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Factors associated with caregiver burden among parents of individuals with ASD: Differences  
across intellectual functioning

Vanessa Vogan, M.A.<sup>1,2</sup>, Johanna K. Lake, Ph.D.<sup>1,3</sup>, Jonathan A. Weiss, Ph.D., C.Psych.<sup>4</sup>,  
Suzanne Robinson, M.A.<sup>4</sup>, Ami Tint, M.A.<sup>4</sup>, & Yona Lunsky, Ph.D., C.Psych.<sup>1,3\*</sup>

<sup>1</sup> Centre for Addiction and Mental Health, Canada

<sup>2</sup> Department of Applied Psychology and Human Development, Ontario Institutes for Studies in  
Education, University of Toronto, Canada

<sup>3</sup> Department of Psychiatry, University of Toronto, Canada

<sup>4</sup> Department of Psychology, York University, Canada

\*Correspondence should be sent to Yona Lunsky, Centre for Addiction and Mental Health, Dual  
Diagnosis Program, 501 Queen Street West, Toronto ON M5V 2B4, [Yona.Lunsky@camh.ca](mailto:Yona.Lunsky@camh.ca),  
Phone: (416)-535-8501 x77813, Fax: (416)-603-9120.

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**Abstract**

Symptoms of autism spectrum disorder (ASD) persist into adolescence and adulthood, when access to health services and supports become difficult. Consequently, most adolescents and adults with ASD remain reliant on their families for support, often resulting in caregiver burden among parents. The present study aims to investigate factors associated with burden in parents of adolescents and young adults with ASD, and to understand how these factors differ across varying levels of intellectual functioning. Of the 297 parents sampled, ASD severity, externalizing behaviours, medical comorbidity and parent age predicted burden in parents of adolescents and young adults with ASD and an intellectual disability (ID), whereas an inability to pay for services predicted burden in parents of individuals with ASD and no ID. Factors associated with caregiver burden differed among individuals with and without ID, and were not limited to symptom severity or mental health problems, but also extended to system factors.

**Key words:** autism spectrum disorder; intellectual disability; caregiver burden; Canada; mental health; parents; service system

Factors associated with caregiver burden among parents of individuals with ASD: Differences  
across intellectual functioning

Approximately 1 in 88 individuals have an Autism Spectrum Disorder (ASD), and the proportion of children diagnosed is on the rise (Centers for Disease Control and Prevention [CDC] 2012). ASD is a neurodevelopmental disorder characterized by social deficits, communicative difficulties and repetitive behaviours, with evidence of cognitive dysfunction. (American Psychiatric Association [APA], 2013). Although ASD is most widely known as a childhood disability, symptoms persist into adolescence and adulthood, where individuals continue to experience social difficulties, communicative impairments, stereotyped behaviour (Ballaban-Gil, Rapin, Ruchman, & Shinnar, 1991; Fecteau, Mottron, Berthiaume, & Burack, 2003; Howlin, Goode, Hutton, & Rutter, 2004; Matson & Horovitz, 2010; see Seltzer, Shattuck, Abbeduto, & Greenburg, 2004 for a review) and comorbid mental health issues (Davis et al., 2011; Palucka & Lunskey, 2007; Seltzer, et al., 2004). Adolescents and adults with ASD also have sustained impairments in academic performance, employment, social relationships (Howlin et al., 2004; Mao, 2012), and adaptive functioning (Chadwick, Cuddy, Kusel, & Taylor, 2005). Despite these significant impairments, access to health services and supports become increasingly difficult as individuals with ASD age out of the pediatric system (Autism Ontario, 2008). After the age of 21, young adults are no longer integrated in public school and child health systems, and identification and coordination of appropriate structured daytime activities can become particularly challenging (Mao, 2012). Consequently, many young adults remain highly dependent on their families for support (Ballaban-Gil et al. 1991; Howlin et al., 2004; Levy & Perry, 2011; Mao 2012). In a recent review of outcomes for adults with ASD, the number of adolescents and adults living with families ranged from approximately 22-70%

(Howlin & Moss, 2012), leaving many parents with the responsibility of health care and social service provision for their adult child, in addition to behaviour management and assistance with daily living.

Caring for an individual with ASD is associated with high levels of caregiver burden—“the perception of psychological distress, anxiety, depression, demoralization, and generalized loss of personal freedom attributed directly to caregiving” (Lawton, 1991, p 182)—from the time of diagnosis (Stuart & McGrew, 2008), and throughout childhood (Lee, Harrington, Louie, & Newschaffer, 2008; Rodrigue, Morgan, & Geffken, 1990), adolescence, and young adulthood (Cadman et al., 2012; Kring, Greenberg, & Seltzer, 2008; Lin, 2011; Lee et al., 2008). Health care costs are substantially higher for children with ASD (Croen, Najjar, Ray, Lotspiech, & Bernal, 2006), and parents report greater financial burden compared to caregivers of children with physical and intellectual disabilities (Xiong et al., 2011). Additionally, parents of individuals with ASD report lower personal well-being compared to parents of those with Fragile X syndrome (Abbedutto et al., 2004), Down syndrome (Abbedutto et al., 2004; Blacher & McIntyre, 2006), cerebral palsy (Blacher & McIntyre, 2006), Attention Deficit Hyperactivity Disorder (ADHD; Cadman et al., 2012), and undifferentiated intellectual disabilities (Blacher & McIntyre, 2006). Caregiver burden is also associated with parent depression, anxiety (Gallagher, Philips, Oliver, & Carroll, 2008; Kim, Greenberg, Seltzer, & Krauss, 2003; Luescher, Dede, Glitten, Fennell & Maria, 1999; Magana, Seltzer, Krauss, Rubert, & Szapocznick, 2002), and reduced caregiver satisfaction (Pruncho, 2003). To add, evidence exists to suggest that psychological distress among families *increases* as children with ASD become older (Marcus, 1984; Koegel et al., 1992), yet the majority of literature focuses on the experiences of families in childhood. To improve outcomes for parents it is important, therefore, to understand more about

child, parent and service system correlates of caregiver burden, particularly for families of individuals with ASD in their adolescent and adult years.

*Child Factors Associated with Burden*

There are a number of child factors linked to caregiver burden for parents of individuals with ASD, including medical problems, ASD severity, mental health issues and intellectual disability (ID). In terms of the relationship between medical issues and caregiver burden, findings remain unclear. Kring et al. (2008) found that comorbid medical disorders in individuals with ASD, particularly sleep and gastrointestinal problems, predicted burden in mothers, whereas Orsmond and colleagues (2006) found no such relationship. No other recent study has considered the impact of medical problems on caregiver burden among parents of children with ASD, which is particularly concerning given the high rates of co-occurring health problems in this population (Bauman, 2010; Buie et al., 2010; Gurney, McPheeters, & Davis, 2006; Danielsson, Gillberg, Billstedt, & Gillberg, 2005; Johnson, Giannotti, & Cortesi, 2009; Richdale, 1999).

There are number of studies which have examined the association between caregiver burden and mental health problems within the broader ID literature (Essex & Hong 2005; Heller, Hsieh, & Rowitz, 1997; Irazabel et al., 2012; Kim et al., 2003; Maes et al., 2003; Magana et al., 2002; Unwin & Deb, 2011). Four of these studies found an association between caregiver burden and maladaptive behaviour (Lin, 2011; Orsmond, Seltzer, Greenberg, & Krauss, 2006) or mental health issues, including anxiety, bipolar disorder, depression, and schizophrenia (Cadman et al., 2012; Kring et al., 2008) among youth, adolescents, and adults with ASD. However, more work is needed in this area, particularly in older adolescents and adults with ASD.

In terms of ASD severity and intellectual functioning, limited research suggests that

caregiver burden is associated with more severe ASD symptomatology (Lin, 2011; Stuart & McGrew, 2008; Seth 2011) and less functional independence (Lin, 2011). However, caregivers of those with less severe ASD *still* report clinically significant levels of burden (Cadman et al., 2012; Fombonne, Simmons, Ford, Meltzer, & Goodman et al., 2001). Despite this, few studies have compared factors that contribute to caregiver burden across all levels of functioning, including those requiring some support and those requiring very substantial support. Results of a study examining caregiver burden among mothers of 32 children with autism identified that poor social maturity (occupation, communication) and low functional independence (cognition) was related to caregiver burden (Seth 2011); although, it was unclear if the presence of a comorbid ID was related to caregiver burden. In addition, Kring and colleagues (2008) found that having an ID was related to higher levels of caregiver burden among individuals with ASD and psychiatric comorbidity. Conversely, in a study examining caregiver burden among individuals with ASD and ADHD, Cadman and colleagues (2012) did not find an association between ID and caregiver burden. However, it is important to consider that only 15% of their sample had a concurrent ID. Studies rarely examine the relationship between caregiver burden and ID solely among adolescents and adults with ASD.

#### *Parent Factors Associated with Burden*

Findings related to caregiver burden and parent or familial factors among individuals with ASD have also been mixed. Kring and colleagues (2008) found that parents with higher levels of education reported greater burden, however, a more recent study did not find this relationship (Cadman et al. 2012). Marital status and marital satisfaction have both been studied with results suggesting that not being married (Orsmond et al., 2006), and lower marital satisfaction was linked to lower levels of burden (Hartley, et al., 2011). Furthermore, one study

examined income and caregiver burden, and found no association (Taylor & Seltzer, 2011). Looking beyond families of individuals with ASD, several studies of caregivers of individuals with ID (some of whom may have had ASD) have reported an association between caregiver burden and parent income (Datta et al., 2002; Essex & Hong, 2005; McManus et al., 2011), education (Al-Krenawa, et al., 2011; Green, 2007; Haveman et al., 1997; Oh & Lee, 2009; Manor-Binyamini, 2011), age (Chou, 2011; Essex & Hong, 2005; Oh & Lee, 2009; Hayden & Heller, 1997) and marital status (Magana et al., 2002), while other, albeit fewer studies, found no relationship (Manor-Binyamini, 2011; Tsai & Wang, 2009). Whereas some studies documented greater burden in younger parents (Essex & Hong, 2005; Hayden & Heller, 1997; Oh & Lee, 2009), other studies reported greater burden in older parents (Chou, 2011).

#### *Service System Factors Associated with Burden*

Recent research on caregiver burden focuses primarily on related parent and child factors, and less on health care and service system factors. A recent study conducted in the United States (U.S.) reported that families living in states with lower per capita Medicaid spending on ASD services were more likely to report financial burden (Parish, Thomas, Rose, Kilany, & Shattuck 2012). Two studies have considered the association between caregiver burden and service need, and results revealed that burden was associated with parents' appraisal of their child's unmet need, but not with service use (Taylor & Seltzer, 2011; Cadman et al., 2012). In a longitudinal study, Taylor and colleagues (2011) found that mother-child relationships arrest improvement upon exit from high school, especially for those adolescents who do not have ID and have *more* unmet service needs. Therefore, there is evidence that families with youth with ASD who are transitioning from adolescence to adulthood are at great

risk. Surprisingly, no other recent studies examined this issue, which is concerning given the significant service system issues faced by this population, particularly for individuals with ASD without ID (Ward & Russell, 2007). In the broader ID literature, higher levels of burden were associated with health care inaccessibility, unmet health care needs (McManus et al., 2011) and lower rates of service receipt (Magana et al., 2002). Together, these findings highlight a need to further study how accessing and using health services for individuals with ASD affect caregivers' perceptions of burden, particularly as they transition to the adult service system. The current study focuses on service affordability, and its relation to caregiver burden.

### *Research Questions*

In summary, very few recent papers have studied caregiver burden among parents of adolescents and young adults with ASD, with the majority focused on young children. Cadman et al. (2012) conducted the most recent study of burden in parents of individuals with ASD and ADHD transitioning to adolescence and adulthood in the United Kingdom (U.K.), but this work did not consider caregiver burden across a range of ASD symptoms or levels of intellectual functioning. This is particularly important as the experience of burden may vary amongst these groups of parents, and researchers have yet to compare the factors that contribute to burden among parents of adolescents and adults with ASD with and without ID.

The present study aims to address these research gaps by exploring the relationship between subjective caregiver burden and a number of *child, parent, and system characteristics* in a Canadian context where some, but not all, health care services for individuals with ASD are funded. Examining this issue from a Canadian perspective is particularly interesting because, unlike the U.S., factors such as parent education and income may play less of a role in family



experiences since most individuals are entitled to emergency and preventative medical/health care free of charge. To achieve this aim, we pose the following questions among a sample of adolescents and young adults with ASD: 1) how is caregiver burden related to the presence or absence of an ID?; 2) what are the relative contributions of child, parent, and service system characteristics to caregiver burden?; and 3) do predictors of caregiver burden vary between parents of individuals with ASD and ID versus those without ID? Consideration of intellectual functioning is in line with the revised Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5; APA, 2013) clinical specifiers in how ASD is understood across the spectrum. Although not the most important determinant of child outcomes, intellectual status is one way of differentiating parents of individuals with ASD who present with diverse clinical profiles and who also receive different types of health-care and school services depending on their level of intellectual functioning. It is important to identify factors associated with caregiver burden across all levels of functioning in order to facilitate the establishment of effective and appropriate interventions that target the unique needs of families. This is among the first studies to explore the interplay between parent, child and system factors on caregiver burden among a sample of adolescents and young adults with ASD.

### Method

The analyses reported here are based on baseline data from a larger longitudinal project examining health service utilization patterns among adolescents and adults with ASD. As part of a baseline survey, parents provided demographic and clinical information about their child including: service use, comorbid medical and psychiatric conditions, severity of ASD, and history of previous hospitalizations. Parents also completed measures related to their own

demographics (age, education, gender) and personal wellbeing (e.g., burden, crisis). Clinical and parent items were largely obtained with previously validated measures (Lawton, Moss, Hoffman and Perkinson 2000; Weiss and Lunsky 2011), while demographic and utilization items were based on measures used in a previous study examining health service utilization patterns among individuals with developmental disabilities. Participants were recruited from Autism service providers and family advocacy organizations, schools and recreational programs throughout Ontario. Efforts were made to reach all regions of the province, including remote and rural settings.

### *Participants*

The current study examined child, parent, and system variables among 297 parents of adolescents and young adults with ASD aged 12 to 30 years ( $M = 17.25$ ,  $SD = 3.96$ ).

Approximately 55% of parents reported that their child had an ID. Descriptive characteristics are summarized for the total sample and by subgroup in Table 1. The majority of individuals with ASD were living with family (98.2%) and over three quarters were male (81.1%). In terms of mental health or behaviour problems, 87.1% of individuals had a history of internalizing problems, and 76.6% had a history of externalizing behaviours. Approximately one third (35.7%) of parents indicated that their child had a medical comorbidity. Parents ranged in age from 33 to 67 ( $M = 48.50$ ,  $SD = 6.22$ ), and three quarters (75.0%) had education beyond high school or partial college. Most respondents were mothers (92.9%), and approximately 74.4% were married. Over one quarter (31.3%) of parents reported that they could not afford services for their child.

### *Measures and Procedures*

All measures used in this study were parent-report questionnaires completed online (80.8%), through telephone interviews (5.4%) or by mail (13.8%). Parents who completed the survey online were younger ( $p < .01$ ), than those who completed mail or phone surveys. No other significant demographic differences were found. Clinical and parent items were largely obtained from previously validated measures (Lawton et al., 2000), while demographic and utilization items were based on measures used in a previous study examining health service utilization patterns among individuals with developmental disabilities. Prior to launching the survey, measures were piloted among 10 families of adolescents and adults with ASD living in Ontario.

### *Subjective Caregiver Burden*

Caregiver burden was assessed using the 9-item Caregiving Burden Scale, a subscale of the Revised Caregiver Appraisal Scale (Lawton et al., 2000). Items measured caregiver's appraisal of the physical, psychological, and social impact of caring for their child with ASD. A total score was calculated by summing scores for each question with higher scores reflective of greater burden. As suggested by Pruncho and McMullen (2004), total scores were categorized into three levels of burden: low ( $<22$ ), moderate (22–27) and high ( $>27$ ). This scale is internally consistent (0.87), has acceptable stability, and is correlated with associated measures (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). In the current study, internal consistency of this measure was also high (0.92).

### *Child Factors*

In terms of child factors, the following variables were examined: age, gender, ASD severity, mental health problems, medical problems, daily activities, residence, and presence of

an ID. To measure ID, parents were asked to indicate their child's level of cognitive ability according to the following seven categories: gifted, normal intelligence, borderline intelligence, mild ID, moderate ID, severe ID and profound ID. Level of cognitive functioning was then re-categorized as non-ID (gifted, average intelligence and borderline intelligence) or ID (mild to profound ID). Externalizing behaviour was assessed through three yes/no questions about whether the child had a history of aggression, self-injury or hurting others. Internalizing problems were assessed through two yes/no questions, about whether the child had a history of anxiety or depression. Sums for externalizing behaviours and internalizing problems were calculated separately.

ASD symptom severity was measured using the Social Communication Questionnaire-Lifetime Version (SCQ; Rutter, Bailey, & Lord, 2003). The SCQ consists of 40 items that are based on the Autism Diagnostic Interview-Revised (ADI-R). This measure has been shown to have strong discriminant validity (Chandler et al., 2007; Witwer & Lecavalier, 2007), convergent validity with the ADI-R (Berument, Rutter, Lord, Pickles, & Bailey, 1999; Howlin & Karpf, 2004) and internal consistency (alpha coefficients 0.81 - 0.93; Naglieri and Chambers, 2009). Scores ranged from 0 to 39, with higher scores reflecting greater ASD severity. In the current study, internal consistency of this measure was acceptable (0.76). For the total sample, the mean SCQ score was 23.77 ( $SD = 5.54$ ) and, as expected, SCQ scores differed between groups,  $t_{(295)} = 7.29, p < .001$ , such that individuals with ID ( $M = 25.75, SD = 5.34$ ) had higher SCQ scores than those without ID ( $M = 21.41, SD = 4.81$ )

#### *Parent Factors*

Parent factors included gender, age, marital status, level of education, and family income. Level of education was categorized as high (college diploma or more) or low (partial diploma or

less), and marital status was categorized as married or not married. Income data was estimated based on mean family residential postal code forward sortation index reported by Statistics Canada (2006). Because the mean income ( $M = \$83\,509$ ,  $SD = \$26\,540$ ) in our sample was greater than the national average, we chose to dichotomize income into two categories: lowest income quartile bracket and highest three income quartile brackets. This allowed us to better understand differences in caregiver burden among parents living in low versus average/high income households. The percentage of average/high income households did not differ by group ( $\chi^2_{(1)} = 1.87, p = .17$ ).

#### *Service System Factors*

To investigate factors associated with service system use, we examined service affordability. Parents were asked the following question: “Can your family afford to pay for services that you need in your community?” Responses were dichotomized into the following two categories: families who could afford services versus those who could not afford services. It is important to note that parent income is different from service affordability, which is impacted by the responsiveness of the health care system within a community. The percentage of families who could not afford services did not differ by group ( $\chi^2_{(1)} = 1.59, p = .21$ ).

#### *Data Analytic Strategy*

Continuous variables were first examined for skewness and outliers. Among the total sample, Pearson (continuous variables) and point biserial (dichotomous variables) correlations were conducted to examine the bivariate relations among predictor variables (child, parent and system factors) and caregiver burden. Variables that were significantly correlated at  $p \leq .05$  were selected for inclusion in multiple regression analyses, and variables were entered simultaneously in the model. These same variables were also included in separate multiple regression analyses

for each group (ASD with ID versus ASD without ID).

## Results

### *Caregiver Burden*

In the current sample, 22.9% reported low, 22.2% moderate, and 54.9% high levels of burden. The mean level of caregiver burden rating was significantly different across groups,  $t_{(291)} = 2.13, p < .05$ , with parents of individuals with ASD and ID having higher ratings ( $M = 29.57, SD = 8.78$ ) than parents of those with ASD without ID ( $M = 27.41, SD = 8.49$ ). However, burden levels were high across *both* groups, with mean scores at or above the clinical cut off for high burden.

### *Child, parent and service system factors associated with caregiver burden in total sample*

ASD severity, medical comorbidity, internalizing problems, externalizing behaviours, parent age, and inability to pay for services were all strongly correlated with caregiver burden in the whole sample (see Table 2). Presence of a comorbid ID diagnosis was moderately correlated with burden ( $p = .03$ ) in the total sample. Child age, parent education, marital status and household income were not associated with burden.

### *Predictors of caregiver burden in total sample: Multiple regression analysis*

An initial multiple regression analysis was conducted to identify predictors of caregiver burden in the total sample (see Table 3). ASD severity, internalizing problems, externalizing behaviours, medical comorbidity, and parent age were all unique contributors to caregiver burden in an overall model that was significant,  $F_{(7, 249)} = 8.36, p < .001$ , accounting for approximately 17% of adjusted variance. There was also a trend for parents to experience greater burden when they could not afford to pay for services ( $p = .06$ ).

*Predictors of caregiver burden by subgroups (ID vs. no ID): Multiple regression analyses*

Regression analyses were repeated to identify predictors of caregiver burden in each subgroup (see Table 4). For parents of individuals with ASD and ID, the overall model was significant,  $F_{(6, 134)} = 5.53, p < 0.001$ , accounting for 16% of the adjusted variance in caregiver burden. ASD severity, externalizing behaviours, medical comorbidity and parent age were significant predictors of burden in this model.

For parents of individuals with ASD without ID, inability to afford services was the only predictor of caregiver burden, and together the overall model was significant,  $F_{(6,109)} = 3.49, p < .01$ , accounting for 12% of the variance in caregiver burden.

### Discussion

The present study examined predictors of burden among parents of adolescents and young adults with ASD and investigated how these predictors differed among individuals with and without ID. Overall, levels of burden were high among all caregivers in this study, consistent with previous findings in the broader ASD and ID literature (Cadman et al., 2012; Kring et al., 2008; Lee et al., 2008; Lin, 2011; Rodrigue et al., 1990; Stuart & McGrew, 2008). Similarly, child variables associated with caregiver burden at the bivariate level included presence of ID (Kring et al., 2008), ASD symptom severity (Lin, 2011; Stuart & McCrew, 2008; Seth, 2011), internalizing problems, externalizing behaviours (Lin, 2011; Kring et al., 2008; Cadman et al., 2012), and comorbid medical problems (Kring et al., 2008). Consistent with studies of caregiver burden among individuals with ID (Chou, 2011), we found an association between parent age and burden, with older parents reporting greater burden. Finally, in terms of system factors, inability to afford services was related to caregiver burden. In multivariate analyses, ASD

severity, internalizing problems, externalizing behaviour, medical comorbidity and parent age predicted caregiver burden in the total sample. However, interestingly, predictors varied according to the child's level of intellectual functioning.

### *Mental Health*

Whether psychiatric comorbidity (e.g., internalizing problems or externalizing behaviour) contributed to caregiver burden depended on the child's level of intellectual functioning. For example, externalizing behaviours predicted burden in parents of children with ASD and ID, but neither predicted burden in parents of individuals without ID. This was surprising given high rates of mental health problems observed in individuals with average intellectual ability (i.e., without ID) in our sample (92% with internalizing and 70% with externalizing problems), as well as those reported in other studies (Ghaziuddin, 2002; Khouzam, El-Gabalawi, Pirwani, & Priest, 2004; Meyer, Mundy, van Hecke, & Durocher, 2006; Tonge, Brereton, Gray, & Einfeld, 1999). Since mental health issues are extremely common among individuals with ASD without ID, it may be that what is contributing to caregiver burden in parents is less about the type of behaviour and more about the severity of the presentation, which we did not assess.

Alternatively, whether internalizing problems or externalizing behaviour among this population is burdensome to parents may be context-dependent and related to the child-environment match. These speculations require more refined and sensitive measures of co-occurring mental health problems in individuals with ASD and average intellectual functioning than the ones used in the present study.



### *Family and Parent Background*

In terms of family background variables, the current study found a relationship between parent age and burden, with older parents reporting more burden. No other parent characteristics were related to burden, unlike Kring et al. (2008) who reported an association with parent education, in which highly educated parents were more burdened. This lack of association in our study could be accounted for by the majority of respondents being highly educated (75%); however, similar non-significant results were reported by Cadman et al. (2012) in a more diversely educated sample. Interestingly, our study (Canada) and the study by Cadman and colleagues (U.K.) were both conducted within the context of socialized health care, whereas the work by Kring et al. (2008) was based out of the U.S. Unlike the U.S., Canada and the U.K. share a government-funded health care system where services are provided *regardless* of income. Thus, income and education (more education generally leads to higher income) may have less influence on caregiver burden in such jurisdictions compared to the U.S. where greater burden is influenced by whether or not an individual has the means to afford services that are unpaid (Parish et al., 2012).

### *Service System*

This is the first study to assess service affordability and caregiver burden among parents of individuals with ASD. While the inability to afford services was related to caregiver burden at the bivariate level, these findings disappeared when accounting for clinical child and parent background factors. Interestingly, it was a significant predictor of burden in parents of individuals with ASD without ID, but not in those with ID. Although the proportion of low-income households and families who could not afford services did not differ between groups, the

inability to pay for services was particularly burdensome for parents of individuals without ID. Higher functioning individuals with ASD are grossly underserved within the mainstream health care system because they do not typically qualify for specialized services for people with ID (see Berney, 2007; Ward & Russell, 2007). As a result, in Ontario as well as other parts of Canada and the U.K. (Royal College of Psychiatrists, 2006), individuals with ASD and average intellectual functioning are unable to access publicly funded clinical and social services for people with developmental disabilities (Autism Ontario, 2008; Lunskey, Gracey & Bradley, 2009) and are often forced to pay out-of-pocket or not receive services at all. This may explain why an inability to pay for services contributed to burden in only parents of individuals without ID, irrespective of family income.

### *Limitations*

This study is subject to a number of limitations that should be considered when interpreting results. One of the most important limitations is the reduction of power associated with the subgroup analyses, which could help explain why only some variables that predicted burden in the overall sample emerged as significant predictors in subgroup analyses. Further, although predictors of caregiver burden differed depending on the child's level of intellectual functioning, differences may not remain the same if the sample was larger, and thus, more research is needed to replicate findings within a larger sample. Additionally, findings were based on parent-report data and we did not have access to corroborating sources to validate diagnoses. However, there is evidence to suggest that parent reported diagnoses are often valid (Daniels et al., 2012). Our study is limited primarily to mothers and almost all individuals with ASD were living with family; thus, findings may not generalize to other caregivers or those residing outside

the family home. In addition, given that the majority of our sample consisted of highly educated parents from average to high-income households, it is possible that we did not adequately capture experiences faced by less educated parents from lower income households. Finally, it is important to recognize that in our study, child, parent and system variables together only accounted for approximately 17% of the variance in caregiver burden. Thus, while the relationships were significant, the associations were small. This speaks to the likelihood that there may be other factors, not assessed in the current study, which contribute to caregiver burden such as negative life events, parent health, problems related to other family members, and service accessibility. Going forward, it will be important to explore the impact of these variables on caregiver burden.

### *Practice Implications*

Despite these limitations, findings from the current study have a number of important implications. It is clear that parents of individuals with ASD experience high levels of burden regardless of their child's level of functioning or cognitive ability, and it is important that we do not underestimate the distress of caring for less severe individuals on the autism spectrum. Factors associated with caregiver burden differed among individuals with and without ID, and were not limited to ASD symptom severity or mental health problems, but also extended to funding and service system issues. At least in Canada, our study suggests that characteristics of the child are stronger predictors than parent characteristics in explaining caregiver burden. Results of this study underscore a need for tailored services and supports that address both child and system level factors. This will allow us to be more precise and sophisticated in how we prevent and respond to caregiver burden in parents and families of adolescents and adults with

ASD. Identifying and recognizing differences among individuals with ASD may help facilitate the establishment of effective and appropriate interventions, whether through, parent, child or system remediation.

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## Tables

**Table 1.** Descriptive Characteristics of Total and Subgroup Samples

	Total Sample (N=297)		ASD and ID <sup>a</sup> (N = 162)		ASD without ID (N = 135)	
	%	Mean (SD)	%	Mean (SD)	%	Mean (SD)
<b>Child Variables</b>						
Age		17.25 (3.96)		17.54 (3.98)		16.90 (3.91)
Gender (male)	81.1		78.4		84.4	
ASD Severity (SCQ <sup>b</sup> )		23.77 (5.54)		25.75 (5.34)		21.41 (4.18)
Psychiatric Problems						
Internalizing Problems	87.1	1.25 (0.67)	83.1	1.04 (0.61)	91.6	1.48 (0.65)
Externalizing Behaviours	76.6	1.67 (1.17)	81.7	1.86 (1.44)	70.3	1.45 (1.16)
Medical Comorbidity	35.7		42.0		28.1	
Daily Activity (unstructured)	11.6		10.6		12.7	
Residence (with family)	98.2		98.6		97.7	
<b>Parent Variables</b>						
Gender (mothers)	92.9		92.0		94.1	
Age		48.50 (6.22)		49.06 (6.49)		47.83 (5.82)
Marital Status (married)	74.4		79.0		68.9	
Education (college diploma or higher)	75.0		73.0		77.4	
Household income (\$)						
Low	25.3	\$58 889.56 (\$4 114.86)	28.4	\$58 468.41 (\$4 231.66)	21.5	\$59 557.59 (\$3 900.82)
High	74.7	\$91 826.50 (\$25 740.14)	71.6	\$91 390.78 (\$25 484.77)	78.5	\$92 303.31 (\$26 129.53)
Burden		28.60 (8.70)		29.57 (8.78)		27.41 (8.49)
Low (<22)	22.9		19.9		26.5	
Moderate (22-27)	22.2		20.5		24.2	
High (>27)	54.9		59.6		49.2	
<b>Service Variables</b>						
Service Affordability (cannot afford)	31.3		34.4		27.5	

<sup>a</sup>Intellectual disability, <sup>b</sup>Social Communication Questionnaire

**Table 2:** Correlation Matrix for study variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. Caregiver burden	—											
2. Child age	0.08	—										
3. Presence of ID <sup>a</sup> in child	0.13*	0.08	—									
4. ASD severity	0.21***	0.03	0.39***	—								
5. Child internalizing problems	0.16**	0.17**	-0.33***	-0.09	—							
6. Child externalizing behaviors	0.27***	0.06	0.18**	0.26***	0.26***	—						
7. Child medical comorbidity	0.17**	0.20**	0.14*	0.23**	-0.01	0.11	—					
8. Parent age	0.15*	0.53***	0.10	0	0.04	-0.09	0.14*	—				
9. Parent education <sup>b</sup>	-0.23	-0.03	-0.05	-0.14*	0.02	-0.13*	-0.03	0.09	—			
10. Parent marital status <sup>c</sup>	-0.10	-0.15*	0.12*	0.06	-0.12*	-0.02	-0.06	-0.13*	0.07	—		
11. Household income <sup>d</sup>	0.06	0.02	-0.08	-0.06	-0.02	0.10	0	0.09	0.09	0.10	—	
12. Service affordability <sup>e</sup>	-0.15*	0.03	-0.07	-0.09	-0.10	-0.17**	-0.04	0.06	0.14*	0.23***	0.03	—

<sup>a</sup>Intellectual disability. <sup>b</sup>Parent education: 0 = *partial diploma or less*, 1 = *college diploma or more*. <sup>c</sup>Parent marital status: 0 = *not married*, 1 = *married*. <sup>d</sup>Household income: 0 = *low income*, 1 = *average/high income*. <sup>e</sup>Service affordability: 0 = *cannot afford*, 1 = *can afford*.

Note: Pearson correlations were conducted for continuous variables and point-biserial correlations were conducted for dichotomous variables.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$



**Table 3.** Multiple regression analysis of predictor variables on caregiver burden in the total sample

<b>Variables</b>	<b><i>B</i></b>	<b><i>SE B</i></b>	<b><math>\beta</math></b>	<b><i>t</i></b>
Presence of ID <sup>a</sup> in child	0.17	0.13	0.08	1.24
ASD severity	0.03	0.01	0.14*	2.16
Child internalizing problems	0.21	0.10	0.14*	2.17
Child externalizing behaviours	0.15	0.05	0.19**	2.91
Child medical comorbidity	0.24	0.12	0.12*	2.01
Parent Age	0.03	0.01	0.16**	2.65
Service affordability <sup>b</sup>	-0.24	0.13	-0.11	-1.93
	<b><i>R</i><sup>2</sup></b>		0.19	
	<b><i>Adjusted R</i><sup>2</sup></b>		0.17	
	<b><i>F</i></b>		8.36***	

<sup>a</sup>Intellectual disability. <sup>b</sup>Service affordability: 0 = *cannot afford services*, 1 = *can afford services*.  
 \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

**Table 4.** Multiple regression analysis of predictor variables on caregiver burden in parents of individuals with ASD with and without ID<sup>a</sup>

Variable	ASD with ID			ASD without ID		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
ASD severity	0.03	0.02	0.18*	0.02	0.02	0.09
Child internalizing problems	0.23	0.14	0.14	0.17	0.13	0.12
Child externalizing behaviours	0.14	0.07	0.17*	0.14	0.08	0.17
Child medical comorbidity	0.36	0.16	0.18*	0.09	0.20	0.04
Parent Age	0.03	0.01	0.17*	0.03	0.02	0.17
Service affordability <sup>b</sup>	-0.09	0.17	-0.04	-0.44	0.20	-0.21*
	<i>R</i> <sup>2</sup>	0.20		0.16		
	<i>Adjusted R</i> <sup>2</sup>	0.16		0.12		
	<i>F</i>	5.52***		3.49**		

<sup>a</sup>Intellectual disability. <sup>b</sup>Service affordability: 0 = cannot afford services, 1 = can afford services.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$