RUNNING HEAD: SERVICE USE OF GIRLS AND WOMEN WITH ASD

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Identifying the Clinical Needs and Patterns of Health Service Use of Adolescent Girls and Women with Autism Spectrum Disorder

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Lay Abstract

Girls and women in the general population present with a distinct profile of clinical needs and use more health services compared to boys and men, but we know very little about the service use patterns of girls and women with Autism Spectrum Disorder (ASD). The purpose of this study was to describe the clinical needs and health service use patterns of adolescent girls and women with ASD and explore differences with boys and men with ASD. Caregivers of 61 adolescent girls and women with ASD and 223 boys and men completed an online survey. Many adolescent girls and women with ASD had co-occurring mental and physical conditions and their parents reported high levels of caregiver strain. Both males and females were reported to frequently use multiple services, particularly those with intellectual disability. Overall, few differences were found between males and females, although a significantly greater proportion of girls and women used psychiatry and emergency department services as compared to boys and men. Though the current study is limited by its use of parent report and small sample size, it suggests that girls and women with ASD may share many of the same high clinical needs and patterns of services use as boys and men with ASD.

Scientific Abstract

Girls and women in the general population present with a distinct profile of clinical needs and use more associated health services compared to boys and men; however, research focused on health service use patterns among girls and women with Autism Spectrum Disorder (ASD) is limited. In the current study, caregivers of 61 adolescent girls and women with ASD and 223 boys and men with ASD completed an online survey. Descriptive analyses were conducted to better understand the clinical needs and associated service use patterns of girls and women with ASD. Sex/gender comparisons were made of individuals' clinical needs and service use. Adolescent girls and women with ASD had prevalent co-occurring mental and physical conditions and parents reported elevated levels of caregiver strain. Multiple service use was common across age groups, particularly among adolescent girls and women with intellectual disability. Overall, few sex/gender differences emerged, although a significantly greater proportion of girls and women accessed psychiatry and emergency department services as compared to boys and men. Though the current study is limited by its use of parent report and small sample size, it suggests that girls and women with ASD may share many of the same high clinical needs and patterns of services use as boys and men with ASD. Areas for future research are discussed to help ensure appropriate support is provided to this understudied population.

Keywords: Autism Spectrum Disorder; Gender/female ASD; sex differences; adult; adolescent; service use

Identifying the Clinical Needs and Patterns of Health Service Use of Adolescent Girls and Women with Autism Spectrum Disorder

Introduction

Individuals with Autism Spectrum Disorder (ASD) often have complex care needs necessitating a wide range of services across the lifespan (Cidav, Lawer, Marcus, & Mandell, 2013; Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016). While girls and women in the general population present with a distinct profile of clinical needs and use more associated health services compared to boys and men (Garland et al., 2005; Ladwig, Marten-Mittag, Formanek, & Dammann, 2000; Rhodes, Goering, To & Williams, 2002), sex/gender[1] specific service experiences among individuals with ASD remain largely unknown. ASD has historically been diagnosed more commonly in males than in females (Fombonne, 2003; Whiteley et al., 2010), and women are disproportionately underrepresented in the ASD literature (Thompson, Caruso, & Ellerbeck, 2003; Watkins, Zimmerman, & Poling, 2014). Research focused on sex/gender specific health service use is especially limited. The current study sought to identify patterns of clinical needs and health service use among a sample of adolescent girls and women with ASD. This information is an important first step to ensure service provision appropriately meets the needs of this understudied population.

On average, women in the general population make greater use of health services than men (Green & Pope, 1999). For instance, women are consistently shown to consult

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[1] We use the term "sex/gender" to acknowledge the intersection of sex specific biological and physiological characteristics with gendered socialization processes (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015; Springer, Stellman, & Jordan-Yong, 2012).

their family physicians more frequently and to use more outpatient mental health services compared to men (Ladwig et al., 2000; Rhodes et al., 2002). There is no evidence to date of differential patterns of service use among girls and women with ASD (e.g., Bromley et al., 2004; Ruble & McGrew, 2007; Shattuck et al., 2011; Zablotsky et al., 2015); however, true sex/gender differences are difficult to discern. Many studies include only small subsamples of girls and women and lack the statistical power to detect small effects, resulting in null findings that are difficult to interpret.

Aside from sex/gender, there are several individual and family clinical need variables associated with service use among individuals with ASD. In predominantly male samples, youth with intellectual disability (ID), more severe ASD symptomology, and/or co-occurring psychiatric or medical conditions, are reported to use more health services (Bromley et al., 2004; Green et al., 2006; Taylor & Henninger, 2015; White, Scahill, Klin, Koenig & Volkmar, 2007; Zablotsky et al., 2015), as do youth whose parents report greater stress (Thomas, Morrissey, & McLaurin, 2007). Overall, less research has focused on correlates of adult service use, though adults with ASD and ID have been shown to use more services than those without ID (Shattuck et al., 2011).

An increasing number of studies highlight the possibility of an altered profile of clinical needs among girls and women with ASD (Kirkovski, Enticott & Fitzgerald, 2013; Van Wijngaarden-Cremers et al., 2014), which may carry sex/gender specific service related implications. Girls who receive an ASD diagnosis have, on average, lower cognitive abilities than boys with ASD (Frazier, Georgiades, Bishop, & Hardan, 2014), although girls with higher IQs may be less frequently diagnosed with ASD (Lai et al., 2011). Among those without ID, girls with ASD may have fewer stereotyped and repetitive behaviors and may exhibit restricted interests that follow social or gender norms more than boys (Van Wijngaarden-Cremers et al., 2014). Girls and women with ASD may also experience higher rates of certain mental and physical health problems than males with ASD (e.g., internalizing problems, sleep problems; Croen et al., 2015; Holtmann, Bolte, & Poutska, 2007; Maddox, Trubanova, & White, 2017). Less is known with respect to the needs of families of girls and women with ASD; however, parents of daughters with ASD and/or ID have reported less anger in addition to closer parent-child relationships when compared to parents of sons with ASD (Gray & Holden, 1992; Lounds, Seltzer, Greenberg & Shattuck, 2007).

This study attempted to address current gaps in the literature by exploring the service experiences of adolescent girls (12-17 years old) and women (18 years and older) with ASD. These age groups were chosen in accordance with the eligibility criteria associated with the different service sectors in Ontario, Canada, which separate child (<18 years) from adult (18+) service provision. Our two aims were to: (1) describe patterns of clinical needs and service use among adolescent girls and women with ASD and (2) compare the experiences of girls and women to age matched groups of boys and men.

Methods

Participants

This study is part of a larger project examining service use in individuals with ASD. The larger sample included 462 parents of adolescents and adults with ASD from across Ontario, Canada. Participants provided baseline information at the first time point and then completed six bimonthly surveys concerning service use over the preceding two months, for a possible total of seven surveys. Inclusion criteria for the current study were met if parents reported their children: (a) were over the age of 11 and (b) received a formal ASD diagnosis, which was verified by meeting a cutoff score of 12 or more on the *Social Communication Questionnaire* (SCQ; Rutter, Bailey & Lord, 2003; $N = 396$) as has been used by other survey-based research involving parent report (Zablotsky et al., 2013). Additionally, data were only retained for the current study if participants completed the final follow up survey, and the time between participants' completed baseline and final survey was no more than 18 months ($N = 284$). There were no significant differences between the current study's subsample ($n = 284$) and those who did not complete the requisite number of surveys in the designated time period ($n = 112$) with respect to most child and parent demographics (child age, child sex/gender, child place of residence, parent age, parent marital status, parent education, neighborhood income), clinical needs (child ASD severity, child ID status, child medical and psychiatric diagnoses, caregiver strain; all p's > .05). However, a significantly greater proportion of non-responders (26.6%) identified as non white/non-Caucasian as compared to those who met study inclusion criteria (17.0%), $\chi^2(2) = 4.57$, $p = .03$, $V = .11$, 95% CI [.00, .21]. On average, the 284 participants in the current study completed a total of 4.33 follow up surveys ($SD = 1.41$) over 14.53 months ($SD = 1.50$). There were no significant sex/gender differences in the mean number of completed surveys or completion time (both p's >.05).

Parent respondents (93.7% female) were 31 to 79 years of age ($M = 49.5$ years, $SD = 7.4$) and the majority ($n = 217$; 76.4%) reported being married or living with a partner. The forward sortation index (first three digits) of participants' postal codes was used to find the median neighbourhood income from the Canadian Census (Statistics Canada, 2006); median neighbourhood incomes ranged from CAN $33,030 to CAN $107,742. Most parents identified as Caucasian (*n* = 234; 82.4%) and completed a college or university degree (*n* = 211; 74.3%). Individuals with ASD (61 female and 223 male) were 12 to 56 years of age (*M* = 18.41 years, *SD* = 6.16) and most (*n* = 259; 91.2%) lived with their families. Approximately 55% (*n* = 157) of individuals with ASD were 12-17 years old, and nearly 45% (*n* = 127) were 18 years or older at time of baseline survey completion. Males and females with ASD in both age groups did not differ with respect to individual or parent respondent demographics, with the exception of parent age for the younger age group (see Table 1). Parents of adolescent girls (*M* = 48.39 years, *SD* = 5.99) were significantly older than parents of adolescent boys (*M* = 45.43 years; *SD* = 5.24), *t*(148)=-2.72, *p* =. 01, *d* = .53, 95% CI [.20, .85].

Insert Table 1

Procedure

Participants were recruited from postings on provincial ASD support organizations' websites and through email lists associated with these organizations. All participants were given the option of completing surveys via mail, telephone interview or online. The majority of participants (*n* = 223; 78.5%) completed online surveys. Parents who completed the surveys online (*M* = 48.67years, *SD* = 6.88) were significantly younger than parents who completed the surveys via mail or telephone interview (*M*= 52.36 years, *SD* = 8.44), *t*(270)=-3.50, *p* = .001, *d* = .48, 95% CI [.24, .72); no other parent or child demographic variables differed according to survey response method. The university and hospital research ethics boards approved this research.

Measures

Clinical needs.

ASD symptom severity. ASD symptom severity was measured by the SCQ (Rutter et al., 2003). The SCQ is a 40-item questionnaire used to assess an individual's developmental history, providing subscales on the severity of communication impairments, social interaction impairments, and restricted, repetitive, or stereotyped patterns of behaviour. For each item, respondents are asked to check either "*yes*" or "*no*" as to whether the specified behaviour is/was demonstrated by the individual in question. The SCQ has been shown to have good discriminant validity (Witwer & Lecavalier, 2007), convergent validity with the *Autism Diagnostic Interview–Revised* (Howlin & Karpf, 2004) and internal consistency (Cronbach's α = 0.81–0.93; Naglieri & Chambers, 2009). In the current study, internal consistency for the overall scale was strong (Cronbach's α = .81). SCQ scores of the sample ranged from 12 to 37 (*M* = 22.60, *SD* = 6.26).

ID status. 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*. ID status was recoded into those with and without ID. Approximately 47% of the sample had ID.

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 and those that did not. Almost half (46.5%) of the sample had at least one associated psychiatric condition and 34.5% had at least one associated medical condition. Many large-scale surveys use dichotomous parent report of psychiatric and medical conditions (Gurney, McPheeters & Davis, 2006; Montes & Halterman, 2007).

Caregiver strain. Subjective feelings of caregiver strain were measured using the 9-item strain subscale of the *Revised Caregiver Appraisal Scale* (Lawton et al., 2000). Items measure parents' perception of the negative impact caregiving has had on their health, wellbeing, 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 strain. Previous studies involving parents of adolescents and adults with developmental disabilities reported good internal consistency (Cronbach's α = 0.87-0.89; Pruchno & McMullen, 2004; Robinson, Weiss, Lunsky & Ouellette-Kuntz, 2016), and the current study showed similar reliability (Cronbach's α = .92). In the current study, caregiver strain scores ranged from 9 to 45, with 50.0% of participants reporting high strain according to published cut-off scores (score >27; Pruchno & McMullen, 2004).

Service use. Participants were asked to report on the services they used throughout the study period at each time point from a list of twelve health and allied health services: family physician; neurology; psychiatry, psychologist, counseling (i.e., individual counseling, group counseling or family counseling); behavioral therapy; occupational therapy; case management; respite; speech-language therapy; physiotherapy; emergency department services. Totals of how many participants used each service at least once within the study period were calculated, in addition to the number of different types of services each participant accessed. Participants used between zero and 12 different services across the study period, with a median of five services (*M* = 4.76, *SD* = 2.44). The three services most likely to be accessed were: family physician (87.3%); respite (63.4%); and case management (48.6%).

Data Analysis

We first provide descriptive analyses of clinical needs and service use of adolescent girls and women with ASD. Secondly, independent *t*-tests and chi-square analyses were conducted to better understand associations between clinical need factors and service utilization among adolescent girls and women. Finally, we examined sex/gender differences by age group with respect to clinical needs and individual and total service use using the above stated bivariate analyses. Adjustments for multiple comparisons were not used in an attempt to maintain the power of our analyses and to avoid type II errors (Perneger, 1998). We aimed to minimise the risk of making inferences based on type I errors, and to maintain transparency about the size and significance of our findings, by presenting precise *p*-values and effect sizes. Effect sizes were calculated with Cohen's *d* when comparing parametric group differences and Cramer's *V* when comparing categorical data (Fritz, Morris, & Richler, 2012). Confidence intervals (95%) are presented for effect size measures.

Results

Clinical Needs

The clinical needs of adolescents and adults with ASD are presented in Table 2. Over half of adolescent girls and women had ID (51.7% and 58.3%, respectively). Approximately 40% of adolescent girls reported at least one comorbid psychiatric diagnosis, with slightly fewer (36.4%) reporting at least one comorbid medical diagnosis. Similarly, the majority of women (60.7%) reported at least one comorbid psychiatric diagnosis and 42.9% reported at least one medical diagnosis. A large proportion of parents of adolescent girls (54.5%) and parents of women (71.4%) reported high levels of caregiver strain.

There were no significant sex/gender differences among adolescents with respect to clinical need variables (all *p*'s > .05). Similarly, there were no significant sex/gender differences among adults with respect to clinical need variables (all *p*'s > .05), with the exception of caregiver strain. Parents of adult women reported greater caregiver strain (*M* = 32.78, *SD* = 7.30) as compared to parents of adult males (*M* = 27.88, *SD* = 9.46), *t*(123)= -2.49, *p* =. 01, *d* = .58, 95% CI [.22, .94].

Insert Table 2

Service Utilization

Adolescent girls used between zero and 11 services at least once during the study period, with a median of six services (*M* = 5.94 services, *SD* = 2.44). Women used between zero and 10 services at least once during the study period with a median of 5.5 services (*M*= 5.11; *SD* = 2.35). Clinical need variables were unrelated to the total number of services use among adolescent girls (all *p*'s>.05); however, women with ID were reported to use significantly more types of services (*M* = 6.07, *SD* = 2.27) compared to women without ID (*M* = 4.10, *SD* = 2.33), *t*(22) = 2.08, *p* =.05, *d* = -.86, 95% CI [-1.69, -.02]. Table 3 presents the percentages of individuals who used each service at least once.

A family physician was the service most likely to be used for both adolescent girls (87.9%) and women (85.7%). Among adolescent girls, this was followed by respite (72.7%) and counseling services (66.7%); for women, respite (67.9%) and psychiatry (64.3%) were the second and third most frequently accessed services.

Concerning sex/gender differences, adolescent girls used a significantly wider range of services (*M* = 5.94, *SD* = 2.44) as compared to boys (*M* = 4.60, *SD* = 2.29), *t*(155) = 2.95 , *p* = .004, *d* = .57, 95% CI [.25, .88]; however, there was no significant sex/gender difference in the total types of services used by adults, *p* = .24. As shown in Table 3, a significantly greater proportion of girls and women accessed psychiatry and emergency department services as compared to boys and men, with small effect sizes (.17 -. 22).

Insert Table 3

Discussion

The purpose of this study was to describe the clinical need and service experiences of adolescent girls and women with ASD. Similar to studies with predominantly young male samples (e.g., Green et al., 2006; Thomas et al., 2007), adolescent girls and women with ASD had prevalent co-occurring mental and physical comorbid conditions and elevated levels of negative caregiver strain. Use of multiple services was common across age groups, particularly among adolescent girls and women with ID. Overall, few sex/gender differences emerged, although significant differences were found with respect to psychiatry and emergency department services. There is increasing interest related to the female profile of ASD (Beggiato et al., 2016; Lai et al., 2015) and results from the current exploratory study highlight important areas for future health service research.

Women and girls with ASD in the current sample demonstrated equally high individual clinical needs as their male counterparts. Of note, approximately 40% of adolescent girls and 61% of women were reported to have at least one comorbid psychiatric diagnosis. These rates are similar to, if not slightly lower than, past research involving mixed sex/gender samples (Buck et al., 2014; Simonoff et al., 2008) and indicate that mental health is clearly a significant area of concern for women and girls with ASD. No significant sex/gender differences were found in the current study with respect to ID status, ASD symptom severity or the presence of comorbid psychiatric and medical diagnoses. Our convenience sample, however, was not intended to be representative and was limited in size.

The majority of parents of girls and women reported clinically elevated levels of negative caregiver strain, with parents of adult daughters reporting significantly higher levels than parents of adult sons. While research focused on parents of adults with ASD is limited, Lounds et al. (2007) conversely found indicators of parental mental health and ratings of positive parent-child relationships to be higher in mothers of adult daughters as compared to sons. These findings were attributed, in part, to normative patterns of parent–child relationships, whereby mothers and daughters report closer relationships than mothers and sons during adulthood (Ryff & Seltzer, 1996). In the current study, we did not examine quality of the parent-child relationship per se, but rather the negative strain of caregiving, which may differ from positive associations. More recent qualitative research (Cridland, Jones, Caputi, & Magee, 2014) highlighted unique caregiving concerns of mothers of adolescent girls with ASD, particularly with respect to the stress associated with their daughters' sexual vulnerabilities and while comparing their own social experiences during adolescence to those of their daughters. Caring for a child with ASD can bring exceptional challenges, which persist across the life course (Lounds et al., 2007). Future research specific to the experiences of parents of women with ASD is needed to clarify the current findings, which, if replicated, may have important implications for caregiver supports.

In terms of service use, adolescent girls accessed a median of six different types of services at least once across the study period, and a significantly wider range of services than adolescent boys. Similar sex/gender differences have been noted in the general population and adolescence is identified as a turning point for males' underutilization of services (Marcell, Klein, Fischer, Allan, & Kokotailo, 2008; Vingilis, Wade & Seeley, 2007). Reproductive care needs among girls and women (e.g., with respect to menarche and contraception) are frequently thought to contribute to sex/gender service use invariances, however, past research in the general population found significant differences exist even after controlling for these care needs (MacIntrye, Hunt & Sweeting, 1996; Nathanson, 1977), and no significant differences were evident in the likelihood of family physician visits in the current study. Sex/gender differences in individual, familial and societal health beliefs, symptom perception, and prevention orientation may influence an adolescent's use of health services (Marcell et al., 2008). Given the lack of significant differences in clinical need variables among male and female adolescents in the current study, future research is needed to examine how similar psychosocial factors may influence sex/gender specific trends of service use in adolescents with ASD.

In contrast, no comparable sex/gender differences emerged in the overall number of services used among adult women and men with ASD. Similar to past research with a predominantly male sample (Shattuck et al. 2011), women with ASD and ID accessed a greater range of services than women with ASD without ID, which may be due to narrower eligibility criteria in the adult service sector for individuals without ID. Improving access to health services for individuals with ASD without ID is acknowledged to be an important priority with many providers reporting insufficient training (Lake, Perry, & Lunsky, 2014; Nicolaidis et al., 2013).

Speaking to the high mental health needs of adolescent girls and women with ASD, mental health counseling was in the top three services used among females in both age groups. Further, a larger proportion of adolescent girls and women accessed psychiatry services as compared to boys and men. While similar female dominant mental health service trends are seen in the general population (Rhodes et al., 2002), girls with ASD may encounter unique mental health concerns in adolescence related to increasing sex/gender specific social demands and societal norms (Cridland et al., 2014; Tierney, Burns, & Kilbey, 2016). Despite their frequent use of mental health services, women with intellectual/developmental disabilities are often excluded from the larger field of women's mental health research (Taggart, McMillan, & Lawson, 2008), and in the limited treatment research on ASD and mental health, sex/gender differences are rarely examined directly (Thompson et al., 2003;Watkins et al., 2014). Recently, girls and women with ASD have qualitatively described mental health problems associated with compensating for or masking their ASD-related social communication difficulties and health care professionals' perceived dismissal or disbelief of their concerns due to their unique presentations (Bargiela, Steward, & Mandy, 2016; Tierney et al., 2016). Given the possibility of sex/gender specific presentation of mental health problems, and responses to pharmacological agents and therapeutic interventions in adults with ASD and other developmental disabilities (Vigod et al., 2016), further research is needed to fully understand the mental health service needs and experiences of girls and women with ASD.

Girls and women were also more likely to visit emergency departments than boys and men, a pattern that replicates research within ASD, the broader intellectual/developmental disability population, as well as adults without these disabilities (Liu, Pearl, Kong, Leslie & Murray, 2016; Lunsky, Klein-Geltink & Yates, 2013). Emergency department visits can be extremely stressful for individuals with ASD and their families (Nicholas et al., 2016). Future research is required to examine factors associated with the increased proportion of females with ASD using emergency department services, with specific attention as to whether these visits are related to gaps in other community-based services.

This study has several limitations. Our sample was small, precluding the ability to adjust for potential Type I error as the risk of Type II error was high. The sex/gender effects that did emerge as significant had only small effect sizes. Further, participants in the current study were parent respondents who largely identified as Caucasian with high levels of education. As such, our results may not generalize to individuals of different backgrounds. According to parent report, approximately 47% of our sample had ID, which is a higher proportion than indicated in the most recent CDC (2014) report. It is important to study clinical needs and associated service use in individuals with ASD across a range of abilities and directly from the perspectives of affected individuals. Additionally, we do not have objective measures of ASD diagnoses, ID or medical and psychiatric comorbid diagnoses. Further, we looked at only the presence or absence of a medical or psychiatric diagnosis, and service experiences may be more related to ratings of severity or clinical significance of such comorbid conditions. With respect to service use patterns, although collected at regular time points to reduce error, our data were reliant on parents' retrospective reports. Future research would benefit from the inclusion of health service records.

Conclusions

The current study suggests that girls and women with ASD may share many of the same high clinical needs and patterns of services use as boys and men with ASD; however, specific sex/gender differences were also highlighted. In particular, mental health services are clearly an area of significant need for this population and the increased use of psychiatry and emergency department services is concerning. As more information regarding potential sex/gender differences in ASD clinical presentation emerges, it is important for future research to continue to clarify the health service experiences of girls and women with ASD to ensure the provision of appropriate support.

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Table 1. *Participant Demographics*

	12-17 years *M*(*SD*) or *N*(%)		
	Male (n = 124)	Female (n = 33)	
Individual with ASD			
Age	14.63(1.71)	14.82(1.72)	t(155) = -.56, p = .57, d = -.11, 95% CI [-.20,.42]
Residence (% with family)†	121(97.6)	33(100)	p = 1.00, V = .07, 95% CI [.00,.23]
Parent			
Age	45.43(5.24)	48.39(5.99)	t(148)=-2.72, p =. 01, d = .53, 95% CI [.20, .85]*
Marital status (% married)	98(79.0)	26(78.8)	χ^2 (2) = .001, p = .98, V = .00
Ethnicity (% Caucasian)†	97(79.5)	27(81.8)	χ^2 (2) = .09, p = .78, V = .02, 95% CI [.00, .17]
Education (% college diploma or higher)†	94(75.8)	22(68.8)	χ^2 (2) = .66, p = .42, V = .07, 95% CI [.00, .22]
Neighborhood income	$66,426.72 ($15,978.55)	$70,719.36 ($15,624.04)	t(155)=-1.38, p =. 17, d = -.27, 95% CI [-.04, .59]

	18 + years *M*(*SD*) or *N*(%)		
	Male (n = 99)	Female (n = 28)	
Individual with ASD			
Age	22.80(6.59)	23.89(6.36)	t(125)=-.78, p = .44, d = .17, 95% CI [-.18, .52]
Residence (% with family)	83(83.8)	22(78.6)	χ^2 (2) = .42, p = .52, V = .06, 95% CI [.00, .23]
Parent			
Age	53.59(7.37)	54.35(6.78)	t(120) = -.47, p = .64, d = .11, 95% CI[-.25, .46]
Marital status (% married)	72(72.7)	21(75.0)	χ^2 (2) = .06, p = .81, V= .02, 95% CI [.00, .18]
Ethnicity (% Caucasian)†	84(84.8)	26(92.9)	p = .36, V = .10, 95% CI [.00, .27]
Education (% college diploma or higher)	71(72.4)	24(85.7)	χ^2 (2) = 2.07, p = .15, V = .13, 95% CI [.00, .30]
Neighborhood income	$67,216.20 ($15,668.46)	$62,781.18 ($12,848.39)	t(125) = 1.37, p =.17, d = - .31, 95% CI [-.67, .05]

†Fisher's exact test was used when cell $n < 5$; * $p \leq .01$

Table 2. *Clinical Needs*

	12-17 years *M*(*SD*) or *N*(%)		
	Male (*n* = 124)	Female (*n* = 33)	
ASD symptom severity	22.48(5.98)	23.39(5.78)	*t*(155)=-.78, *p* =. 44, *d* = .16, 95% CI [-.16, .47]
ID status (presence)	53(48.6)	15(51.7)	χ^2 (2) = .09, *p* = .77, *V* = .03, 95% CI [.00, .18]
Psychiatric diagnosis (presence)	51(41.1)	13(39.4)	χ^2 (2) = .03, *p* = .86, *V* = .01, 95% CI [.00, .15]
Medical diagnosis (presence)	36(29)	12(36.4)	χ^2 (2) = .66, *p* = .42, *V* = .07, 95% CI [.00, .22]
Caregiver strain	26.36(9.09)	27.91(7.99)	*t*(155)=-.89, *p* =. 38, *d* = .18, 95% CI [-.13, .46]
	18 + years *M*(*SD*) or *N*(%)		
	Male *(n* = 99)	Female *(n* = 28)	
ASD symptom severity	22.54(6.45)	22.39(7.53)	*t*(126)= .10, *p* =.92, *d* = -.02, 95% CI [-.37, .33]
ID status (presence)	50(54.9)	14(58.3)	χ^2 (2) = .09, *p* = .77, *V* = .03, 95% CI [.00, .20]
Psychiatric diagnosis (presence)	51(51.5)	17(60.7)	χ^2 (2) = .74, *p* = .39, *V* = .08, 95% CI [.00, .25]
Medical diagnosis (presence)	38(38.4)	12(42.9)	χ^2 (2) = .18, *p* = .67, *V* = .04, 95% CI [.00, -.21]
Caregiver strain	27.88(9.46)	32.78(7.30)	*t*(123)= -2.49, *p* =. 01, *d* =.58, 95% CI [.22, .94]*

* *p* ≤ .01

Table 3. *Service Use*

	12-17 years *N*(%)		
	Male (n = 124)	Female (n = 33)	
Family doctor †	110(88.7)	29(87.9)	$p = 1.00$, $V = .01$, 95% CI [.00, .14]
Neurology	18(14.5)	8(24.2)	$\chi^2(2) = 1.78$, $p = .18$, $V = .11$, 95% CI [.00, .26]
Psychiatry	36(29.0)	18(54.5)	$\chi^2(2) = 7.52$, $p = .01$, $V = .22$, 95% CI [.06, .38]**
Psychology	35(28.2)	13(39.4)	$\chi^2(2) = 1.53$, $p = .22$, $V = .10$, 95% CI [.00, .26]
Counseling	70(56.5)	22(66.7)	$\chi^2(2) = 1.12$, $p = .29$, $V = .09$, 95% CI [.00, 21]
Behavior therapy	53(42.7)	19(57.6)	$\chi^2(2) = 2.31$, $p = .13$, $V = .12$. 95% CI [.00, .28]
Occupational therapy	38(30.6)	13(39.4)	$\chi^2(2) = .91$, $p = .34$ $V = .08$, 95% CI [.00, .23]
Case management	53(42.7)	17(51.5)	$\chi^2(2) = .81$, $p = .37$, $V = .07$, 95% CI [.00, .23]
Respite	84(67.7)	24(72.7)	$\chi^2(2) = .30$, $p = .58$, $V = .04$, 95% CI [.00, .20]
Speech language therapy	32(25.8)	12(36.4)	$\chi^2(2) = 1.44$, $p = .23$, $V = .10$, 95% CI [.00, .25]
Physiotherapy	14(11.3)	8(24.2)	$\chi^2(2) = 3.63$, $p = .06$, $V = .15$, 95% CI [.00, .31]
Emergency department	27(21.8)	13(39.4)	$\chi^2(2) = 4.24$, $p = .04$ $V = .17$, 95% CI [.00, .32]*
	18 + years *N*(%)		
	Male *(n* = 99)	Female *(n* = 28)	
Family doctor †	85(85.9)	24(85.7)	$p = .1.00$, $V = .00$
Neurology†	20(20.2)	3(10.7)	$p = .40$, $V = .10$, 95% CI [.00, .28]
Psychiatry	41(41.4)	18(64.3)	$\chi^2(2) = 4.59$, $p = .03$, $V = .19$, 95% CI [.00, .36]*
Psychology	21(21.2)	10(35.7)	$\chi^2(2) = 2.49$, $p = .12$, $V = .14$, 95% CI [.00, .31]
Counseling	52(52.5)	15(53.6)	$\chi^2(2) = .01$, $p = .92$, $V = .01$, 95% CI [.00, .13]
Behavior therapy	34(34.3)	12(42.9)	$\chi^2(2) = .69$, $p = .41$, $V = .07$, 95% CI [.00, .25]
Occupational therapy	29(29.3)	8(28.6)	$\chi^2(2) = .01$, $p = .94$, $V = .01$,95% CI [.00, .12]
Case management	55(55.6)	13(46.4)	$\chi^2(2) = .73$, $p = .39$, $V = .08$, 95% CI [.00 .25]
Respite	53(53.5)	19(67.9)	$\chi^2(2) = 1.82$, $p = .18$, $V = .12$, 95% CI [.00, .29]
Speech language therapy†	23(23.2)	4(14.3)	$p = .43$, $V = .09$, 95% CI [.00, .26]
Physiotherapy†	7(7.1)	4(14.3)	$p = .26$, $V = .11$, 95% CI [.00, .28]
Emergency department	23(23.2)	13(46.4)	$\chi^2(2) = 5.78$ $p = .02$, $V = .21$, 95% CI [.00, .39]*

† Fisher's exact test was used when cell $n < 5$; * p <.05; **$p \leq .01$