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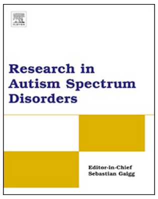

Predictors of health service use among adolescents and adults with autism and aggression

Melissa Paquette-Smith[a,b], Jonathan A. Weiss[c], Julie Dergal[b], Johanna Lake[b,c], Yona Lunsky[b,*]

[a] *Department of Psychology, University of California, Los Angeles, United States*
[b] *Azrieli Centre for Adult Neurodevelopmental Disabilities, Centre for Addiction and Mental Health, Canada*
[c] *Department of Psychology, York University, Canada*

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ABSTRACT

Background: Clinical guidelines recommend that psychosocial interventions be used before medication to manage aggressive behavior in individuals with autism. However, the extent to which a multidisciplinary approach is implemented and the factors that influence service use in this complex population are not well understood.
Methods: In this study, parents of 182 adolescents and adults with autism and a history of aggression were asked to report on their child's health service use every two months for a year. Individuals that used services in this time period (N = 158) were classified into three groups: users of psychotropic medication alone (n = 28, 17.7%); psychosocial services alone (n = 33, 20.9%); or users of both (n = 97, 61.4%).
Results: Although the majority of the sample (82.3%) received guideline recommended treatment (i.e., psychosocial services or a combination of psychosocial services and psychotropic medication), 17.7% were using psychotropic medication alone. Several enabling variables, including visiting a family physician in the two-months prior to baseline, having higher parental education, and having parents who reported being able to effectively access services predicted using psychosocial services alone or in combination with medication. Predisposing and need variables (i.e., being younger and having no psychiatric disorders) also predicted using psychosocial services compared to medication alone.
Conclusions: Understanding predictors of service use can help to identify and address barriers that may prevent adults with autism and aggression from accessing guideline recommended care.

1. Introduction

A number of pharmacological and psychosocial interventions exist to address aggressive behavior among individuals with autism (Fitzpatrick, Srivorakiat, Wink, Pedapti, & Erickson, 2016; Thyer & Pignotti, 2010). While there is a growing body of research on health service use in children with autism (including the use of medication and psychosocial services; Barrett et al., 2012; Boulet, Boyle, & Schieve, 2009; McLennan, Huculak, & Sheehan, 2008; Ruble, Heflinger, Renfrew, & Saunders, 2005; Siller, Reyes, Hotez, Hutman, & Sigman, 2014; Wang, Mandell, Lawer, Cidav, & Leslie, 2013), little is known about the services and supports to treat

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[*] Corresponding author at: Centre for Addiction and Mental Health, University of Toronto, 1001 Queen Street West, Toronto, Ontario, M6J1H4, Canada.

E-mail address: yona.lunsky@camh.ca (Y. Lunsky).

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aggression in older adolescents and adults. Although a multidisciplinary approach is often recommended, we do not know the extent to which families are able to access these services in practice.

Focusing on heath service use among individuals with autism and aggression is important for three reasons. First, aggression in autism is a common co-occurring concern. For example, large scale studies suggest that 53%–68% of children with autism demonstrate aggressive behavior (verbal and physical) toward others (Kanne & Mazurek, 2011; Mazurek, Kanne, & Wodka, 2013). Second, aggression is associated with psychiatric hospitalizations, emergency visits (Mandell, 2008), sleep problems (Goldman et al., 2011; Mayes & Calhoun, 2009; Mazurek & Petroski, 2015), family stress (Lecavalier, Leone, & Wiltz, 2006), and crisis-intervention referrals (Shoham-Vardi, Davidson, & Cain, 1996) in individuals with autism. Finally, aggression is associated with greater psychotropic medication use (Tsakanikos, Costello, Holt, Sturmey, & Bouras, 2007), which can lead to negative health outcomes like weight gain and metabolic disorders (see Posey, Stigler, Erickson, & McDougle, 2008; Stigler, Potenza, Posey, & McDougle, 2004 for a review). Given the prevalence of aggressive behavior and its association with poor clinical outcomes, it is important to study the types of services accessed by this population.

Best practice guidelines for the treatment of aggressive behavior in individuals with autism recommend that psychosocial interventions, including behaviorally-based psychosocial approaches, be used as the first method of treatment (NCCMH, 2013; NICE, 2012). These recommendations stem from a relatively large body of work suggesting that behavioral interventions (especially those that employ antecedent manipulations, changes in instructional context, reinforcement based strategies, and behavior reduction strategies) can effectively decrease or eliminate aggression (Brosnan & Healy, 2011). According to clinical guidelines, pharmacological interventions should be used as a secondary method of treatment, and only when psychosocial interventions demonstrate limited or no response, or when psychosocial interventions cannot be delivered due to the severity of the behavior (NCCMH, 2013; NICE, 2012). Even in cases where behavioral problems are severe, a combination of medication and behavioral approaches has been shown to be more effective than medication alone (Research Units on Pediatric Psychopharmacology Autism Network, 2009). Although medication can be effective in addressing symptoms of autism and reducing aggression (Posey et al., 2008; Shea et al., 2004), it does not target the *function* of the behavior (Bryson, Rogers, & Fombonne, 2003; Doyle & McDougle, 2012). Thus, guidelines recommend that medication be prescribed in conjunction with other non-pharmacologic approaches (e.g., psychological services, speech and language therapy, occupational therapy, and behavioral therapy); however the extent to which this occurs in practice is unknown.

1.1. Purpose and study objectives

Although both psychopharmacological and psychosocial therapies can be used to manage aggression, the variables that impact access to one treatment approach over another are not well understood. Much of the previous work on service use has focused on the types of services that children with autism receive (e.g., Goldstein, 2002; Green et al., 2006; McLennan et al., 2008; Rao, Beidel, & Murray, 2008; Rogers & Vismara, 2008). Less attention has been paid to the services used by older adolescents and adults with autism (Khanna, Jariwala, & West-Strum, 2013; Nicolaidis et al., 2013), who might be particularly vulnerable to service disparities. Indeed, caregivers tend to report declines in the availability and accessibility of specialized services as their children transition into adulthood (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Cheak-Zamora, Teti, & First, 2015). Further, no work has examined predictors of service use among adolescents and adults with autism and a history of aggression. Some studies have identified predictors of medication use (Esbensen, Greenberg, Seltzer, & Aman, 2009; Lake, Balogh, & Lunsky, 2012), however, no work has investigated which factors might predict families' decisions to use medication alone compared to psychosocial approaches or a combination of the two. Understanding what predicts service use is important for the planning, delivery, and funding of treatment and services for individuals with autism, and can lead to improved functional outcomes.

According to Andersen's Behavioral Model of Health Services Use (Andersen, 1995), a combination of predisposing, enabling and need predictors could account for why certain health services are accessed. In the case of adolescents and adults with autism and aggression, predisposing factors such as the child's age or intellectual disability status may influence the availability of services. For example, studies have shown that access to psychosocial services tends to decline as children transition into adulthood (Cheak-Zamora et al., 2015, 2013), whereas the use of psychopharmacological treatments tends to increase (Esbensen et al., 2009). Enabling variables, including parent education level, income and their ability to access services can also impact service use (Liptak et al., 2008; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Thomas, Morrissey, & McLaurin, 2007) and may influence whether families take a combined approach or use medication alone to manage aggression. For example, previous work suggests that families who are connected with a primary care physician have greater access to therapy and transition planning services and are more likely to receive guideline recommended care (Benevides, Carretta, & Lane, 2016; Cheak-Zamora & Farmer, 2015). Finally, clinical need variables, such as the severity of the presenting problem and the presence of psychiatric or medical comorbidities, may also influence what treatments are adopted. Indeed, parents of children with extensive clinical needs, including psychiatric comorbidities, report using more services than those without (Cidav, Lawer, Marcus, & Mandell, 2013).

The aim of this study was two-fold: First, we described the health service use of a sample of adolescents and adults with autism who had a history of aggression. Then, using Andersen's Behavioral Model of Health Services Use (Andersen, 1995) as the theoretical framework, we examined the predisposing, enabling and clinical need variables that predicted whether individuals were using psychotropic medication alone, psychosocial services alone (i.e., visits with a psychologist, behavior therapist, occupational or speech and language therapist), or a combination of psychotropic medication and psychosocial services.

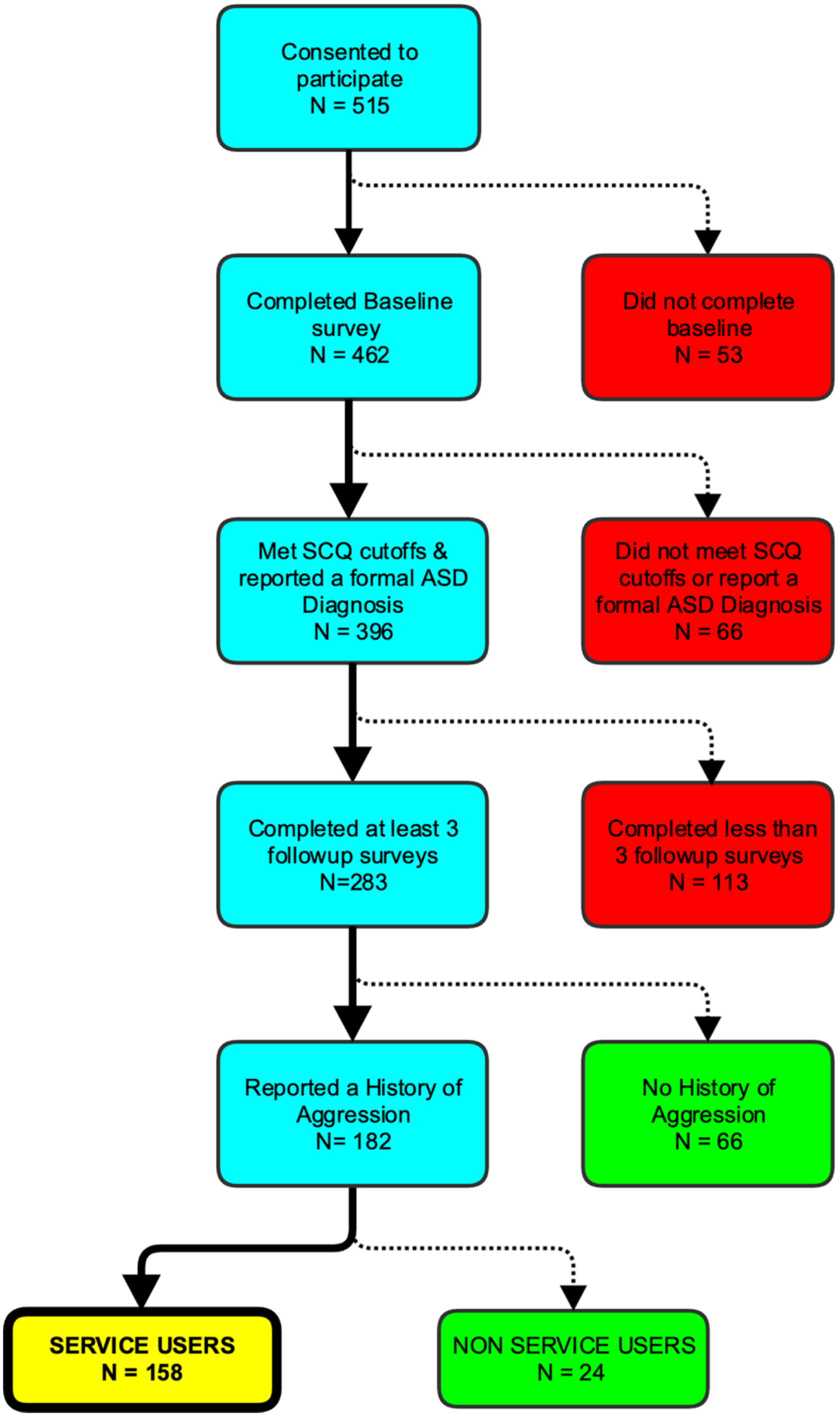

Fig. 1. Diagram of participants that were recruited and met study inclusion criteria.

2. Methods

2.1. Participants

Parents of individuals with autism were recruited from across Ontario, Canada, as part of a longitudinal survey on the heath service use of individuals with autism. Families were recruited from flyers and websites of collaborating community agencies that support individuals with autism (See Fig. 1). A total of 515 families consented to participate in the study and 462 completed the baseline survey. The baseline survey asked about demographic information, their child's current medical and psychiatric diagnoses, medication use and social service use. Parents were then contacted every two months for a one-year period to complete follow-up surveys on the medication and services their child used in the preceding two-months. This method of tracking service use over time, instead of asking families to reflect on a year's worth of services at a single time point, was employed to increase reporting accuracy and address the fact that the underreporting of services can increase over the sampling period (i.e., there is greater underreporting at 12 months compared to 2 months; Bhandari & Wagner, 2006). Most surveys were completed online (81.4%) and a small proportion were completed by mail (12.1%) or over the phone (6.5%). To be included in the present study, families had to meet the following criteria: 1) The child was 12 years of age or older and had a formal autism diagnosis, which was confirmed by meeting a cutoff score of 12 or more (Brooks & Benson, 2013) on the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003; N = 396); 2) The family completed at least three follow-up surveys in addition to the baseline survey (N = 283), to ensure that at least four time points, or eight months of service use, were captured (Range: 8–14 months; Median = 12 months); and 3) The child had a history of parent reported aggression and/or a history of hurting others at baseline (N = 182). Of the 182 individuals that met the above criteria, 158 (86.81%) reported using psychotropic medication, psychosocial services, or a combination of the two during the 8- to 14-month reporting period. The remaining 24 (13.19%) did not report using any of those services in the time period studied and thus were not included in the main analysis.

2.2. Measures

The following predisposing, enabling and need measures were used to explain service use patterns over the 8- to 14-month reporting period:

2.2.1. Predisposing factors

Predisposing (or demographic) variables such as the child's age, gender and intellectual disability status (ID) were collected as part of the baseline survey. Given that service access might decline as children transition out of the youth service system, child age was recoded into two groups, individuals over 18 and under 18. Parents also reported their child's intellectual disability (ID) status. ID status was recoded into children that had an ID (i.e., mild, moderate, severe or profound) and those that did not have an ID (i.e., borderline IQ, average or gifted). Data for parents who did not know their child's ID status were coded as missing.

2.2.2. Enabling factors

Participating parents were asked to report their highest level of education, which was dichotomized into two groups: parents with a lower level of education (i.e., less than a college diploma) and parents with a higher level of education (i.e., a college diploma or higher). The parent's median neighborhood income was computed based on the first three digits of their postal code (Statistics Canada, 2006). For family physician visits, parents were asked to report at baseline whether their child had seen a family physician (no/yes) in the last two months. Service accessibility was measured by parents' response on a five-point Likert scale (i.e., 1-disagree a lot to 5-agree a lot) to the following statement, "I am able to effectively access the services that my child needs." Responses were later dichotomized into those that had lower service efficacy (i.e., those that disagreed, disagreed a lot or were neutral about their ability to access services) and those that had high service efficacy (i.e., those that agreed or agreed a lot to the statement above).

2.2.3. Need factors

Parents were asked to list their child's current psychiatric diagnoses and responses were dichotomized into participants that reported a psychiatric disorder and those that did not. Parents also indicated whether their child had a history of psychiatric hospitalizations (no/yes).

2.3. Outcome variables – three user groups

Participants were classified into one of three user groups based on the psychotropic medication and social services they received during the baseline and reporting period.

2.3.1. Psychotropic medication users

Parents were asked to list all current medications their child was taking at baseline, and were asked to report on any medication changes every two months thereafter. Medications were then categorized according to their therapeutic class. An individual was classified as a psychotropic medication user if any of the following medications were used during the 8- to 14-month reporting period: antidepressants, anxiolytics, atypical and typical antipsychotics, stimulants, mood stabilizers, and antihypertensives. Antihypertensives such as clonidine and guanfacine were classified as psychotropic medications as they have psychoactive properties that have been used to treat symptoms of autism (Aman, Lam, & Bourgondien Van, 2005; Arnsten, Scahill, & Findling, 2007; Langworthy-Lam, Aman, & Bourgondien, 2002; Logan et al., 2012; Posey et al., 2008). Anticonvulsants were included in the mood stabilizer category if there was no reported seizure disorder (Esbensen et al., 2009; Lake et al., 2012; Spencer et al., 2013).

2.3.2. Psychosocial service users

Parents were asked to report on the services their child received at baseline and every two months during the 8-to 14-month reporting period. We acknowledge that it can be difficult to divide therapies across professional lines and there can be overlap in the types of therapies offered by different providers. For the purposes of this study, we included any providers that may be providing services that could reduce aggression under psychosocial services. Psychosocial services were broadly defined as visiting a psychologist, behavioral therapist, speech and language therapist, and/or occupational therapist. These services were chosen because they are commonly used psychosocial therapies among individuals with autism, and have been recommended to address aggression (NCCMH, 2013; NICE, 2012; Thomas et al., 2007). Given that many strategies designed to reduce aggressive behavior focus on improving the communication of needs, managing distress and improving functional behaviors (Fitzpatrick et al., 2016; Matson, Dixon, & Matson, 2005; NCCMH, 2013) we chose to include speech therapy and occupational therapy as psychosocial services. Even in cases where psychosocial services do not directly target aggression, interacting with a practitioner to develop new skills may have an additional benefit of reducing behavioral issues.

2.3.3. Users of both psychotropic medication and psychosocial services

Individuals were classified as users of both services if they used both psychotropic medication and any of the psychosocial services noted above during the 8-to 14-month reporting period.

2.4. Data analysis

Descriptive statistics, chi-square tests, and ANOVAs were used to compare the predisposing, enabling, and need factors between the three user groups: psychotropic users only, psychosocial service users only, and users of both psychotropic and psychosocial services. When differences at the $p < .10$ level were detected, post-hoc analyses were conducted to determine which of the 3 groups differed from one another. In order to examine the relative contribution of these factors in predicting service use patterns, all the predisposing, enabling and need variables that were significant at $p < .10$ were entered into a multinomial logistic regression. The multinomial odds of belonging to a particular user group was computed relative to the odds of belonging to the psychotropic only group. The psychotropic only group was selected as the reference category because it is the least recommended service outcome.

3. Results

Of the 182 adolescents and adults with autism and a history of aggression, the majority (n = 158, 86.81%) reported using psychotropic medication, psychosocial services, or a combination of the two during the reporting period. The 24 participants that received no services during the reporting period did not differ from those who received services in terms of their age ($X^2 = 0.04$, $p = .842$), gender ($X^2 = 0.92$, $p = .337$), or ID status ($X^2 = 0.36$, $p = .548$). However, non-users did differ from service users in that their parents were more educated, $X^2 = 4.20$, $p = .040$, they were less likely to visit their family physician in the two months prior to baseline, $X^2 = 6.75$, $p = .009$, and they were less likely to have a psychiatric diagnosis, $X^2 = 4.31$, $p = .038$. These 24 individuals were excluded from the predictive analyses.

Of the 158 adolescents and adults who used some service, more than half used a combination of psychosocial services and psychotropic medication (61.4%; $n = 97$). The remaining participants used either psychosocial services only (20.9%; $n = 33$), or psychotropic medication alone (17.7%; $n = 28$). In terms of the types of services that psychosocial service users accessed, 57.2% used behavior therapy, 34.2% speech therapy, 37.5% occupational therapy and 34.2% accessed services from a psychologist at least once over the course of the study period.

3.1. Predisposing factors

As shown in Table 1, there was a significant association between child age and the type of services used. Psychotropic only users and users of both were more likely to be over the age of 18 (64.3% and 44.3% respectively) compared to those using psychosocial services alone (24.2%). There were no significant differences between user groups in terms of gender or ID status.

3.2. Enabling factors

There were significant differences between the groups with respect to parents' perceived ability to access services (see Table 1). Individuals in the psychotropic only group were less likely to have parents that reported being able to effectively access services (17.9%) compared to those using psychosocial services only (51.5%) and those using both (59.4%). There was a trend indicating that belonging to a particular service user group was associated with seeing a family physician in the 2 months prior to baseline (at $p = .063$), and, post hoc tests suggested that psychotropic users were significantly less likely to have seen their family physician in the two months prior to baseline compared to psychosocial service users and users of both (46.4% versus 72.7% and 68.0%, respectively). There were no differences between the groups in terms of their median neighborhood income. There was a trending association between service user group membership and parental education ($p = .077$); post hoc tests indicated that users of psychosocial services alone had significantly higher levels of parental education (87.9%) than those who used a combination of psychotropic and psychosocial services (68.0%).

3.3. Need factors

Psychotropic only users and users of both psychotropic and psychosocial services were more likely to have a diagnosed psychiatric

Table 1

A Comparison of the Characteristics of Adolescents and Adults with Autism and a history of Aggression Across Service User Groups (N = 158).

	Users of Psychotropic Medications Only (N = 28) N (%)	**Users of Psychosocial Services Only (Psychologist/BT/OT/ Speech) (N = 33) N (%)**	**Users of Both Psychotropic Medications and Psychosocial Services (N = 97) N (%)**	X^2	*p*
Predisposing Factors					
Child Age					
12-17	10 (35.7)	25 (75.8)+ + +	54 (55.7)	9.92	.007**
18+	18 (64.3)+	8 (24.2)	43 (44.3)		
Child Gender					
Male	25 (89.3)	24 (72.7)	76 (78.4)	2.60	.272
Female	3 (10.7)	9 (27.3)	21 (21.6)		
Intellectual Disability[b]					
No	15 (60.0)	9 (33.3)	36 (41.4)	4.07	.131
Yes	10(40.0)	18 (66.7)	51 (58.6)		
Enabling Factors					
Parent Education					
Low (< college diploma)	9 (32.1)	4 (12.1)	31 (32.0)	5.14	.077†
High (≥college diploma)	19 (67.9)	29 (87.9) + + +	66 (68.0)		
Neighborhood Income[a]	68,532.6 (17,666.5)	65,734.1 (14,158.8)	67,384.8 (16,294.9)	0.24	.789
Family Physician Visit prior to baseline					
No	15 (53.6)+; + +	9 (27.3)	31 (32.0)	5.52	.063†
Yes	13 (46.4)	24 (72.7)	66 (68.0)		
Effectively Access Services[c]					
No	23 (82.1)+; + +	16 (48.5)	39 (40.6)	14.97	.001**
Yes	5 (17.9)	17 (51.5)	57 (59.4)		
Need Factors					
Psychiatric Disorder					
No	10 (35.7)	25 (75.8) + + +	41 (42.3)	13.15	.001**
Yes	18 (64.3)+	8 (24.2)	56 (57.7)		
History of Psychiatric Hospitalizations					
No	23 (82.1)	30 (90.9)	77 (79.4)	2.24	.326
Yes	5 (17.9)	3 (9.1)	20 (20.6)		

†$p < .1$, *$p < .05$, **$p < .01$.

For post-hoc tests: + Denotes significant ($p < .05$) differences between users of psychotropic medications only and users of psychosocial services only; + + denotes significant differences between users of psychotropic medications only and users of both; and + + + denotes significant differences between users of psychosocial services only and users of both psychotropic medications and psychosocial services.

[a] Continuous variable; mean and standard deviation are reported instead of an N(%), F reported instead of Chi-square.

[b] N = 139.

[c] N = 157.

disorder compared to those using psychosocial services alone (64.3% and 57.7% versus 24.2%). Overall, fewer than 20% of service users had a history of psychiatric hospitalizations, and no differences were noted between groups.

3.4. Predictors of service use

Bivariate predisposing, enabling and need predictors ($p < .10$) were entered together in a multinomial logistic regression predicting membership in one of the three user groups (see Table 2). Given guideline recommendations that psychotropic medication be used as a last resort and in combination with psychosocial services, “users of psychotropic medications only” (the least recommended service outcome) was coded as the reference group. Thus, odds ratios represent the odds that someone will use one of the guideline recommended treatments (i.e., psychosocial treatment or a combination of medication and psychosocial) instead of using psychotropic medication alone. The overall model was significant, -2 Log likelihood = 108.05, $\chi^2 = 50.67$, df = 10, $p < .001$, and accounted for approximately 32.6% of the variance in user group membership (Nagelkerke R Square = 0.326). There was a significant main effect for each of the five variables (meaning that all five variables contributed significantly to the model).

Most of the predictors of receiving guideline recommended treatment (i.e., psychosocial services or a combination of psychosocial and psychotropic services) were enabling variables. For example, individuals who visited their family physician in the two-months prior to baseline, were more likely to use guideline recommended treatment options (i.e., psychosocial $b = 1.48$, Wald χ^2 (1) = 5.75, $p = .016$ or both $b = 1.15$, Wald χ^2 (1) = 5.60, $p = .018$). Similarly, parents that reported being able to effectively access services also predicted using psychosocial services ($b = 1.48$, Wald χ^2 (1) = 4.89, $p = .027$) or a combination of psychosocial services and psychotropic medication ($b = 2.02$, Wald χ^2 (1) = 12.88, $p < .001$). Parents with higher education, $b = 1.53$, Wald χ^2 (1) = 4.42, $p = .036$ were more likely to use psychosocial services alone compared to psychotropic medication alone. Predisposing factors, such as being under the age of 18, also increased the likelihood that an individual would use psychosocial services alone compared to psychotropic medication alone, $b = 1.70$, Wald χ^2 (1) = 7.49, $p = .006$. Individuals with lower clinical needs, namely those without a diagnosed psychiatric disorder, were more likely to use psychosocial services alone, $b = 1.69$, Wald χ^2 (1) = 7.50, $p = .006$.

Table 2

A Multinomial Logistic Regression of Predisposing, Enabling and Need Factors Related to Service Use (N = 157).

	Users of Psychotropic Medications Only [reference group]	Users of Psychosocial Services Only (Psychologist/BT/OT/Speech) Odds Ratio+ [95% CI]	Users of Both Psychotropic Medications and Psychosocial Services Odds Ratio+ [95% CI]
Predisposing			
Younger Child Age (12-17 years)	ref	5.45** [1.62 to 18.35]	2.16 [0.83 to 5.62]
Enabling			
High Parental EducationServices	ref	4.62* [1.12 to 19.21]	1.23 [0.45 to 3.35]
Visited family physician in the 2-months prior to baseline	ref	4.38* [1.31 to 14.62]	3.14* [1.22 to 8.12]
Able to Effectively Access	ref	4.38* [1.18 to 16.19]	7.52** [2.50 to 22.65]
Need			
No Psychiatric Disorder	ref	5.40** [1.61 to 18.03]	1.16 [0.44 to 3.02]

$^{\dagger}p < .1$, $^{*}p < .05$, $^{**}p < .01$.

+Odds ratios compare each service user group to individuals that use psychotropic medications only (reference category).

4. Discussion

This study examined the service utilization patterns of adolescents and adults with autism and aggression. Consistent with previous work (Kanne & Mazurek, 2011; Matson & Rivet, 2008), our study found that a history of aggression was common among adolescents and adults with autism, which was exhibited by nearly two-thirds of our sample. Approximately 61% of this group used both psychotropic medication and psychosocial services, with the others remaining split evenly between using psychosocial services alone and psychotropic medication alone. Adolescents and adults with autism and a history of aggression were more likely to receive guideline recommended care (i.e., psychosocial services or a combination of psychotropic medication and psychosocial services) if they had seen their family physician in the two months prior to baseline, and had parents who reported being able to effectively access services for their child. Individuals who were younger, had no psychiatric diagnosis and whose parents were more educated were more likely to access psychosocial services versus using psychotropic medication alone. These findings suggest that treatment decisions are not simply associated with clinical presentation, but may also be influenced by child demographic and enabling factors. Given that guidelines recommend a multidisciplinary approach to care, the psychotropic medication alone users may represent a vulnerable group who require closer examination.

In the regression model, visiting a family physician in the two-months prior to baseline, and parents being able to effectively access services for their child, emerged as important predictors of accessing some psychosocial intervention (with or without psychotropic medication). Behavior problems can be a common reason for seeking family physician services among individuals with autism (Hassiotis & Turk, 2012). It is possible that regular contact with a primary care physician may be a proxy for taking a proactive care approach, as well as one mechanism to advocate for additional psychosocial services. Decreased parent self-efficacy in this population has been associated both with higher child need and with experiences of barriers to service access and caregiver burden (Weiss, Tint, Paquette-Smith, & Lunsky, 2016). Indeed, in our study these systemic barriers may make it particularly difficult for parents with low service efficacy to access psychosocial services. Although, neighborhood income did not predict service use, in the regression model parents with higher education were more likely to use psychosocial services alone compared to psychotropic medication alone. Parents with a higher level of education may be more skilled in navigating a complex service system and may have more financial resources to access private services (Shattuck et al., 2011; Thomas et al., 2007; Wei, Wagner, Christiano, & Shattuck, 2014). In the province of Ontario, the cost of medication for adults with developmental disabilities is publicly covered by disability income support; in contrast, allied heath therapies often have long waiting lists and are sometimes only available privately. Further research is required to examine the constellation of services accessed and the factors that drive families and physicians to pursue certain treatment options over others.

Consistent with previous research on service use in children with autism, associations were observed between accessing psychosocial services alone and predisposing variables, such as age. Other studies have suggested that psychosocial services are more available for younger, school-aged children compared to adolescents and adults (Cidav et al., 2013; Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Khanna et al., 2013). As children age, the cost of services increases (Cidav et al., 2013; Wang et al., 2013), and there tends to be greater psychotropic medication use (Esbensen et al., 2009). Consistent with these findings, we found that individuals over the age of 18 were more likely to use psychotropic medication alone than psychosocial services alone. The age difference we see here might reflect age-related systemic barriers in the health care and social service sectors. For example, in Ontario, youth with autism can receive psychosocial services through the school board and children's treatment centers. These services are not available to them as adults. In contrast, psychotropic medication can be paid for by disability care support for adults, whereas such coverage is not available to youth unless their parents receive income support.

4.1. Implications

The association between enabling factors (such as a lack of family physician visits, lower parental education and lower ability to access services) and optimal service use patterns may be an indication that despite clinical guidelines (Myers & Johnson, 2007; NCCMH, 2013; NICE, 2012) and the potentially adverse side effects of medication use (Posey et al., 2008; Stigler et al., 2004), there may be systemic barriers that prevent some individuals with autism from accessing psychosocial services. For example, throughout Canada, public health insurance covers only physician care. Access to allied health professionals within the public system can be fraught with long waitlists as only a limited number of hospitals and community organizations provide access to these professionals. Psychosocial services are sometimes covered by private or employer health insurance plans, but others may have to be paid out-of-pocket. These costs can continue to rise as a child reaches adulthood and can no longer access school-based supports. Additionally, there is a shortage of services and expertise available for older individuals with autism, as most services and interventions are directed towards children (Autism Ontario, 2008). We acknowledge that given differences in how services are accessed and billed in different parts of the world, this pattern of results may not generalize to other populations (e.g., American families).

Family physicians also play an instrumental role in assisting families in accessing psychosocial services that they may not otherwise be unaware of or have access to. In the current study, those who had recently visited their family physician were more likely to use psychosocial services. Previous research has found that accessing primary care services reduces the likelihood of emergency visits among those with developmental disabilities, and allows for the early identification of health issues (Lennox et al., 2007; Lunsky, Balogh, & Cairney, 2012; Wood, Hall, Hou, Wludyka, & Zhang, 2007). The Canadian Consensus Guidelines promote the role of primary care combined with an interdisciplinary approach among those with developmental disabilities (Sullivan et al., 2018). Increasing awareness and education among professionals, families, and individuals with autism about the availability of an evidenced-based decision making approach to using psychotropic medication may be useful in empowering individuals and improving outcomes.

4.2. Study limitations

This study had several limitations. First, the study relies on parent report over time, as opposed to administrative health records. While parent report has been shown to be quite reliable (Daniels et al., 2012; Kogan et al., 2009) and has been used extensively in previous research (e.g., Lin, Yu, & Harwood, 2012; Weiss & Lunsky, 2010), there is the possibility of sample bias and that under or overreporting may have occurred. Second, history of aggressive behavior was operationalized broadly as ‘issues with aggression or hurting others’. Therefore, the type, frequency, severity, or timing of aggressive behavior were not captured, limiting our ability to determine how specific aspects of aggression relate to service use. It is also important to note that these results are correlational in nature, and service use is based on a combination of clinical and systemic factors. Given our data we are unable to ascertain the quality and quantity of the services received. We also do not know where they are receiving services, psychosocial services maybe available through children’s treatment centers, school and privately. Additional information such as the behaviors targeted by each service, how long the individual had been taking medication, how frequently it was being monitored, and whether other services had been tried first, are important variables to examine in future work. Despite these limitations, this study is the first to examine service use among adolescents and adults with autism and a history of aggression, and to identify predictors of different types of service use. Having a better understanding of what predicts service use provides valuable information to help understand and address barriers that may prevent adolescents and adults with autism and aggression from accessing guideline recommended services.

Declaration of Competing Interest

There are no known conflicts of interest associated with this publication.

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References

Aman, M. G., Lam, K. S. L., & Bourgondien Van, M. E. (2005). Medication patterns in patients with autism: Temporal, regional, and demographic influences. *Journal of Child and Adolescent Psychopharmacology, 15*(1), 116–126.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

Arnsten, A. F., Scahill, L., & Findling, R. L. (2007). Alpha-2 Adrenergic receptor agonists for the treatment of attention-deficit/hyperactivity disorder: Emerging concepts from new data. *Journal of Child and Adolescent Psychopharmacology, 17*(4), 393–406. https://doi.org/10.1089/cap.2006.0098.

Autism Ontario (2008). *Forgotten: Ontario adults with autism and adults with aspergers*Retrieved fromhttp://www.autismontario.com/Client/ASO/AO.nsf/object/Forgotten+Report+Autism+Ontario/$file/Forgotten+Report+Autism+Ontario.pdf.

Barrett, B., Byford, S., Sharac, J., Hudry, K., Leadbitter, K., Temple, K., ... Green, J. (2012). Service and wider societal costs of very young children with autism in the UK. *Journal of Autism and Developmental Disorders, 42*(5), 797–804. https://doi.org/10.1007/s10803-011-1306-x.

Benevides, T. W., Carretta, H. J., & Lane, S. J. (2016). Unmet need for therapy among children with autism spectrum disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal, 20*(4), 878–888.

Bhandari, A., & Wagner, T. (2006). Self-reported utilization of health care services: Improving measurement and accuracy. *Medical Care Research and Review, 63*(2), 217–235. https://doi.org/10.1177/1077558705285298.

Boulet, S. L., Boyle, C. A., & Schieve, L. A. (2009). Health care use and health and functional impact of developmental disabilities among US children, 1997-2005.

Archives of Pediatrics & Adolescent Medicine, 163(1), 19–26. https://doi.org/10.1001/archpediatrics.2008.506.

Brooks, W. T., & Benson, B. A. (2013). The validity of the social communication questionnaire in adults with intellectual disability. *Research in Autism Spectrum Disorders, 7*(2), 247–255. https://doi.org/10.1016/j.rasd.2012.10.002.

Brosnan, J., & Healy, O. (2011). A review of behavioral interventions for the treatment of aggression in individuals with developmental disabilities. *Research in Developmental Disabilities, 32*(2), 437–446. https://doi.org/10.1016/j.ridd.2010.12.023.

Bryson, S. E., Rogers, S., & Fombonne, E. (2003). Autism Spectrum disorders: Early detection, intervention, education, and psychopharmacological management. *The Canadian Journal of Psychiatry, 48*(8), 506–516.

Cheak-Zamora, N. C., & Farmer, J. E. (2015). The impact of the medical home on access to care for children with Autism Spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(3), 636–644. https://doi.org/10.1007/s10803-014-2218-3.

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). “Transitions are scary for our kids, and they’re scary for us”: Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 548–560. https://doi.org/10.1111/jar.12150.

Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics, 131*(3), 447–454. https://doi.org/10.1542/peds.2012-1572.

Cidav, Z., Lawer, L., Marcus, S. C., & Mandell, D. S. (2013). Age-related variation in health service use and associated expenditures among children with autism. *Journal of Autism and Developmental Disorders, 43*(4), 924–931.

Daniels, A. M., Rosenberg, R. E., Anderson, C., Law, J. K., Marvin, A. R., & Law, P. A. (2012). *Verification of parent-report of child autism spectrum disorder diagnosis to a web-based autism registry*257–265. https://doi.org/10.1007/s10803-011-1236-7.

Doyle, C. A., & McDougle, C. J. (2012). Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. *Dialogues in Clinical Neuroscience, 14*(3), 263–279.

Esbensen, A. J., Greenberg, J. S., Seltzer, M. M., & Aman, M. G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(9), 1339–1349. https://doi.org/10.1007/s10803-009-0750-3.

Fitzpatrick, S. E., Srivorakiat, L., Wink, L. E., Pedapti, E. V., & Erickson, C. A. (2016). Aggression in autism spectrum disorder : Presentation and treatment options. *Neuropsychiatric Disease and Treatment, 12,* 1525–1538. https://doi.org/10.2147/NDT.S84585.

Goin-Kochel, R. P., Myers, B. J., & Mackintosh, V. H. (2007). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 1*(3), 195–209. https://doi.org/10.1016/j.rasd.2006.08.006.

Goldman, S. E., McGrew, S., Johnson, K. P., Richdale, A. L., Clemons, T., & Malow, B. A. (2011). Sleep is associated with problem behaviors in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(3), 1223–1229. https://doi.org/10.1016/j.rasd.2011.01.010.

Goldstein, H. (2002). Communication intervention for children with autism: A review of treatment efficacy. *Journal of Autism and Developmental Disorders, 32*(5), 373–396. https://doi.org/10.1023/A:1020589821992.

Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O’Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27*(1), 70–84. https://doi.org/10.1016/j.ridd.2004.12.002.

Hassiotis, A., & Turk, J. (2012). Mental health needs in adolescents with intellectual disabilities: Cross-sectional survey of a service sample. *Journal of Applied Research in Intellectual Disabilities, 25*(3), 252–261. https://doi.org/10.1111/j.1468-3148.2011.00662.x.

Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders, 41*(7), 926–937. https://doi.org/10.1007/s10803-010-1118-4.

Khanna, R., Jariwala, K., & West-Strum, D. (2013). Use and cost of psychotropic drugs among recipients with autism in a state Medicaid fee-for-service programme. *Journal of Intellectual Disability Research, 57*(2), 161–171. https://doi.org/10.1111/j.1365-2788.2012.01563.x.

Kogan, A. M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., ... van Dyck, P. C. (2009). Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US 2007. *Pediatrics, 124*(5), 1395–1403. https://doi.org/10.1542/peds.2009-1522.

Lake, J. K., Balogh, R., & Lunsky, Y. (2012). Polypharmacy profiles and predictors among adults with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*(3), 1142–1149. https://doi.org/10.1016/j.rasd.2012.03.005.

Langworthy-Lam, K. S., Aman, M. G., & Bourgondien Van, M. E. (2002). Prevalence and patterns of use of psychoactive medicines in individuals with autism in the Autism Society of North Carolina. *Journal of Child and Adolescent Psychopharmacology, 12*(4), 311–321.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(Pt 3), 172–183. https://doi.org/10.1111/j.1365-2788.2005.00732.x.

Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R., & Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: A cluster randomized trial. *International Journal of Epidemiology, 36*(1), 139–146. https://doi.org/10.1093/ije/dyl254.

Lin, A. S. C., Yu, S. M., & Harwood, R. L. (2012). Autism spectrum disorders and developmental disabilities in children from immigrant families in the United States. *Pediatrics, 130*(November)), S191–S197. https://doi.org/10.1542/peds.2012-0900R.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children’s Health. *Journal of Developmental & Behavioral Pediatrics, 29*(3), 152–160. https://doi.org/10.1097/DBP.0b013e318165c7a0.

Logan, S. L., Nicholas, J. S., Carpenter, L. A., King, L. B., Garrett-Mayer, E., & Charles, J. M. (2012). High prescription drug use and associated costs among medicaid-eligible children with autism spectrum disorders identified by a population-based surveillance network. *Annals of Epidemiology, 22,* 1–8. https://doi.org/10.1016/j.annepidem.2011.10.007.

Lunsky, Y., Balogh, R., & Cairney, J. (2012). Predictors of emergency department visits by persons with intellectual disability experiencing a psychiatric crisis. *Psychiatric Services, 63*(3), 287–290. https://doi.org/10.1176/appi.ps.201100124.

Mandell, D. S. (2008). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1059–1065.

Matson, J. L., Dixon, D. R., & Matson, M. L. (2005). Assessing and treating aggression in children and adolescents with developmental disabilities: A 20-year overview. *Educational Psychology, 25,* 151–181. https://doi.org/10.1080/0144341042000301148.

Matson, J. L., & Rivet, T. T. (2008). Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual & Developmental Disability, 33*(4), 323–329. https://doi.org/10.1080/13668250802492600.

Mayes, S. D., & Calhoun, S. L. (2009). Variables related to sleep problems in children with autism. *Research in Autism Spectrum Disorders, 3*(4), 931–941. https://doi.org/10.1016/j.rasd.2009.04.002.

Mazurek, M. O., Kanne, S. M., & Wodka, E. L. (2013). Physical aggression in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(3), 455–465. https://doi.org/10.1016/j.rasd.2012.11.004.

Mazurek, M. O., & Petroski, G. F. (2015). Sleep problems in children with autism spectrum disorder: Examining the contributions of sensory over-responsivity and anxiety. *Sleep Medicine, 16*(2), 270–279. https://doi.org/10.1016/j.sleep.2014.11.006.

McLennan, J. D., Huculak, S., & Sheehan, D. (2008). Brief report: Pilot investigation of service receipt by young children with autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1192–1196. https://doi.org/10.1007/s10803-007-0535-5.

Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics, 120*(5), 1162–1182.

NCCMH (2013). *Autism: The management and support of children and young people on the autism spectrum.* Leicester and London. Retrieved fromhttp://www.nccmh.org.uk/guidelines_autism_CYP.html.

NICE (2012). *Autism in adults: Diagnosis and management. NICE clinical guideline.* London. Retrieved from142. http://nice.org.uk/guidance/cg142.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine, 28*(6), 761–769. https://doi.org/10.1007/s11606-012-2262-7.

Posey, D. J., Stigler, K. A., Erickson, C. A., & McDougle, C. J. (2008). Antipsychotics in the treatment of autism. *The Journal of Clinical Investigation, 118*(1), 6–14.

https://doi.org/10.1172/JCI32483.

Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social skills interventions for children with Asperger's syndrome or high-functioning autism: A review and recommendations. *Journal of Autism and Developmental Disorders, 38*(2), 353–361. https://doi.org/10.1007/s10803-007-0402-4.

Research Units on Pediatric Psychopharmacology Autism Network (2009). Medication and parent training in children with pervasive developmental disorders and serious behavior problems: Results from a randomized clinical trial research. *Journal of the American Academy of Child and Adolescent Psychiatry, 48*, 1143–1154. https://doi.org/10.1097/CHI.0b013e3181bfd669.

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology, 37*(1), 8–38. https://doi.org/10.1080/15374410701817808.

Ruble, L. A., Heflinger, C. A., Renfrew, J. W., & Saunders, R. C. (2005). Access and service use by children with autism spectrum disorders in Medicaid Managed Care. *Journal of Autism and Developmental Disorders, 35*(1), 3–13. https://doi.org/10.1007/s10803-004-1026-6.

Rutter, M., Bailey, A., & Lord, C. (2003). *The social communication questionnaire (SCQ)*. Los Angeles, CA: Western Psychological Services.

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post high school service use among young adults with autism spectrum disorder. *Archives of Pediatric Adolescent Medicine, 165*(2), 141–146. https://doi.org/10.1001/archpediatrics.2010.279.Post.

Shea, S., Turgay, A., Carroll, A., Schulz, M., Orlik, H., Smith, I., & Dunbar, F. (2004). Risperidone in the treatment of disruptive behavioral symptoms in children with autistic and other pervasive developmental disorders. *Pediatrics, 114*(5), e634–e641. https://doi.org/10.1542/peds.2003-0264-F.

Shoham-Vardi, I., Davidson, P. W., & Cain, N. N. (1996). Factors predicting re-referral following crisis intervention for community-based persons with developmental disabilities and behavioral and psychiatric disorders. *American Journal on Mental Retardation, 101*(2), 109–117.

Siller, M., Reyes, N., Hotez, E., Hutman, T., & Sigman, M. (2014). Longitudinal change in the use of services in autism spectrum disorder: Understanding the role of child characteristics, family demographics, and parent cognitions. *Autism, 18*(4), 433–446. https://doi.org/10.1177/1362361313476766.

Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C., Dennen, T., ... Jain, A. (2013). Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics, 132*(5), 833–840.

Statistics Canada (2006). *2006 Census of Population (No. Catalogue no. 94-581-XCB2006003)*.

Stigler, K. A., Potenza, M. N., Posey, D. J., & McDougle, C. J. (2004). Weight gain associated with atypical antipsychotic use in children and adolescents. *Pediatric Drugs,* 33–44.

Sullivan, W. F., Diepstra, H., Heng, J., Ally, S., Bradley, E., Casson, I., ... Witherbee, S. (2018). Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian Family Physician Medecin de Famille Canadien, 64*(4), 254–279. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/29650602.

Thomas, K. C., Morrissey, J. P., & McLaurin, C. (2007). Use of autism-related services by families and children. *Journal of Autism and Developmental Disorders, 37*(5), 818–829. https://doi.org/10.1007/s10803-006-0208-9.

Thyer, B. A., & Pignotti, M. (2010). Science and pseudoscience in developmental disabilities: Guidelines for social workers. *Journal of Social Work in Disability & Rehabilitation, 9*(2), 110–129. https://doi.org/10.1080/1536710X.2010.493480.

Tsakanikos, E., Costello, H., Holt, G., Sturmey, P., & Bouras, N. (2007). Behaviour management problems as predictors of psychotropic medication and use of psychiatric services in adults with autism. *Journal of Autism and Developmental Disorders, 37*(6), 1080–1085. https://doi.org/10.1007/s10803-006-0248-1.

Wang, L., Mandell, D. S., Lawer, L., Cidav, Z., & Leslie, D. L. (2013). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders, 43*(5), 1057–1064. https://doi.org/10.1007/s10803-012-1649-y.

Wei, X., Wagner, M., Christiano, E. R. A., & Shattuck, P. (2014). Special education services received by students with autism spectrum disorders from preschool through high school. *The Journal of Special Education, 48*(3), 167–179. https://doi.org/10.1177/0022466913483576.Special.

Weiss, J. A., & Lunsky, Y. (2010). Service utilization patterns in parents of youth and adults with intellectual disability who experienced behavioral crisis. *Journal of Mental Health Research in Intellectual Disabilities, 3*, 145–163.

Weiss, J. A., Tint, A., Paquette-Smith, M., & Lunsky, Y. (2016). Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. *Autism, 20*(4), 425–434. https://doi.org/10.1177/1362361315586292.

Wood, D., Hall, A., Hou, T., Wludyka, P., & Zhang, J. (2007). Continuity of care to prevent emergency room use among persons with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(4), 219–228.