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Autism Spectrum Disorder & Maternal Employment Barriers: A Comprehensive Gender-Based Inquiry

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Abstract

This paper presents a systematic literature review of the autism spectrum disorder (ASD) and maternal employment disruption in order to explore what mothers of these children do using a critical lens. Although a broad range of peer-reviewed scholarly publications exist on many topics related to ASD, specific family issues such as the potential employment challenges of the maternal employment of children with ASD, have been explored in less detail until recently. ASD has generated much discussion and research. We report the most recent data over the last decade. Through a comprehensive literature review, we identify a range of papers on the topic of ASD and parental employment disruption. This project, then, highlights relevant international Canadian and internationals research findings, including the United States, China, the United Kingdom (UK) and Sweden. The review and its critical commentary show how structures which act to exclude children with ASD cause parents to seek employment adjustments in order to manage their complex situations. Parents, especially mothers of children with ASD, have fewer employment opportunities. This situation has substantial economic impact on families. This trend extends beyond preschool child care as obtaining capable and reliable child care support is an ongoing issue that exists well into the school years—and beyond. Supportive, accommodating, and especially flexible employment situations make employment possible, at times, for mothers of children with ASD.

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Introduction

Adults and adolescents aged 15 and over who have learning-related disabilities make up about 2% of the Canadian population; those with developmental disabilities, in addition, comprise approximately 0.6% (Statistics Canada, 2017). Until very recently, no data existed that are “comprehensive, comparable, [and] national-level” in Canada, though a 2010 study of certain jurisdictions found a prevalence rate of 1 in 94 children with a diagnosis of ASD[1] (Government of Canada, 2016, para. 4). The Public Health Agency of Canada (2018) provided such cross-Canada statistics and found that 1 in 42 boys and 1 in 165 girls aged 5–17 years old were diagnosed with ASD. In comparison, 8–year-old males in the United States were 4.5 times more commonly identified with ASD than 8-year-old females in 2012. Among six provinces and one territory of Canada (Newfoundland and Labrador, Prince Edward Island, Quebec, British Columbia, Nova Scotia, New Brunswick, Yukon) Newfoundland and Labrador had the highest prevalence of ASD, which was 2.3 above the average (17.5 per 1000) and Yukon had the lowest (8.0 per 1000). In these provinces, ASD prevalence has had an upward trend from 2003 to 2015. In the United States, the currently accepted prevalence rate is 1 in 68 children (Centres for Disease Control & Prevention, 2016], representing an increase in excess of 1000% (Cidav, Marcus & Mandell, 2012).

ASD is defined as a “complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid,

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[1] While we employ the term ASD and "person-first" language for disability (i.e., "children with disabilities"), we acknowledge the complexities of the term "ASD" and the importance of differing terminology for ASD, particularly as it comes from autistic and disability communities (see Kenny et. al., 2016; Titchkosky, 2001).

repetitive behaviors" (American Psychiatric Association, 2013; Craig, Fanizza, Russo, Lucarelli, Lorenzo, Pasca & Trabacca, 2017). Beginning in 2013, the term ASD was employed as a heterogeneous umbrella term applied to a group of previously-named pervasive developmental disorders. Individuals diagnosed with ASD are considered on a continuum or spectrum inside this diagnostic category within the social communication domain, if their condition meets the indicated criteria of deficits in the areas of social communication/interaction, and restricted/repetitive behaviour (including severity levels) (Tsai & Ghaziuddin, 2014; Watt & Wagner, 2013). However, ASD has been theorized through multiple lenses, with many writers challenging the continual persecution and denigration that those with autism receive and how autism is seemingly constructed as 'abnormal' or 'abject' (McGuire, 2011; Lester, Karim & O'Reilly, 2014; Thomas & Boellstorff, 2017).

Although a broad range of peer-reviewed scholarly publications exist on many topics related to ASD, including parental stress (Houser, McCarthy, Lawer & Mandell, 2014), specific family issues, such as the potential employment challenges of the parental caregivers of children with ASD, have been explored in less detail—until recently. Watt and Wagner's (2013) overview summarized that "mothers of young children with a disability were less likely to be employed full time and/or employed outside of the home than were mothers of young children without a disability, especially if the disability included complicated medical needs" (p. 23), and even more so when examining a specific diagnosis like ASD.

Literature Review

The level of support needed for parenting children with ASD is a family unit issue, a parenting issue, and a gendered issue. Baker and Drapela (2010) explain how having a family member with a disability “is likely to create employment challenges for the family breadwinner(s). Traditionally, women have been expected to provide the bulk of care for ailing family members” (p. 584). As such, much emotional and physical labour, parenting duties, and loss of workplace opportunities commonly become the onus of the mother of the child with a disability (Hill, Jones, Lang, Yarker & Patterson, 2014, p. 166).

As children with ASD are diverse individuals, and the diagnosis itself is broad, parental experiences then will also be diverse and differentiated from other disabilities. Researchers have noted the uniqueness of the experience of having a child with autism in comparison with other chronic or physical disabilities (Baker & Drapela, 2010, p. 584) and that mothers may reduce their employment hours or quit working outside the home to care for their child with a developmental disability (Hill et. al. 2015**,** p. 167). Houser, McCarthy, Lawer, and Mandell (2014) also noted this theme in related literature, reflecting that “there may be something about ASD that differentiates it from other special health care needs in the degree and nature of its impact on families’ daily routines, employment, financial status, and childcare arrangements” (2014, p. 682). This form of gendered labour requires further exploration in the literature to understand the systemic barriers which place extraneous duties upon mothers of children with developmental disabilities and prevent them from employment outside of the home. Ryan and Runswick-Cole (2008) argue that non-disabled mothers of children with disabilities experience much disablism, themselves, and are positioned in liminal situations societally as they are unrecognized within professional situations for their work at home while "little value generally is placed upon the skills, expertise, and resources that mothers of disabled children accumulate" (p. 205).

Characteristics of School-Age Children with Autism

Montoes and Halterman (2006) found that parents of children with autism, as compared to nonautistic children within a large US-based survey (*n* = 9583), had statistically significantly “more contacts with teachers regarding behaviour problems at school” (p. 381) and were more likely to receive grades below the A/B level. The authors noted that “importantly, in 84% of the cases, parents of children with autism reported that their child’s disability was affecting learning, a significantly higher percentage than reported by parents of children with other disabilities” (p 382). It is reasonable to postulate that parenting is still an involved process, even though children with ASD might be attending school, as the children in Montoes and Halterman's study were described as receiving lower school grades and evaluation in comparison to children without a disability.

With the rate of ASD rising for multiple reasons (Johnson & Myers, 2007) including recent changes to diagnostic criteria in the newest iteration of the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013), changing understandings of the lack of social and cultural supports for children with ASD and their parents is becoming crucial. Although such related research focused on parental employment has been fairly rare, some examples are evident. Saunders, Tilford, Fussell, Schulz, Casey, and Kuo (2015) completed a secondary statistical data analysis (2009-2010 data) of a US National Survey of Children with Special Heath Care Needs. They found that parenting children diagnosed with both intellectual disability (ID) and ASD resulted in a greater likelihood of parental financial problems, a greater likelihood of abandoning outside employment, or of decreasing hours of work. Ouyang, Grosse, Riley, Bolen, Bishop, Raspa, and Bailey (2014) utilized the same data set, but also looked at families with children with the complex genetic disability of Fragile X Syndrome, “one of the principal single-gene disorders associated with autism” (p 1519) and found a negative impact financially and family-wise for the ASD-only family groups. It is also important to recognize that children with ASD might not be “just” children with ASD, but that they may also have coincident dual diagnoses, such as ID (25% of cases) and additional health concerns including medical (e.g., epilepsy, digestive issues), behavioural, and mental health diagnoses (e.g. depression, anxiety), which add additional complexity to the lives of children who are solely diagnosed with ASD (Government of Canada, 2016; Saunders, Tilford, Fussell, Schulz, Casey & Kuo, 2015). Montes and Halterman (2006) echoed these findings by articulating that the prominence of multiple diagnoses alongside ASD during childhood (p. 383).

As noted above, research-based explorations of potential employment challenges for the parents of children with ASD are just beginning to emerge in academic literature. Provincially, nationally, and internationally, though, it appears so far that children with ASD are likely to be associated with “substantial loss of household income” (Montes & Halterman, 2008, p. 821) and that “autistic children were more likely to have fathers who worked part-time rather than having full-time employment” (p. 381). Although many studies exist related to parenting children with ASD (Watt & Wager, 2013), it appears that only a limited number of studies are available on the topic of potential employment challenges of parents—including mothers—of children with ASD.

Watt and Wagner concurred: “almost no research has considered parental employment and parenting a child with AS[D] specifically” (2013, p. 23), and Stoner and Stoner (2014) added that “no research has examined the role of workplace support, especially as it pertains to working parents of children with ASD” (p. 85).

The following review of recent English-language literature (2010 to present) includes four international studies in three countries, seven North American research projects (five US-based studies and two Canadian studies), and a single provincial study specific to the context of Newfoundland and Labrador. One international study through a critical disability studies lens is explicated, alongside the systemic gendered barriers mothers of children with ASD experience which disable them from entering further work outside the home.

Research Findings: International

McCabe (2010) carried out a qualitative examination of maternal experiences around employment in China—where a child with ASD was being parented—entitled: *Employment Experiences, Perspectives, and Wishes of Mothers of Children with Autism in the People’s Republic of China*. The author reviewed literature related to maternal employment in the context of disabled children and the specific contexts of employment, parenting, and ASD in China, where no guaranteed and/or free services are available and noted this research as the first of its kind. McCabe provided open-ended questionnaires (n = 70) and follow-up interviews (n = 12) carried out in Mandarin Chinese to parents involved in a parent training program in Beijing. Of these 70, 36 had full time and 7 had part-time employment; 19 had thought about ceasing working while 23 had not; and 18 felt that “either one parent or the mother in particular, should quit her job and stay home both to care for and teach the child full-time" (p 123). After coding and thematizing interview data, the author elucidated two overall themes: "Satisfaction of Work" and "Being Responsible and Making Sacrifices" (p. 125). Within this first theme, mothers shared details of their enjoyment around being employed and described it as beneficial in many tangible (e.g. income) and intangible (e.g. identity) ways, as well as temporarily distancing them from ongoing worries around their children with ASD. One parent took a three-month leave from work and found that "I was in a horrible mood all the time… I realized this would not have a good result. He may get better, but I'll go crazy!" (p. 125). However, they also noted valuing support and flexibility in work environments. In the second instance, participants discussed both responsibility and sacrifice, as well as multiple reasons for continuing to work. However, the difficulty in finding professional services) was also a concern that added to the complexity of decision-making around employment, and reasons to stay at home full-time were limited to teaching and caring for children with ASD—viewed as a sacrifice and stressor which may not have had what they saw as beneficial results such as "a belief that early intervention will be enough to allow their children to attend school with no supports" (p. 2009). Overall:

> The[se] data paint pictures of women who are wholly responsible for and dedicated to the wellbeing of their children, whether through earning money to provide for them, or staying home to raise and teach them, or trying to do both" (p. 23).

Ou et. al. (2015) also examined issues in China related to raising children with ASD, entitled *Employment and Financial Burden of Families with Preschool Children Diagnosed with Autism Spectrum Disorders in Urban China*. Using a questionnaire analyzed with descriptive and analytical statistical measures, the authors used a large group of families raising three to six-year-old children with ASD (*n* = 459), another disability (*n* = 418), or no disability (*n* = 424) primarily from the Shandong and Hunan provinces. Following a review of literature related to ASD, family life, and its financial implications (including employment), this study was created to provide empirical data and inform policy makers through an exploration of ASD, parental employment, and financial implications. In terms of employment, significant differences were found across groups and families; those raising children with ASD reported a 57.5% rate of job difficulties related to childcare, and 52.3% had resigned jobs or not accepted them—far higher than either two family groups. Other outcomes included a “15-fold increase in the likelihood of job problems in the past 12 months” (p 9), although paternal education acted somewhat as a protective factor, a 41.7% income loss, and cost of education equal to 89.9% of earnings (also significant differences). Overall, they concluded that having a young child with ASD is related to more employment and financial stress for families than other disabilities, and such families require additional supports and services, which are limited and restricted as “Caregivers, typically mothers, have to be with their autistic children by themselves every moment in daily life, even when the child attends teaching in special education schools” (p. 12).

In an exploratory phenomenological UK study examining *Employment Experiences of Parents of Children with ASD or ADHD*, Hill et al. (2014) examined the impact of parenting children with Attention Deficit Hyperactivity Disorder (*n* = 10) or ASD (*n* = 10) in a carer role related to the work environment. They briefly examined literature related to parenting children with disabilities and the home environment, the work environment, and associated economic patterns and impacts. This qualitative study then explored factors that facilitated and posed barriers in employment, and any changing employment histories when parenting children with neurodevelopmental diagnoses of ADHD by interviewing 10 parents of children in each diagnostic category living in the UK (18 mothers). During the analyses of resulting data sets, eight common themes emerged within three topics, with the greatest number related to barriers/facilitators of employment. Parents of children with ASD noted post-diagnostic frequency of job change or transition to self-employed or freelance work situations, demoted or changed roles as "their previous career did not offer the flexibility and support necessary to balance care and employment" (p. 170)—while seeking jobs that allowed for flexibility and did not disrupt government benefits. The themes that related to barriers/facilitators included: "Availability of child care support; Understanding of the condition by others; Organizational policies and work practices; Line manager support; Colleague support; Loss of opportunity" (p 170) [semi-colons added]. One relevant example was the workplace attitude that parenting responsibilities should dramatically decrease with age (not necessarily correct); another was lack of available child care or respite support: "These parents had no choice other than to take employment that allowed them the flexibility of being available to drop off and pick up their child, and to look after them during the holidays" (p. 172); and "parents of a child with ASD also reported attempting to fit their work around their child's needs, although some stated that their attempts to do this were unsuccessful and they had abandoned their employment as a result" (p. 172).

McEvilly, Wicks, and Dalman (2015) explored employment issues among families raising children with ASD in an international context in a project entitled: *Sick Leave and Work Participation Among Parents of Children with Autism Spectrum Disorder in the Stockholm Youth Cohort: A Register Linkage Study in Stockholm, Sweden*. After reviewing literature related to the rising prevalence of ASD and its family impact, the authors turned to the specifics of ASD in Stockholm County, Sweden, and its 1% prevalence of ASD. In contrast to the two above-noted research projects in China, Sweden is considered to have "one of the world's most developed support systems in place, including laws and compensatory measures, to enable all parents to work, with additional support and services available to families who have a child with a disability" (p. 2157) such as an additional 10 days per year for parent training or medical appointments. These data were taken from available local and national statistical information data sets (e.g. the Multigenerational Register) and following exclusion criteria, a large sample of biological family data still remained (*n* = 149,567 mothers and the same sample size of fathers) providing information about mother, father, and sibling units with children from four to 17 years of age (including 1685 children with ASD and 1207 children each with ASD and an ID) which were analyzed with descriptive and analytical statistics. They found that parents of children with ASD, in particular mothers, had to request sick leave more often and work less in comparison to parents of children without ASD (p. 2160) and have a higher likelihood of fatigue, depression, and stress, which may be associated with a greater burden (i.e. effects of dual diagnoses of mental health in children with ASD). Overall, McEvilly, Wicks, and Dalman (2015) concluded that:

> … being a parent of a child with ASD is associated with higher maternal and paternal sick leave and lower work participation. The study found that ASD without ID but not ASD with ID was associated with sick leave lasting 15–365 days, but that both ASD with and without ID were associated with long term sick leave, not being in the labor force and low income (p. 2166).

United States

Literature in the US context includes the large-scale study entitled, *Mostly the Mother: Concentration of Adverse Employment Effects on Mothers of Children with Autism* (Baker & Drapela, 2010). Framed around employment as a gendered construct, the issue of maternal employment for mothers of children with ASD encompasses many potential negative outcomes around employment of women in general, who may be taking on multiple roles combining motherhood and employment, perhaps as the lone head of a family unit which may include a child with ASD. The authors reviewed literature related to maternal employment, work-life balance, and family friendly work-life policies. Baker and Drapela (2010) created a 58-question survey entitled *Autism, Health Care, and Public Policy: Experiences of Families with Health Care Systems*, recruited 326 participants (97% parents) who were recruited from the Pacific Northwest area of the United States, and analyzed the resultant data with descriptive and analytical statistics.

The authors noted that the processes of supporting children with ASD can be both unpredictable, sporadic, and affect mothers’ employment the most (66% of respondents). Mothers may have been unable to access supporting services; may have been busy with the complexities of medical care; may have needed to change jobs (20%) or working hours (38%); worked less (53%); taken leaves (25%); not accepted a job (60%) or promotion (23%); and may have experienced “distinct effects on maternal employment” (p. 587). For example:

> … if employers are not willing to accommodate such needs for flexible labour force participation schedules and either sanction or reprimand parents for attempting to accommodate work and family needs; then, the mother – who serves as the default caregiver in most families – may reduce her labour force participation to care for her child with autism (p. 587).

The authors found “a statistically significant effect on the likelihood that the mother’s employment was perceived as being most affected as a result of having a child with autism” (p 589), such as being reprimanded at work. Baker and Drapela (2010) also suggested that:

> It is possible to argue that concentrating the adverse employment effect on the mother’s labor be perceived as desirable by many families. After all, mothers are traditionally understood as more nurturing and engaged parents than are fathers (in fact, the term ‘parenting’ has only recently replaced ‘mothering’ as the more salient description of the activity of raising one’s child). Children with disabilities might be believed to particularly benefit from having a mother who does not engage in paid labor outside the home (p. 590).

Researchers Cidav, Marcus, and Mandell (2012) carried out a US-based quantitative study entitled: *Implications of Childhood Autism for Parental Employment & Earnings*. The authors summarized previous research on healthcare costs, family economics, and employment patterns around ASD, and then focused on issues that have emerged around specific parental employment when parenting children with ASD—the first study of its kind. Particularly relevant are these assertions:

> ASD is often characterized by behavioral challenges that can lead to greater parental labor market disruption. Time-intensive or unpredictable health conditions like ASD are more likely to negatively affect maternal work hours and participation (p. 618).

Utilizing a national sample from the ongoing health care survey entitled Medical Expenditure Panel Survey (2002-2008), the authors calculated the “average annual loss of parental earnings associated with raising a child with autism in the United States” including calculated “foregone earnings” (p. 618). They also emphasized that changing employment might include increased work, overtime work, and additional jobs—which related equally to foregone family and leisure time and entered into changing labour patterns. Data were analyzed with descriptive and analytic statistics using three groups of families: those with ASD (*n* = 261), those with other health issues (*n* = 2921), and those within none (*n* = 64 349), as well as outcomes related to parental and family employment, weekly work hours, and annualized earnings. As well as group characteristics of families of children with ASD, Cidav, Marcus, and Mandell (2012) found that in the ASD group related to labour force participation, mothers were 6% less likely to be employed (67% employment rate), fathers were as likely to be employed (92% employment rate), and that families were 9% less likely to have dual-parent working families. Related to weekly hours of work, mothers had 7 fewer hours of work per week, fathers were as likely to work the average number of hours, and families worked 5 fewer hours overall. Related to parental earnings, mothers earned $14,775 less, fathers earned as much, and families altogether earned $17,763 less, with total average annual incomes of $57,100. Compared to other disabilities such as emotional/behavioural disorders:

> …effects are more pronounced for among families of children with autism. It is likely that because the systems that care for children with autism are so fragmented, many more challenges are raised for families in attending to the ongoing needs of their children. Parents are called on to serve as their child's caregiver, case manager, and advocate and to navigate numerous bureaucracies to obtain essential services for their child (p. 622).

In summary, the authors asserted that "we found that it is the mother whose labour market outcomes are substantially affected by having a child with autism," that "mothers of children with ASD are less likely to work, work fewer hours per week, and earn substantially less than mothers of children with no health limitation," and that "our findings suggest that mothers of children with ASD, who potentially could earn more because of their higher educational level and age advantage, actually earn less as a result of the burden of caring for their children with ASD" (p. 622). Overall:

> The major conclusion emerging from our analysis is that childhood autism has substantial economic impact on families. Given that these families face substantial health care expenses, the potential economic impact of having lower income in addition to these expenditures is substantial (p. 622).

They suggested that it is essential for families of children with ASD to have a stable and adequate level of income, to decrease barriers to its obtainment, and to address both healthcare and workplace policies.

Stoner and Stoner's qualitative study (2013) is entitled: *How Can We Make this Work? Understanding and Responding to Working Parents of Children with Autism*. They utilized a collective case study approach, including eight dyads of educated parents of varied ages with dedicated careers. The authors used semi-structured interviews in a face-to-face format and both within-case and cross-case analyses. One area that emerged as impactful for employed parents of children with ASD was its emotional impact. One parent shared that "the barriers at work are when people don't understand, and there is no sympathy there in the same way as if I would have heart surgery on my kid'' (p. 89). In addition, the child with ASD became first priority—above employment—yet parents remained committed to their careers and desired no reductions in workload or expectations. Three positively labelled themes emerged: ongoing motivation to succeed, career-wise; a strong sense of fairness and responsibility to their employers; and the respite that working could provide, noting that "the primary caregiver parent bore a much more stressful and intense level of responsibility" (p. 88). From their employers, these parents desired not concessions but rather understanding, sincerity, support, and flexibility (e.g., make-up time), with the latter as critical and “the single most common workplace challenge that employed parents of children with ASD face[d]” (p. 90). This aspect included events that were planned for parents of non-disabled children but challenging when a child with ASD was involved (e.g., specialist appointments) as well as crisis situations. The researchers concluded that:

> …given the escalating rates of ASD and its eventual likelihood to touch more and more workplaces, it seems prudent for all workplaces to begin a discussion of how to address the needs of working parents of children with disabilities in general (as some have done) and with ASD in particular (a much rarer occurrence) (p. 94).

House, McCarthy, Lawer, and Mandell (2014) also carried out a phenomenological study in an urban area of the US entitled: *A Challenging Fit: Employment, Childcare, and Therapeutic Support in Families of Children with Autism Spectrum Disorders.* House et. al. interviewed 37 parents who had children with ASD, as well as utilizing surveys, record reviews, and interviews. They examined literature related to parental employment, financial status, and childcare arrangements of parents raising children with ASD, all as background information to explore self-reported parental information around both work and family factors that led to helping and hindering “satisfying work-and-family-life” (p. 684). It is notable that almost all (35 out of 37) of these responses were from mothers. Participants described their post-diagnosis employment as an active adaptation. Over one-third of the families (mostly mothers) made employment change (resigning work or decreasing hours of work) noting that child care was an ongoing issue often linked to employment decisions due to a lack of “a reliable system of well-trained respite care providers” (p 690). As well: “It is arguably the case that those parents of children with ASD who most need stable and reliable care arrangements are least able to expend the time and resources necessary to secure them” (p. 692).

Parental dyads where both partners worked typically arranged, at a minimum, for as-needed work-from-home hours. Another noted strategy was having one stay-at-home parent (typically the maternal parent) without whom they could not envision managing lives, who would also research treatment options, and labelled the coordinator of services as “a full-time job (or jobs) within itself” (p. 690), a station described as both demanding and unpaid. Overall, their complex parenting lives were in an ongoing flux.

> Despite the financial challenges that accompany such arrangements, parents in our sample tended to integrate the demands of care coordination with the demands of paid employment by ensuring, through various means, that one parent would be nearly always at home (p. 691).

House et. al. (2014) made four recommendations, including the potential option of paid family leave.

Stoner and Stoner (2016) followed up earlier work with the publication of *Career Disruption: The Impact of Transitioning from a Full-Time Career Professional to the Primary Caregiver of a Child with Autism Spectrum Disorder* in order to explore further the career disruption and related coping mechanisms of such employment change. They utilized interviews from 16 US-based parents (eight married parental dyads) with professional careers. Three phases emerged from these explorations: the first phase of career disruption; the second phase of career loss and its impact; and the third phase of personal significance. It is important to note that only one family was able to continue with both parents working.

The first career disruption phrase was an intense struggle of six months to a year and a half, including the involved processes of obtaining diagnoses and services which were both time and emotionally intensive. Finances—as well as love and devotion—were the "pivotal factor" in decision-making around career disruption (e.g. who stayed at home) but "primary caregivers indicated that they quit work not because they wanted to do so, but because there were no other practical alternatives" (p. 108). It is notable that "the value of emergency support was absolutely essential and critical, even though it was sought and needed infrequently" (p. 110). The second phase of impactful career loss had emotional and financial outcomes, including feelings of grief, loss, underutilization, loneliness, and isolation. Support from either their employed spouses, family, and/or support groups helped somewhat to ameliorate these effects. In the third phase of such personally significant transitions, these new order stay-at-home parents learned new-to-them skills such as advocacy, consultation, and speaking, by which they were able to use previous career-related skills and gain some personal energy, validation, and significance.

Research Findings: Canadian

In a Canadian context, Watt and Wagner (2013), developed *Parenting a Child with Autism Spectrum Disorder: Parental Work Context*. The authors reviewed literature related to ASD and parental stress, the psychosocial environment of parenting children with ASD, and ASD along with parental working situations and outcomes. Watt and Wagner provided a set of four standardized questionnaires (e.g. *Work Factors Scale*) to 28 two-parent families in Canada, with (n = 15) and without (n = 13) a child with ASD. The questionnaire focused on topics including work, stress, work satisfaction, as well as general psychological health. It is important to note that in the comparison group of families without a child with ASD, 100% of the fathers had permanent full-time jobs, and 65% of the mothers worked in full-time positions. In the group with children with ASD, only 79% of the fathers and 44% of the mothers worked full-time.

Using repeated measures analysis, the authors examined outcomes related to four potential hypotheses and found that, overall, the parents of children with ASD had lower satisfaction of contentment around their jobs; however, they did not miss more time at work. The authors postulated that “parents of children with disabilities may be influenced by the substantial nature of their parenting role into accepting positions that meet the needs of the family, but are not necessarily ultimately satisfying” (p. 32). Generally, the research found little relationship between work outcome variables and parents, excepting “a noted relationship between increased maternal distress and less self-reported time missed for family reasons for mothers parenting a child with AS” (p. 33), again with the assumption that distressed mothers may have employment as a respite, and have peer support.

Hodgetts, McConnell, Zwaigenbaum, and Nicols (2014) published a two-phase mixed-methodology study entitled: *The Impact of Autism Services on Mothers’ Occupational Balance and Participation*. They reviewed literature around maternal responsibilities in parenting children with ASD—incorporating occupational and leisure outcomes. One outcome of such literature noted that “mothers also spend a significant amount of time finding, accessing, and retaining services; coordinating services between sectors; advocating for their children; and driving their children to appointments” (p. 82). The authors extended this issue and took a unique look at how services themselves impacted material workforce and leisure pursuit, what the disruptive characteristics were around these services, as well as related to children and families.

Utilizing both adapted standardized surveys (*n* = 139) and semi-structured interviews (*n* = 19), the authors used quantitative (e.g. confirmatory factor analysis) then qualitative (grounded theory-based; coding and thematizing) methods to explain the related experiences of mothers of children, adolescents, or young adults with ASD in Alberta. The researchers found that 78% of surveyed mothers shared that "the professional supports and services for their child impacted their employment above and beyond the lived experience of parenting a child with autism" (p. 87). More specifically:

> Half of the mothers chose their job to specifically meet their child's service needs, almost one-third of the mothers decreased work hours and/or stopped working because of their child's service needs, and almost one-fifth of the mothers moved their family to a new geographical location to access services (p. 87).

Only six of 18 interviewees were able to work full-time and only nine part-time, as labelled under *Occupational Imbalance & Sacrifice*. Twelve mothers cited service provision needs (i.e. appointments, advocacy, time, organization) as the reason they worked fewer (or no) hours of employment. Two themes emerged related to workforce participation from these interviewees: the disruption of both employment and discretionary time ("Something Had to Go", pp. 87-88) and lost workforce opportunities ("Lost Opportunity", p. 88). The following example describes such an impact:

> For one mother, service needs were so intense that she sold her lucrative personal business, in which she took a lot of pleasure and pride, after close friends repeatedly expressed worries over her and her son's wellbeing: '[My friends] said, "You're going to drop one day and you're going to be no good to you or your son."'

School entry did not solve these employment disruptions due to ongoing appointments, programs, transportation, and the need to accomplish tasks during the school day in order to be available consistently in after-school and evening hours. One mother reflected: "there is no way that it could all jive if I worked outside the home, because that is my job, to keep it all rolling" (p. 88). The authors found that "current child resources [are] largely dependent on maternal implementation. This dependence on mothers' care despite the personal costs on mothers is a detriment of current care delivery models for many families" (p. 90). Recommendations included being attentive to the demands placed on the family unit around service provision, and its related demands (e.g. therapeutic homework), attending to continuity of services, and providing both policy and practices supporting maternal occupation balance, overall "to encourage services that directly and indirectly support, rather than burden, mothers of children with autism" (p. 91).

In 2015, The Autism Society of Newfoundland and Labrador (Audas, Ryan, Harris Walsh, Wells, & Murphy) produced a *Needs Assessment of the Autism Spectrum Community of Newfoundland & Labrador*. This comprehensive 82-page document was the culmination of a year-long process of information gathered from 640 survey responses and 40 interviews, "giving unprecedented insight into the needs of the ASD community" (p 6). Parental employment emerged as an issue categorized under *Insurance & Finances*:

> Caregivers of preschoolers were most often unemployed or working full-time, perhaps because one parent may leave work to raise children during their early years, particularly after an ASD diagnosis. Caregivers of school-age children primarily work full-time [63.9%]. Of the caregivers of school-aged children, 26.7% reported working part time; this was commonly explained by the burden placed on families following an ASD diagnosis. Caregivers of adults were more likely to be retired. Partners' employment status was primarily full-time across all age categories. Nearly half of respondents (49%) reported a change in employment following the diagnosis of ASD in their family. Most notably, 75% of preschooler caregivers reported a change in employment following ASD diagnosis (p. 63).

It is also notable that these data were within the context where 53.5% of families paid out of pocket for some services (e.g. speech therapy) and that “overwhelmingly, parents felt costs associated with ASD were significant” (p. 66)

Summary

Although results of most studies are typically limited and cannot be generalized to every population, situation, and/or region, and although almost all research focuses on two-parent households (noted as more likely in this particular population; Audas, Ryan, Harris Walsh, Wells, & Murphy, 2015; Cidan, Marcus, & Mandell, 2012), specific time periods (2010 to present), and only some geopolitical contexts (provincial, national, international; focused on the United States), it appears that the following pathways have a likely probability when it comes to self-reported information from parents of children with ASD (2010 to present):

1. Having a child with a disability appears to be more likely than not associated with adverse effects on parental employment, especially evident following an ASD diagnosis / during the preschool years.
2. Parents tend to proactively seek employment adjustments in response to the complex realities of raising children with ASD, rather than seeking extensive employment accommodations.

3. Fathers and mothers of children with ASD are less likely to work full time, with mothers even less likely to continue to work full-time—even though this change can substantially affect the financial earnings of mothers and family units overall.
4. Such adverse employment effects tend to be substantially more focused on maternal employment.
5. Adverse work-related effects appear to be more evident and specific to parenting children with an ASD diagnosis, as compared to those with no disabilities or other disabilities/health conditions
6. Complexities such as multiple diagnoses may again be associated with lower levels of parental employment and greater financial impact.
7. Obtaining capable and reliable child care support is an ongoing issue, but high levels of complex maternal parenting demands also extend into the school years.
8. Employment that is supportive, flexible, and accommodating makes employment possible at times, but jobs that do not provide this leeway may be compromised, changed, decreased, or abandoned.
9. Flexibility appears to stand out as the prominent need for employed parents of children with ASD.
10. Such adverse effects appear to be related to the provision of support services for children and families with ASD; yet, appear to persist even in the context of national policies designed to support and accommodate families of children with disabilities.

It is important to note what is missing from the discussion—the impact of school exclusion for school-aged children and the longevity of impacts when children move into adult services (e.g. unemployment). It is also essential to emphasize what is ubiquitous in the discussion—language around maternal burden, disruption, and sacrifice, yet a willingness do what is needed for one’s children with ASD despite employment, financial, and personal repercussions.

Moreover, it is necessary to consider how the systemic barriers mothers of children with ASD experience, in terms of gendered labour and expectations, and lack of supports and resources, can disable their ability to seek employment outside the home. Ryan and Runswick-Cole (2009) note how mothers of children with ASD must often move from being "advocates" to "activists" in their support for their children with ASD within and outside of the school system. Within Ryan and Runswick-Cole's (2009) study, many mothers noted the systemic barriers in which their parenting duties would not allow them to balance full-time work. One mother of a child with ASD stated, "I mean, I just gave up work because it was just so tense and I knew Simon would have more acute problems settling into school" (p. 47), with another participant mentioning how the experience of being a mother of a child ASD has left her "*physically, mentally, emotionally, completely consumed*" and taking anti-depressants (p. 48, emphasis in original). This is not to place blame upon children with ASD, but to challenge a system which operates to exclude individuals with autism while placing responsibility upon parents–particularly mothers–of children with ASD with little accompanying structural support. As noted above, policy change, while important, does not often equate into structural changes or support services for parents of children with disabilities, despite good intentions.

Citing Hochschild's (1983) theorization of "emotional labour" is "the management of feelings to create a publicly observable facial and body display" (cited in Runswick-Cole, 2013, p. 107). Runswick-Cole notes the emotional labour involved in being a mother of a child with disabilities and the expectation that mothers will "wear it all with a smile" (p. 107). In the interviewed mothers' performances of being "mothers of children with disabilities," participants employed props, such as wheelchairs, to signal their children as disabled and their role as a mother of a children with disabilities (p. 111), and would respond to scripts from others, such as "You are obviously the right person, you've been chosen!" (p. 114) in which others deem parents "the right fit" for being a parent of a children with disabilities. Mothers of children with ASD commonly feel pressure to perform the "good mother" (Douglas, 2016; Knight, 2013), as mothers are societally expected to derive intrinsic rewards and gratification from mothering a child with ID while ignoring their sacrifices and socio-emotional distress and strain (p. 666). Thus, dissolving the binary between "good" and "bad" mothers can aid in allowing mothers space to express the physical/emotional/social duress they are placed under and the gendered expectations they receive through socio-cultural constructions of idealized mothers and motherhood (Knight, 2013, p. 670). Khanlou, Mustafa, Vazquez, Davidson, and Yoshida (2017) emphasize the intersections of disability, motherhood, and migration for immigrant mothers of children with developmental disabilities reveal how, "Immigrant mothers caregiving children with DDs [developmental disabilities] therefore have a double burden, with the intersection of mothering responsibilities unique to their child(ren)'s DDs, the process of migration and settlement, as well as language, social, and cultural barriers in accessing health-care services for their children and themselves" (p. 615). Thus, future literature examining the systemic barriers which mothers of children with disabilities experience should consider the ethno-racial identities, cultural and social locations, and citizenship status of mothers and how this further impacts their access to programming, supports, and potential employment.

Constructions of race intersect with disability and motherhood for mothers of children of colour, particularly black children with disabilities, since generalizations of racialized children as "deviant" and "disobedient" often result in higher special education and exclusion rates for black students compared with white peers (Erevelles, 2014, cited in Yergeau, 2017; Graves & Ye, 2017; Morgan et al. 2017). Melanie Yergeau (2017) writes in *Authoring Autism: On Rhetoric and Neurological Queerness* how "when autistics of color are disclosed, statements such as 'I am autistic' are often interpreted both callously and elliptically by white and allistic others" (p. 158). For mothers, the incarceration and criminalization of their children through racial productions and assumptions creates greater stress and hardship as mothers must not only maneuver an ableist and discriminatory system that is hostile towards those with autism, but also racist stereotypes and prejudices which construct racialized children with disabilities, in particular boys, as violent, dangerous, and excludable (Hill, 2011; United States Government Accountability Office, 2018). Black children with ASD are commonly diagnosed much later than white children with ASD, with Gourdine, Baffour, and Teasley (2011) explicating in a US context how racial identification and socio-cultural contexts can affect access to service provision: "Research demonstrates that racial and ethnic minorities receive lower quality of services related to healthcare than nonminority groups and that these disparities are related to historic inequalities" (p. 459). Thus, it is necessary to consider the emotional, social, economic, and physical impacts this holds on mothers, particularly racialized mothers, as further maternal support is required as parents can begin to feel isolated and overly dependent on community and familial supports (see Burkett, Morris, Anthony, Shambley-Ebron, & Manning-Courtney, 2017).

Cumulatively, our investigation into the barriers mothers of children with ASD experience societally posits specific recommendations for policymakers and educators. Such agents must consider how mothers of children with ASD experience structural marginalization and subjugation under systems which expect them to carry the majority of emotional and physical care for their children. Moreover, a lack of supports and flexibility for mothers from employers commonly leads to feelings of frustration and incapacity as parents struggle to balance the many appointments required with schools and outside agencies and their own respective work schedules (Hodgetts et al, 2014). As noted, the barriers that mothers experience in the workplace can be theorized as a form of disablement itself which systemically and structurally prohibits mothers from entering the workplace outside the home while enforcing norms which expect them to be altruistic and content with their caregiver role (Knight, 2013; Runswick-Cole, 2013). Indeed, the complexities of the experiences of mothers of children with ASD is important for further inquiry under psychological, sociological, and critical disability studies lenses to understand how children with ASD can continue to be supported within and outside of school systems while providing mothers and all caregivers with the means to be gainfully employed outside the home, if desired.

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