

**PURPOSE**

The purpose of the research was to identify where disparities occur between mothers and fathers of children and youth on the autism spectrum in regard to their work lives and the amount of caretaking responsibility they undertake, and the implications of these roles and patterns on parents’ reported mental and physical health in the Ontario context.

**BACKGROUND**

Being a primary caregiver of an individual on the autism spectrum can bring certain benefits, such as family bonding and sensitivity (Markoulakis, Fletcher & Bryden 2012); however, there are also increased stresses which arise for many families, including having to manage, organize and finance therapy and other services, advocate for their children, and provide or finance specialized, long-term care (McLaughlin & Schneider 2019). Many such families simultaneously face increased expenses (necessitating additional employment), while at the same time face heightened care responsibilities (necessitating decreased employment). Both mothers and fathers may serve as primary caregivers or breadwinners. Following traditional patriarchal gender patterns, however, fathers are more likely to take on additional work responsibilities to finance costly therapies and services that are not sufficiently provided in the public realm, while mothers tend to take on the majority of the caregiving roles, often sacrificing or downgrading their own careers in order to do so, which may have significant implications for women’s professional development and income earning capabilities. For example, Cidav, Marcus & Mandell (2012) found that, in the United States, family incomes were 28% lower than average for those who have a child with autism and 21% lower compared to families whose child has another health limitation. While fathers’ incomes were unaffected, on average, “mothers of children with ASD earn 35% less than mothers with children with other limitations and 56% less than mothers of children with no health limitation.” Our research examined the relationships between work patterns, gender and stress among parents of children and youth on the autism spectrum in the Ontario, Canada context.

**METHODS**

654 parents/primary caregivers of children and youth with autism in Ontario completed a 179 question online detailed survey with closed and open-ended responses in the summer of 2018. Supplementary qualitative interviews were conducted with limited participants to probe more detailed information. Statistical and thematic qualitative analyses were conducted using Qualtrics, SPSS and NVivo software.

**DEMOGRAPHIC SUMMARY**

- The average age of respondents was 42
- Most respondents (92%) were women
- 86% of respondents had a spouse, and around three quarters were married (74%).
- Families’ total annual income (before taxes) was \$96,144 on average
- 86% had one child with ASD (14% had 2-3 children with ASD)
- 80% of the children were male, with an average age of 10.

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**FINDINGS**

One of the major sources of stress among caregivers relates to the amount of time they have to sacrifice from other activities due to lack of societal supports. On average, caregivers estimated they spend 14 hours per week facilitating service provision for their children (e.g. researching, navigating, facilitating, transporting, and/or providing services) and 10 hours advocating for their children, for a total of **24 hours per week**. Many respondents had to quit or downgrade their jobs in order to make up this lost time, with implications differing significantly by gender.

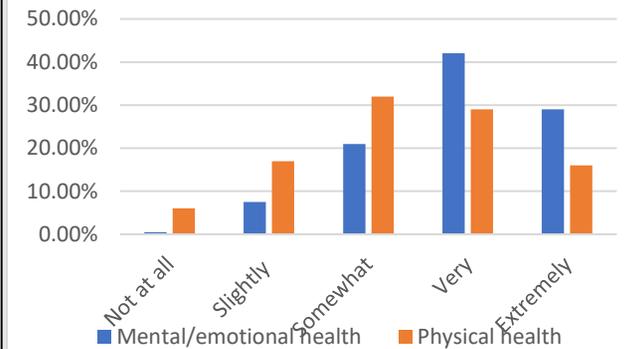
**Figure 1: Work Implications by Gender**

	Women	Men	Difference
Average Hours Worked per Week	23 hrs	39 hrs	16 hrs
% who work LESS than desired (due to time to manage ASD)	45 %	21 %	24 % points
% who work MORE than desired (due to added costs of ASD)	19 %	31 %	12 % points

Respondents were asked to report on their work habits as well as those of their spouse/partner (if applicable). Women were found to be much more likely to take on less hours or quit their jobs entirely in order to be able to care for and advocate for their child, with 45% stating that they worked less than desired. On the other hand, men were found to be much more likely to work more hours or second jobs at unfavourable times, such as evenings and weekends, in order to provide for their families’ increased expenses, with 31% reporting they worked more than desired. These differences resulted in stark disparities in income earning potential, with female caregivers on average working 16 hours less of paid employment per week than their male counterparts (see Figure 1). Results also demonstrated substantial disparities between the experiences of stress in relation to work and caregiving. Significant mental and physical health correlations were found both among those who work *more or less* hours than desired to support their children, while the most positive health outcomes were found among those parents whose desired work patterns were not impacted by such considerations.

The majority of participants reported that managing the stressors associated with caring for their autistic child impacted their mental and physical health either somewhat, very or extremely (see Figure 2), but these findings varied based on employment patterns. In fact, 78% of respondents who were working *less* than they desired reported that their mental health was very or extremely impacted; 74% of those reporting that they worked *more* than desired reported that their mental health was very or extremely affected, compared to 48% of those who reported the same while working the number of hours they desired.

**Figure 2: Impacts on Mental/Emotional and Physical Health**



For both mothers and fathers, work was identified as a major source of stress, due to factors such as the difficulty of securing understanding and flexible employers, and/or the inability to earn sufficient income while maintaining complex and often unpredictable care responsibilities.

**Common qualitative themes included:**

- Parents must work extra jobs in order to pay for therapy costs, resulting stress/well-being implications (particularly no free time for self-care – e.g. unable to sleep enough, cook and eat well, socialize, exercise, etc.).
- Parents want to work less to take better care of child, but have to work more to pay for their therapies and other expenses.
- Parents have to use all vacation leave / sick days for children’s needs.
- Parents were forced to leave jobs and/or work reduced hours and/or work a different, more flexible job, in order to take children to appointments, be available when school sends child home, etc.

**CONCLUSION**

There are insufficient resources for children and youth on the autism spectrum, which causes many parents to have to choose between being a caregiver and being able to pursue their ideal career, especially for mothers. Additionally, the stress related to caregiving and work varies widely based on gender, with both men and women facing distinct but overlapping challenges of trying to finance their children’s therapies and services, while also taking on increased care demands. Further supports and benefit programs, including employment protections as well as improved therapy and respite funding, could better help caregivers to support their children, while maintaining a work-life balance that promotes gender equity as well as overall family health and well-being.