children with ASD. Participants included 132 mothers of children diagnosed with ASD aged 4–21 years. Professional support and behaviour problems were found to be significant predictors of positive gain in mothers of children with ASD. The clinical implications of these results are discussed.

Even though raising a child with autism spectrum disorder (ASD) is often associated with stress (Lecavalier, Leone, & Wiltz, 2006), many parents report positive aspects of parenting their child. Personal growth (Hastings & Taunt, 2002), an enriched spiritual life (Gray, 2006), and a re-evaluation of life priorities (Myers, Mackintosh, & Goin-Kochel, 2009) are all tied to caring for a child with ASD, suggesting that raising a child with a disability may involve positive gain in families (King et al., 2006). Positive gain is defined as the perceived benefits of raising a child, including growing as a person, learning new skills, and becoming more determined to face challenges. Given that positive gain is associated with positive outcomes for parents, it is important to investigate the variables associated with such gains.

There is emerging research on parents of children with ASD and parents of children with intellectual disability (ID) that shows positive gains are positively correlated with psychological acceptance in fathers of children with ID (MacDonald, Hastings, & Fitzsimons, 2010), negatively correlated with stress in mothers of young adults with ID (Blacher & Baker, 2007), and positively correlated with mothers' perceptions of their child as a source of happiness, strength and family closeness (Hastings, Allen, McDermott, & Still, 2002).

Having access to professional supports may also be related to the positive gain associated with caring for a child with ASD, as supports are related to healthy adaptation (Siklos & Kerns, 2006). However, some studies have shown that professional supports are associated with reduced parental stress (Chan & Sigafos, 2001; King, King, Rosenbaum, & Goffin, 1999), while others have suggested it might be associated with increased stress (Sloper & Turner, 1992). To date, no study has specifically examined how professional supports relate to perceptions of positive gains in families of children with ASD.

Authors

Jennifer MacMullin,
Ami Tint,
Jonathan Weiss

Department of Psychology,
York University,
Toronto, ON

Correspondence

jenmacm@yorku.ca

Keywords

positive gain,
professional support,
behaviour problems,
autism spectrum disorders,
mothers

The purpose of the present study was to investigate the relationship between professional support and positive gain for mothers of children with ASD. It was hypothesized that professional support would be positively correlated with positive gain and that professional support would be a predictor of positive gain, after controlling for maternal age and child gender.

Method

Participants

Participants included 132 mothers of children diagnosed with ASD aged 4–21 years (108 boys and 24 girls; $M = 11.71$, $SD = 4.61$). Children's diagnoses included autism (46.6%; $n = 61$), Asperger syndrome (32.1%; $n = 42$), pervasive developmental disorder-not otherwise specified (19.8%; $n = 26$) and other diagnoses (1.5%; $n = 2$). Almost all children (99.2%; $n = 129$) were living with their parents.

Procedure

Mothers were recruited through several different ASD support organizations (e.g., Autism Ontario, Asperger Society of Ontario). After giving informed consent, participants completed online measures of demographics, child problem behaviours, positive gain, and professional support. This study was part of a larger survey of family experiences of individuals with developmental disabilities. The York University Research Ethics Board approved this study.

Measures

Behavior Problem Inventory Short Form (BPI-S; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001)

The 10-item Aggressive/Destructive Behavior subscale of the BPI-S was used. Items were rated on a 5-point frequency scale ranging from *never* (0) to *hourly* (4). The BPI-S has a test-retest reliability of .64 and high internal consistency ($\alpha = .82$) (Rojahn et al., 2001). Internal consistency for the current study was $\alpha = .84$.

Positive Gain Scale (PGS; Pit-ten Cate, 2003)

The PGS consists of five items that examine the benefits for the parent of raising an individual with ASD and two items that assess the benefits for the family. The items were rated on a 5-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5), with higher scores representing more positive gain. The internal consistency for the current study was $\alpha = .87$.

Professional Support

Professional support was assessed by asking mothers to select which professional supports were being used by their child with ASD from a predetermined list that included general practitioner/family doctor, psychiatrist, behaviour therapist, assertive community treatment team, counselling/therapy, crisis plan, case manager/social worker, service coordinator, advocacy, planning, and support worker, occupational therapist, employment supports, specialized transportation, respite services, government funded intensive behaviour services, part-time educational assistant at school, and full-time educational assistant at school. The total number of professional supports was calculated by summing all of the supports. The mean number of supports used by mothers was 3.62 ($SD = 1.99$).

Results

Correlations

Pearson's product-moment correlation analyses were conducted to examine the zero order associations among behaviour problems, positive gain, and professional support. Positive gain was significantly correlated to professional support $r = .37$, $p < .001$, but not to behaviour problems, $r = -.06$, $p = .54$.

Hierarchical Regression

A hierarchical regression was conducted to test the hypothesis that professional support would predict positive gain. Maternal age, child gender, and behaviour problems were entered in the first step. At step 1, maternal age was a significant predictor of positive gain. At step 2, professional support was a significant predictor of positive gain, accounting for 16% of the unique variance

Table 1. Professional Supports Predicting Positive Gain in Mothers of Children with ASD (n = 101)

Variable	Model 1			Model 2		
	B	SE B	β	B	SE B	β
Constant	1.69	.12		1.50	.12	
Maternal age	-.01	.01	-.21*	-.01	.01	-.14
Child gender	-.05	.04	-.12	-.05	.04	-.12
Behaviour problems	-.07	.10	-.07	-.19	.09	-.20*
Professional support				.04	.01	.42***
R ²		.07			.23	
F for change in R ²		2.49			19.68***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

in positive gain. The overall model accounted for 23% of the variance in positive gain.

Discussion

The results from this study indicate that professional support was linked to positive gain in mothers of children with ASD, after controlling for maternal age and child gender. Further, as the number of professional supports increased, positive gain also increased.

Maternal age and behaviour problems were also significant predictors of positive gain. Behaviour problems have been consistently linked with lower levels of maternal well-being, so the finding that behaviour problems are a significant predictor of positive gain was not surprising, once the model also took into account the number of professional supports received (Abbeduto et al., 2004). After taking into account the professional supports received by mothers, maternal age ceased to remain significant. To date, no studies have longitudinally examined age related changes in positive gain, and understanding how parent and child age interacts with these other factors is an important area of further inquiry.

This study is not without limitations. First, although the data suggest that more professional supports could lead to higher positive gain, the analyses are correlational and the relationship between professional support and positive gain is likely transactional, as parents

with more positive gain may be more likely to seek out and engage in professional support. Second, we did not investigate whether mothers were on any waiting lists for services or whether mothers were satisfied with services; both could influence positive gain. Last, only mothers were included. Including multiple informants such as fathers, grandparents, and siblings would provide a more complete understanding of positive gain in families.

Overall, the current study demonstrated that professional support is an important contributor to positive gain for mothers of children with ASD. Directions for future research include investigating other variables that may influence positive gain in families, such as satisfaction with support services. The specific aspects of professional supports that encourage positive gain in families could also be investigated. Subgroup differences could be examined by comparing samples from different cultural, ethnic, and socio-economic backgrounds.

Key Messages from This Article

People with disabilities: Sometimes mothers feel better when they get help from other people.

Professional: Professional support contributes to positive gain in mothers of children with ASD.

Policy makers: Policies to increase professional support may increase positive gain in mothers of children with ASD.

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G. I., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, 109, 237-254.
- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 112(5), 330-348.
- Chan, J. B., & Sigafos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Child and Youth Care Forum*, 30, 253-263.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- 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.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107(2), 116-127.
- King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology*, 24(1), 41-53.
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development*, 32(3), 353-369.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183.
- MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities*, 23, 27-37.
- 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 affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684.
- Pit-ten Cate, I. (2003). *Positive gain in mothers of children with physical disabilities*. Doctoral thesis, University of Southampton, England, UK.
- Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., & Smalls, Y. (2001). The Behavior Problems Inventory: An instrument for the assessment of self-injury, stereotyped behavior, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders*, 31, 577-588.
- Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, 36(7), 921-933.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, 18(5), 259-282.