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Perceived self-efficacy in parents of adolescents and adults with Autism Spectrum

Disorder

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Abstract

Many parents of adolescents and adults with Autism Spectrum Disorder (ASD) experience difficulty accessing appropriate services for their children, and may report low levels of parent self-efficacy. In an effort to identify the factors that contribute to the difficulties these families face, this study examined the role of demographic, systemic and clinical need variables as they relate to parents' experience of self-efficacy. Participants included 324 parents of individuals with autism spectrum disorder, 12-25 years of age. Results suggest that parent self-efficacy is related to a number of variables and not simply a child's clinical situation, including child age, parent immigrant status, barriers to service access, and caregiver burden. Given the crucial role that parents often play in the lives of individuals with ASD across the lifespan, it is important that service providers support the efforts of parents who provide and access care for their children.

Keywords: access to services, autism spectrum disorder, parent self-efficacy, parenting

Individuals with autism spectrum disorder (ASD) have considerable needs across many domains, and parents are crucial in their provision of care. Supporting a parent's perceived competency to meet the demands of providing and obtaining care for their children, often referred to as parent self-efficacy (Coleman & Karraker, 1998), is an important endeavor (Gaugler et al., 2005; Gitlin et al., 2003; Sherwood et al., 2007). It is particularly relevant to study self-efficacy in parents of adolescents and adults with ASD, given that increasingly adults with ASD are living with their parents (Anderson, Shattuck, Cooper, Roux & Wagner, 2014; Howlin & Moss, 2012; Kogan et al., 2008; Lakin, Prouty, & Coucouvanis, 2007), and that the transition to adulthood can be especially difficult for them (Billstedt, Gillberg, & Gillberg, 2007; Eaves & Ho 2008; Taylor & Seltzer 2011). Combined with the fact that families are situated in a service system that is often described as not ready to provide adequate supports to these age groups (Taylor & Seltzer, 2011a; Shattuck et al., 2012), there is even greater responsibility on parents of adults to provide care for their children in the face of limited external support.

Though an emerging field of research has documented correlates and predictors of service use of adolescents and adults with ASD (e.g., Taylor & Henninger, 2015; Shattuck et al., 2012), only a handful of studies to date have examined predictors of parent self-efficacy in this group. In the literature on youth with ASD, increased levels of parent self-efficacy have been associated with decreased parental anxiety, depression, and child behavioral problems (Hastings & Brown, 2002; Kuhn & Carter, 2006; Weiss, Cappadocia, MacMullin, Viecili & Lunsky, 2012). For instance, Hastings and Brown

(2002) found parent self-efficacy acted as a mediator between child behavior problems and maternal anxiety and depression, while for fathers, parent self-efficacy moderated the relationship between child behavior problems and paternal anxiety. There is also research with parents of individuals with developmental disorders to suggest that selfefficacy can be enhanced through intervention, translating into improved child, parent and service outcomes (Heller, Miller, & Hsieh, 1999; Keen, Couzens, Muspratt, & Rodger, 2010; Sofronoff & Farbotko, 2002). For example, in a sample of parents of young children with ASD aged 2-4 years, Keen and colleagues (2010) found improvements in parent self-efficacy, child adaptive behavior and reductions in childrelated parenting stress, following a professionally supported intervention targeting parenting competence. In a rare study focused on adults, Heller et al. (1999) found families in a consumer directed family support program for parents of adults with developmental disabilities reported higher levels of parent self-efficacy, fewer unmet service needs, and greater community involvement of the family member with the developmental disability, as compared to families on the waiting list. A better understanding of the predictors of parent self-efficacy in families of adolescents and adults with ASD is needed to appropriately inform such intervention practices. Predictors of Parent Self-Efficacy in ASD

Demographics. Parent self-efficacy may be impacted by both child and parent demographic variables. The limited research to date yields mixed findings regarding the impact of child age on parents' perceived ability to successfully care for their child (Benson, 2014; Kuhn & Carter, 2006), though parents may adjust to their caregiving

demands and experience an improvement in psychological wellbeing as their children with ASD grow older (Benson, 2014; Gray, 2002; Lounds, Seltzer, Greenberg, & Shattuck, 2007). Utilizing a cohort sequential design with a sample of 113 mothers of children with ASD aged 7-14 years, Benson (2014) found mothers' ratings of selfefficacy remained stable across a seven-year period. Conversely, in a cross-sectional analysis of 170 mothers of children with ASD aged 2-10 years, mothers' ratings of selfefficacy increased with child age (Kuhn & Carter, 2006). To our knowledge, no study has examined the relations among child age and self-efficacy in parents of older adolescents and adults with ASD. With respect to child sex, parents of daughters report less stress in addition to greater caregiving satisfaction when compared to parents of sons with ASD (Lounds, Seltzer, Greenberg & Shattuck, 2007; White & Hastings, 2004), a finding that may also extend to perceived self-efficacy but requires further study.

Parent demographic variables may also be related to self-efficacy. In the general parenting literature, self-efficacy has been associated with maternal education and family income (Coleman & Karraker, 2000), possibly representing the ability of parents of higher socioeconomic status to more successfully advocate for their children's service needs (Benedict, 2006). Parents with higher incomes and education have been shown to access more services for their children with ASD (Chiri & Warfield, 2012; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007), though the link to self-efficacy has yet to be established. Similarly, children with ASD from immigrant families are often underserved in a variety of service

domains (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004), and it has been suggested that this may be due to their unfamiliarity with the majority culture and low levels of self-efficacy (Bailey et al., 1999).

Systemic Characteristics. Systemic characteristics that promote or obstruct service use, including the affordability, availability and accessibility of services (Andersen, 1995; Stiffman, Pescoslido, & Cabassa, 2004), may be particularly important in determining parents' appraisal of their self-efficacy. Parents who cannot afford services may feel less efficacious, given that the cost of services related to care for individuals with ASD can be incredibly high (Ciday, Lawer, Marcus, & Mandell, 2013; Croen, Najjar, Ray, Lotspeich & Bernal, 2006; Ganz, 2007; Kogan et al., 2008), particularly when public funding does not cover services. This is the case often with adolescents or adults with ASD, where public funding for early intervention services can far outweigh funding for older individuals (Madore & Pare, 2006), and that the total cost of care for adults with ASD is higher than that of children with ASD (Buescher, Ciday, Knapp, & Mandell, 2014). Even if families can afford services, barriers to accessing services may present as considerable impediments, particularly as youth age (Douma, Dekker & Koot, 2006; Weiss & Lunsky, 2010). Certainly, parents report a lack of available appropriate services and difficulty accessing information about those services (Eaves & Ho, 2008; Griffith, Totsika, Nash, Jones & Hastings, 2012; Hare, Pratt, Burton, Bromley, & Emerson, 2004). However, no one has studied how systemic variables relate to parent self efficacy.

Clinical needs. The level of children's clinical needs, which in ASD may be pervasive and far reaching, place considerable responsibility on parents to act as service navigators (Boulet, Boyle, & Schieve, 2009) and places considerable demands on parents to manage often chronic stressors (Weiss, Wingsiong, & Lunsky, 2014), which may impact their self-efficacy. Children with ASD have known deficits in sociocommunicative competence (Tager-Flusberg, Joseph, & Folstein, 2001; Volkmar, Lord, Bailey, Schultz, & Klin, 2004), as well as high rates of co-occurring functional impairments, and associated physical, emotional, and behavioral problems (Gillham, Carter, Volkmar, & Sparrow, 2000; Gurney, McPheeters, & Davis, 2006; Simonoff et al., 2008). Higher levels of such child clinical needs are consistently related to lower parent self-efficacy in this population (Benson, 2014; Hastings & Brown, 2002; Weiss et al., 2012; Weiss, MacMullin & Lunsky, 2014), though studies have yet to examine how these demands relate to self-efficacy after taking into account both demographic and systemic factors.

The psychosocial needs of parents themselves may also impact their appraisal of self-efficacy. A number of studies assert a strong association between elevated mental health problems (e.g., stress, depression) in parents of individuals with ASD and compromised self-efficacy (Kuhn & Carter, 2006; Weiss et al., 2013). These studies did not examine whether the parent mental health difficulties were specific to their role as a caregiver, which is important in the context of understanding what impacts parental appraisals of their ability to provide and access care. The relationship between caregiver burden, defined as "the perception of psychological distress, anxiety, depression,

demoralization, and generalized loss of personal freedom attributed directly to caregiving" (Lawton, Moss, Kleban, Glicks-man, & Rovine, 1991, p. 182) and parent self-efficacy has not yet been studied.

Current Study

The current study examined the role of demographics (e.g., child age, gender, maternal education, maternal immigrant status, family median income), systemic factors (e.g., affordability and barriers to services), parent (e.g., caregiver burden), and child clinical needs (e.g., severity of ASD symptoms, presence of child's psychiatric or medical comorbidity) as predictors of parent self-efficacy.

Method

Participants

Participants included 324 parents of individuals diagnosed with ASD. Parents were 31 to 65 years of age (M = 47.7, SD = 6.0) and most (n = 258, 79.6%) reported being married or living with a partner (see Table 1 for details on demographics). The majority of respondents were mothers (93.8%). The forward sortation (first three digits) of participants' postal codes was used to find the median household income from Statistics Canada's 2006 Canadian Census (Statistics Canada, 2006), ranging from \$34,029 to \$101,455. The majority of parents noted being born in Canada (73.8% of fathers and 76.9% of mothers). In approximately 14.5% of families, both parents were immigrants to Canada. Most mothers completed a college or university degree (73.1%). Paternal education was similar in distribution.

Individuals with ASD (81.8% male) were 12 to 25 years of age (M=16.8, SD=3.3). Only individuals with a clinical cutoff above 12 on the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) were included in the current study, as has been used in other recent research involving mothers of individuals with ASD (Corsello et al., 2007; Zablotsky, Anderson, & Law, 2013). While we were unable to confirm diagnosis using gold standard clinical measures, a number of studies have used similar survey-based methods to study this population (Blumberg et al., 2013; Gurnery et al., 2006; Mazurek, Shattuck, Wagner & Cooper, 2012; Montes & Halterman, 2007), including the 2011-2012 National Survey of Children's Health (CDC, 2013) and the 2011-2012 National Health Interview Survey (CDC, 2012), and parent report of ASD diagnosis combined with screening tools has been validated in recent years (Daniels et al., 2011). Most individuals with ASD (93.8%) were living with their families at the time of survey completion.

Insert Table 1

Procedure

The current study is part of a larger project examining service utilization in parents of adolescents and adults with ASD. Convenience and snowball sampling methods were employed to recruit participants from across Ontario, Canada. Participants were recruited from postings on ASD support organizations' websites (e.g., Autism Ontario,

Kerry's Place Autism Services) and through email lists associated with these organizations. Parents registered for the study through the study website, or by contacting research staff. Once participants provided informed consent, they chose to complete the survey online, by mail, or over the telephone. Participants were given a \$20 honorarium after the survey was completed. This research was approved by the university and hospital research ethics boards.

Measures

Demographic Factors.

Parents were asked their age, highest level of education attained (maternal education was used in the current study), whether they were immigrants to Canada (whether mother was born in Canada or not was used in the current study), and their child's age and sex.

Systemic Factors.

Affordability of Services. Parents were asked the following question: "Can your family afford to pay for services that you need in your community?" and responses were dichotomized into Yes-No response. Prior research has also employed a dichotomous categorization of service affordability (Schieve et al., 2012), and in the current sample, 31.2% noted not being able to afford a service.

Perceived Barriers to Service Access. Parents were asked whether they had experienced any of 13 reasons for not obtaining help, and if there were any other reasons that they did not receive the supports they required (see appendix A for list of barriers). All parents were asked about barriers they experienced regardless of whether they

received supports. These reasons were the top 13 barriers noted by parents in prior studies of service utilization in parents of individuals with developmental disabilities (Douma et al., 2006; Weiss & Lunsky, 2010). Parents noted between 0-11 barriers (median = 3 barriers), with a mean of 3.2 (SD = 2.2).

Clinical Need Factors.

ASD Symptom Severity. ASD symptom severity was measured by the Social Communication Questionnaire (SCQ; Rutter et al., 2003). The SCQ is a 40-item questionnaire intended to assess the individual's developmental history, providing subscales on the severity of communication impairments, social interaction impairments and restricted, repetitive or stereotyped patterns of behavior. Each item asks parents to check either 'yes' or 'no' as to whether that behavior is/was demonstrated by the individual in question. The response is then assigned a point rating of 1 (presence of abnormal behavior) or 0 (absence of abnormal behavior). The SCO has been shown to have good discriminant validity (Witwer & Lecavalier, 2007), convergent validity with the Autism Diagnostic Interview-Revised (ADI-R) (Howlin & Karpf, 2004) and internal consistency (Cronbach's $\alpha = .81-.93$; Naglieri & Chambers, 2009). The SCO has also been shown to have good sensitivity and specificity in past research involving adolescents and adults with ASD (Berument, Rutter, Lord, Pickles & Bailey, 1999), In the current study, internal consistency for the overall scale was strong (Cronbach's $\alpha =$.81).

Psychiatric and Medical Diagnoses. Parents were asked to provide current medical and psychiatric diagnoses for their child with ASD. Medical and psychiatric diagnoses were each dichotomized into those that had at least one comorbid diagnosis (presence) and those that did not (absence). Almost half of the sample had an associated psychiatric condition (46.9%), and 32.4% had an associated medical condition. Many large scale surveys use dichotomous parent report of psychiatric and medical conditions, including in regression analyses, as was conducted in the current study (Gurney et al., 2006; Mazurek et al., 2012; Montes & Halterman, 2007).

Caregiver burden. Subjective feelings of parental burden were measured using the 9-item burden subscale of the Revised Caregiver Appraisal Scale (Lawton, Moss, Hoffman & Perkinson, 2000). Items measure parent's perception of the negative impacts caregiving has had on his or her health, well-being, social life and personal relationships. Items are rated on a 5-point Likert scale, ranging from 1 (never) to 5 (nearly always), with higher overall scores reflective of greater burden. A previous study involving parents of adults with developmental disabilities reported good internal consistency (Cronbach's $\alpha = .87$; Pruchno & McMullen, 2004), and the current study showed similar reliability (alpha coefficient = .92). More than half of the current sample reported having high burden (burden score $\geq 27,54.9\%$) according to previously published cutoff scores (Pruchno & McMullen, 2004).

Outcome Variable

Parent self-efficacy was assessed using an adapted Mastery Subscale of the Revised Caregiver Appraisal Scale (Lawton et al., 2000). We kept the original 6-item scale that asked parents to rate a series of statements about their perceived ability to care for their child on a 5-point Likert scale, from 1- (disagree a lot/never) to 5- (agree a

lot/nearly always) (e.g., I am pretty good at figuring out what my child needs). Parents were also asked two additional questions that pertain directly to their perceived knowledge and skill in accessing services for their child: "I am knowledgeable about the service system that _____ is involved in" and "I am able to effectively access the services that _____ needs". The average of these 8-items was taken to create a mean self-efficacy score (range 1.25 - 4.75, M = 3.26, SD = 0.72) with higher scores indicative of greater self-efficacy. The scale was found to have good internal consistently (Cronbach's $\alpha = .80$).

Data Analysis

Bivariate analyses were first conducted to determine the relationship among predictor variables and with the parent self-efficacy variable. Pearson product moment and point-biserial correlations were used to examine the relationships among different continuous and dichotomous demographic (child age, maternal education, median income, immigrant status, child gender), systemic (sum of barriers, affordability of service), and clinical need (ASD symptom severity, psychiatric and medical comorbidity, caregiver burden) predictors with parent self-efficacy. A hierarchical multiple regression analysis was conducted to test the relative contributions of each set of predictors, entering all demographic, system, and clinical need factors in a standard fashion.

Results

Only small correlations emerged among the predictor variables (all r < .30), and a number of small correlations emerged between predictor variables and parent self-

efficacy. Specifically, greater efficacy was related to having children who were younger (r = -.19, p < .01), mothers who were born in Canada (r = -.20, p < .001), fewer barriers to service access (r = -.29, p < .001), no psychiatric comorbidity (r = -.15, p = .01), and less caregiver burden (r = -.42, p < .001). Table 2 provides descriptive statistics of predictor variables.

Table 2

Predictors of Parent Self-Efficacy.

As shown in Table 3, child age and maternal immigrant status were significant predictors in the first step when only the demographic variables were entered, with an overall model that was significant, F(5, 318) = 5.21, p < .01, accounting for a total of 7.6% of the variance in parent self-efficacy. Systemic factors (affordability and barriers) accounted for a significant increase in the parent self-efficacy variance, F(2, 316) =16.12, p < .001, $\Delta R^2 = 8.6\%$, in an overall model that was significant and accounted for 16.1% of the variance. As shown in Table 3, both barriers and whether families could afford services were significant. Clinical need factors (ASD symptom severity, the presence of a comorbid medical or psychiatric diagnosis and caregiver burden) were entered as the final set of predictors. The final overall model was significant, F(11, 312)= 12.00, p< .001, R² = 29.7%, with clinical need variables accounting for a 13.6% increase in the parent self-efficacy variance, F(4, 312) = 15.10, p < .001. In this final

model, child age, maternal immigrant status, total barriers, and caregiver burden were significant predictors of parent self-efficacy.

Insert Table 3

Discussion

This is the one of the few studies to examine how child and parent demographics, clinical needs, and systemic factors are related to parents' self-efficacy in parents of adolescents and young adults with ASD. Parents often act as the gateway to service use, and it is important that we support their sense of mastery and efficacy in this role. The current sample's average self-efficacy rating suggests a moderate level of self-efficacy is present, though the range also suggests that some parents are experiencing very low levels, and others, very high. Results suggest that parent self-efficacy is associated with a number of variables and not simply the clinical needs of the child, including the age of the child, the parent's immigrant status, number of barriers endorsed, and perceived level of caregiver burden.

Child age and maternal immigrant status were significant predictors of parent self-efficacy in the final model. These findings are consistent with past research on patterns of service utilization in older individuals with ASD (Hendricks & Wehman, 2009; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Taylor & Seltzer, 2011a, 2011b), and highlight the scarcity of, and difficulties many families face in accessing supports and services for older children with ASD. Mothers who immigrated to Canada were more likely to report lower self-efficacy in their perceived ability to meet the needs of their child. This may be caused in part, by a lack of familiarity with how the Canadian service system works, as well as language and cultural barriers, which could directly impact their ability to access services (MacDonnell, Dastjerdi, Bokore, Khanlou, 2012). There are also cross-cultural differences in the interpretation of disease and non-majority populations have been shown to exhibit greater fear of stigmatization, and this too may relate to one's perceived efficacy of working within larger systems of care (Brugge Edgar, George, Heung, & Laws, 2009; Pruchno, Patrick & Burant, 1997; Welterlin & LaRue, 2007). Cultural competence, an awareness of acculturation dynamics, and planning for English as second language are a few of the many recommendations put forth to clinicians in order to better support culturally and linguistically diverse families (Welterlin & LaRue, 2007).

In addition to demographic correlates, we found that parents' experience of the service system was an important predictor of their perceived self-efficacy. Negative parental beliefs about professionals, services and the service system, and feeling that problems were not so serious, have been barriers implicated in past research on service access for parents of individuals with developmental disabilities (Douma et al., 2006; Pruchno & McMullen, 2004), and it is important for services to be aware that parents may feel less able to engage or support their children when confronted with a broad range of attitudinal and organizational barriers. Affordability of service did not emerge as significant in our final model, although we know that income and service access are related more generally (Chiri & Warfield, 2012; Thomas et al., 2007). This may be due

to differences in the way that autism services are funded in the population we surveyed. In Canada, many of the services for individuals ASD are covered under a provincial health care plan and under social services, which may have dampened the effects of service affordability on parent self-efficacy in our study.

In terms of clinical contributors, parent-reported levels of burden were highly related to their perceived self-efficacy. Caring for a child with ASD is known to be related to family distress and particular challenges above what would be expected of parenting typically developing children or children with intellectual disabilities without ASD (Kogan et al., 2008; Siklos & Kerns, 2006), with 54.6% of parents in the current study reporting high levels of burden. Higher levels of parent burden were also associated with caring for a child with more severe ASD symptomatology. Parents with such fatigue report feeling less efficacious, even though they likely have a greater need for services than families without these issues. Findings reported here extend the association of self-efficacy and broader dimensions of parent well-being found in quantitative (Kuhn & Carter, 2006; Nachshen & Minnes, 2005; Weiss et al., 2012) and qualitative research (White, McMorris, Weiss, & Lunsky, 2012).

There are a number of methodological limitations to our research findings. First, participants were recruited through community service and ASD advocacy agencies, and largely through online means. These recruitment procedures may have led to sampling bias, as the experiences of families who are connected to service providers may differ from those who are not affiliated with community agencies. Online surveys may have excluded parents who do not have access to computers or the Internet, and although

participants were also given the options of paper and pencil or telephone interview survey completion, only a minority (16% paper-and-pencil; 4% telephone interview) chose these options. Given the reliance on parent report, we do not have objective measures of ASD, medical, or psychiatric comorbid diagnoses, and perceptions of burden and self-efficacy come from the same respondent. Additionally, only the presence or absence of a medical or psychiatric diagnosis was available, and parent selfefficacy may be more related to ratings of severity or clinical significance of such comorbid conditions. Another limitation stems from the broad way in which we attempted to measure the affordability of services. It is important for future research to further elucidate how these constructs influence perceived parent self-efficacy in greater detail, which may lead to accounting for more variance in the same constructs. Finally, the cross-sectional nature of the data limits interpretations of causality.

The current study's findings suggest several predictors of self-efficacy in parents of adolescents and adults with ASD. However, there are other factors that may explain significant portions of the remaining variance. For example, children with ASD from families of minority race and ethnicities have also been found to receive fewer services and at a later age (Mandell, Listerus, Levy, & Pinto-Martin, 2002; Shattuck et al., 2011). As well, rural residence may affect parent self-efficacy, as past research has demonstrated geographic barriers to service provision, including distance, limited training and availability of rural service providers, and aspects of rural culture such as stigma associated with seeking certain services (Hauenstein et al., 2007). These variables have yet to be examined with respect to parents' self-efficacy. While

examining the predictive characteristics of demographic, systemic, and clinical need factors on parent self-efficacy was a valuable preliminary step, further research identifying how these factors influence families' service utilization can help ensure a more effective and equitable distribution and receipt of services. Future research will need to test the mediating or moderating role of parent self-efficacy in linking clinical need to service use, ideally using longitudinal design.

Conclusions

When taken together, barriers to service use, child age, immigrant status and caregiver burden were found to be the most important predictors of parents' perceived self-efficacy. Given the crucial role that parents play in the lives of individuals with ASD across the lifespan, it is imperative that service providers support the efforts of parents who provide and access care for their children with ASD. These results suggest that interventions that aim to support parents or improve a parents' engagement with the service system need to consider a host of factors, including child and parent demographics, the experience of systemic barriers, and current level of parents' caregiving burden. It may be quite difficult for example to target parent self-efficacy when perceived burden is high and parents have experienced multiple barriers to services receipt. Recent discussions of approaches to support parent resilience and wellbeing have focused on a balanced approach to intervention, where problem focused coping strategies, linked with promoting self-efficacy, are provided in combination with mindfulness-based strategies, linked with promoting psychological acceptance (Marsh, 2003; Walsh, 2003; Weiss et al., 2012). The former set of strategies is thought to be

most helpful in situations where change is feasible, such as addressing problem behaviors that can be remediated, and the latter useful for situations that are beyond parent control. Because so many parents are multiply stressed, experiencing acute and chronic stressors, it is advisable to aim to provide a suite of approaches that they can try (i.e., the notion of a 'tool-kit'), including teaching parents to work with the realities of their situation, providing up to date information about the state of services for their contexts (e.g., current waiting lists and costs for service), and linking parents to other parents when social support is lacking and fatigue is high. Further research in the area could serve as an impetus to policy makers to improve the financing, coordination and delivery of services to ensure effective care for individuals with ASD and their families.

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Table 1. Sample Demographics

Parent Characteristics	Frequency (%)
Parent age*	
< 40 years old	26 (8.6)
40-49	164 (54.1)
50-59	107 (35.3)
60+	6 (2.0)
Gender (female)	304 (93.8)
Marital status	
Married/living with partner	258 (79.6)
Unmarried	66 (20.4)
Income	
<\$50,000	52 (16.0)
\$50,000 - 74,000	176 (54.3)
\$75,000+	96 (29.6)
Child Characteristics	
Age group (in years)	
12-14 years old	91 (28.0)
15 - 17	115 (35.5)
18 - 20	73 (22.5)
21 - 24	45 (13.9)
Gender (male)	265 (81.8)
ASD diagnosis	
Autism	88 (27.2)
Asperger's/high Functioning Autism	105 (32.4)
ASD/PDD-NOS	131 (40.4)
Living at home (Yes)	304 (93.8)

ASD: autism spectrum disorder; PDD-NOS: pervasive developmental disorder not otherwise specified. *n = 303

Variable	Mean (SD) or				
	Frequency (%)				
Demographic factors					
Child age range (12 – 25 years)	16.8 (3.3)				
Child gender (male)	265 (81.8)				
Median income range (\$34,029 – \$101,445)	\$66,235.0 (15,873.20)				
Maternal education range (1–8)	6.1 (1.4)				
Maternal immigrant (yes)	75 (23.1)				
Systemic factors					
Affordability of services (no)	101 (31.2)				
Barriers range $(0-11)$	3.2 (2.3)				
Clinical need factors					
ASD severity range (12 – 37)	23.1 (6.2)				
Psychiatric diagnosis (yes)	152 (46.9)				
Medical diagnosis (yes)	105 (32.4)				
Caregiver burden range (9 – 45)	27.8 (8.7)				

Table 3. Relative contributions of the predisposing, enabling, and clinical need predictors of self-efficacy

Variable	Model 1			Model 2			Model 3		
	В	SE B	В	В	SE B	ß	В	SE B	В
Constant	4.17	.31		4.51	.30		4.80	.32	
Child age	04**	.01	18	04***	.01	20	04***	.01	18
Child gender	02	.10	008	04	.10	02	.007	.09	.004
Maternal education	006	.03	01	03	.03	05	.002	.03	.004
Maternal immigrant	33**	.09	19	30**	.09	17	23**	.08	14
Median income	<001	<.001	04	<001	<.001	04	<001	<.001	01
Sum of barriers				09***	.02	27	07***	.02	21
Affordability				.16	.08	.10	.09	.08	.06
ASD severity							.01	.006	.11
Medical comorbidity							.10	.08	.07
Psychiatric comorbidity							09	.07	06
Caregiver burden							03***	.004	39
R^2	.08			.16			.30		
F	5.21***			8.69***			12.00***	k	

 $p^{**} < .01, p^{***} < .001$

Appendix A: Perceived Barriers to Service Access Items

- 1. The problem did not seem so serious
- 2. Want to handle problems ourselves
- 3. Problem was considered temporary
- 4. Negative experiences with professional help
- 5. Not knowing where to find help
- 6. Fear of being too big a burden
- 7. Too busy / other priorities
- 8. The steps to seek help are too overwhelming
- 9. Having difficulties in describing the problems and needs
- 10. Other people did not want the family to seek help
- 11. No trust in professional help
- 12. Fear of labeling / stigma
- 13. Distance too far to get help