

research Changing the Clinical Picture of Parents raising children with autism

Research examining the positive and negative impacts on mothers and fathers, by Terry Diamond, Ph.D.



Terry is the recipient of the 2003 Autism Society Ontario Studentship Award for Autism Spectrum Disorder Research administered through Ontario Mental Health Foundation

My experience with families suggests that some parents raising children with autism are quite distressed, others appear to be doing okay, and still others report that having a child with autism has had a positive impact on how they view people, on their career or on their perspective on life. Research has yet to really identify the factors that result in these differences. The goal of my research was to explore various factors that may make a difference in how a child with autism impacts mothers and fathers. This study examines how parents' beliefs about their parenting ability may impact on their feelings of overall well-being. Similarly, this study also explores parents' beliefs about their ability to intervene on behalf of their child at school, in the community and politically. The importance of parents' thoughts and beliefs about their ability to manage, teach and advocate for their child has not previously been looked at in parents of children with autism. In addition to looking at the beliefs that parents hold, this study also looks at other factors that may make a difference in how parents are impacted by their experience of raising a child with autism, including perceived social support from formal and informal sources, coping strategies and involvement in advocacy.

The purpose of the current investigation was to explore the positive and negative impacts of raising a child with autism as well as the coping resources that may make a difference for mothers and fathers. The coping resources of interest were empowerment beliefs, self-efficacy beliefs, advocacy involvement, formal and informal social supports, and emotion and task-oriented coping styles. Participants consisted of 114 mothers and 76 fathers raising children between 2 and 12 years of age with Autism Spectrum Disorder (ASD). Results indicated both differences and similarities between how mothers and fathers were impacted by their experience of raising a child with ASD.

Perhaps the most prominent strength of the current study is its inclusion of a relatively large sample of fathers of children with autism, allowing for a comparison between mothers and fathers experiences, as well as an examination of the differences within these two groups. The present study also extends research by examining positive impacts on the family and perceptions of positive changes in parents as a consequence of raising a child with autism. It is the first I am aware of that examines the role that advocacy involvement and empowerment beliefs play in relation to the impact on parental well-being. It is also one of the first studies to examine the relationship between

parenting self-efficacy beliefs and parent well-being in parents of children with autism.

The results of the study have implications for how clinicians assess and provide support to mothers and fathers. Findings indicate that helping to facilitate the provision of support from informal sources both within the family and within the community (e.g., spouses, friends, extended family, neighbours) can have powerful effects on both mothers' and fathers' well-being, and even promote the development of positive changes in mothers as a consequence of raising a child with autism. Connecting families with formal support services may require greater thought and exploration to ensure that mothers, who are often the primary caregiver, have appropriate and helpful formal supports in place (e.g., daycare, social workers, early intervention programs) while at the same time ensuring that interactions with formal supports services are not increasing levels of parental distress for fathers or having negative impacts on family life (e.g., increased financial strain, disruption of family routine, increased demands on time). The current study clearly supports examining parents' coping styles to determine relative reliance on emotion-oriented versus problem-focused strategies. Parents who appear to be relying more heavily on emotion-oriented coping strategies such as blaming themselves for procrastinating, for not knowing what to do or for being too emotional are at greater risk for increased parental distress, for experiencing their child's symptoms and behaviours as more stressful and for perceiving the child with autism as having greater negative impacts on the family. In general, findings support guiding parents toward taking a more active problem-solving approach to coping, such as outlining their priorities, determining a course of action and following it, and analyzing the problem before reacting. The present findings also support placing an emphasis on helping strengthen feelings of parenting self-efficacy in parents of children with autism. The relationship observed in the current study between greater parenting self-efficacy beliefs and improved parent and family outcomes, even after taking into account the severity of the child's symptoms and behaviours, strongly supports the need for clinicians not only to provide parents with knowledge, skills and strategies, but perhaps more importantly, to promote parental beliefs that regardless of the severity or frequency of their child's difficulties, they have the ability to deal with their child effectively and are truly the experts.

Findings in the current study also encourage clinicians and researchers to take a more

contemporary view of parents raising children with autism. Consistent with the findings of past qualitative research, results of the present study indicate that not all parents of children with autism are overwhelmed or distressed by their role as parents. Furthermore, although parents recognize the negative impact that raising a child with autism can have on the family, parents also endorse positive impacts on the family and even positive changes in themselves as a consequence of being faced with such a challenge. To presume that we know what an individual parent's experience of their child has been, rather than to explore each parent's situation as unique is to remove a parent's opportunities to recognize not only

the challenges they face but also the positive life changes to be celebrated.

This article is based on findings extracted from the author's dissertation research titled, *Positive and Negative Impacts of Raising a Child with Autism: An examination of the direct and moderating effects of various coping resources*. The author would like to thank the families who volunteered their time to participate in this study as well as Autism Society Ontario for their generous support of this research project. This research is part of larger study conducted in collaboration with Dr. Adrienne Perry and Tara Smith that involves further examination of mothers, fathers, and siblings of children with autism.

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