

BRIEF REPORT: Services for Adults and Adolescents with ASD in Ontario – Parent and Professional Perspectives

Abstract

The present study aimed to examine the availability, accessibility, and effectiveness of services for adolescents and adults with autism spectrum disorder (ASD) in Ontario, as perceived by parents and professionals in the field. Attendees at a 2008 Autism Ontario conference (N = 175) responded to a survey designed by the organization and rated each of these aspects for 11 specific services. Data analyses revealed a disparity in participants' views of service availability among respondents from the Central region, and differences in views of accessibility and effectiveness among those in Southern Ontario. Possible explanations for these trends are discussed.

It is estimated that autism spectrum disorders (ASD) affect 1 in 150 individuals in the United States (Centers for Disease Control and Prevention, 2007), with similar prevalence rates worldwide (Fombonne, 2005). Despite the data that an estimated 50,000 of the 70,000 individuals with ASD in Ontario are adults, there exists no consistent policy or funding for programs and services for this age group (Autism Ontario, 2008). Given the recent government policy paper highlighting the importance of seamless care across the lifespan (Province of Ontario, Ministry of Community and Social Services, 2006), research is indeed needed to ascertain the state of the resources available for this population.

A review of research on outcomes for adults with ASD clearly illuminates the everyday difficulties they face. Although a small proportion show some improvement in core autism symptomology from childhood through adulthood (i.e., impairments in social skills, communication and restricted/repetitive behaviours) (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004), outcomes for the majority are “poor” or “very poor” (Howlin, Goode, Hutton, & Rutter, 2004). Studies show that few adults secure employment, maintain peer relationships, or engage in interactive social activities, and the majority remain dependent upon parents and other caregiver resources (Moxon & Gates, 2001; Howlin et al., 2004; Orsmond, Krauss, & Seltzer, 2004). Even among adolescents and young adults, limited independence, poor economic status, and unmet social needs are common (Eaves & Ho, 2008). This cannot only be strenuous for caregivers, it also generates considerable societal cost—a conservative U.S. estimate of the per capita lifetime cost of care and treatment for an individual with autism is \$3.2 million, with the preponderance of that cost resulting from adult care (Ganz, 2007).

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When discussing services for adults and adolescents with ASD, it is important to consider the viewpoints of parents and of professionals who work in the field, as these caregivers are instrumental in accessing, enabling and providing services. Both parties are deeply invested in the lives of persons with ASD and desire the most favourable of outcomes for those in their care. They may, however, have differing opinions on various aspects of the services with which they are involved. In a study of 25 families of young children with autism, 40% of parents reported difficulties accessing services, and 64% felt the services received were ineffective in meeting their children's needs (Kohler, 1999). Conversely, professionals have been found to be more informed and have a better understanding of early intervention services than parents of children using them (Wesley, Buysse, & Tyndall, 1997). The divergent perspectives reflected in these findings may also hold true with regard to adult services, and may hinder collaboration between parents and professionals, an important component of service development, implementation, and evaluation (MacKean, Thurston, & Scott, 2005; Dinnebeil, Hale, & Rule, 1996).

Elements of service availability and effectiveness have been investigated in other geographical regions and for other populations, but not yet with regard to adolescents and adults with ASD in Ontario. This province has a well-developed, wide-ranging, intensive intervention program for young children with ASD, which has been found to yield improvements in cognitive levels and adaptive behaviour, including communication and socialization skills (Perry et al., 2008). Recent analyses of interviews with parents of individuals with developmental disabilities revealed a consistent theme of falling through the cracks for youth when transitioning from child to adult ser-

vices, which, in Ontario, must occur by 21 years of age (Weiss & Lunsky, 2008). In order to ensure the continuity of quality services and sustained improvement for persons with ASD, programs for older individuals must be addressed as well.

The purpose of this study was to analyze the availability, accessibility and effectiveness of services for adolescents and adults with ASD in Ontario, as rated by parents and professionals in the field. We sought to examine whether there are discrepancies in parents' and professionals' perceptions of these variables across service types, and whether there are different trends in the ratings given by respondents in different regions of the province.

Method

Participants

Respondents were attendees at a provincial Autism Ontario conference held in Hamilton in 2008. In total, 234 attendees participated, however, those who completed only the first few items on the questionnaire were excluded. Of the 225 remaining participants, 24.8% were parents of an individual with ASD, 74.2% were professionals in the field, 0.9% were self-advocates, and 5.3% were "other," including spouses and siblings (note: sum of percentages is not equal to total sample, as choices were not mutually exclusive). Only data supplied by parents or professionals were included in analyses, with none of the respondents overlapping in their roles. Respondents were from of all regions across Ontario (as defined by the Community Networks of Specialized Care), although the majority resided in the Central and Southern regions (see Table 1). Given the uneven distribution of respondents across regions, we

Table 1. Representation of Parents and Professionals From Regions of Ontario

	<i>Parents n (%)</i>	<i>Professionals n (%)</i>
Central	14 (31.1%)	78 (50.6%)
Eastern	3 (6.7%)	14 (9.1%)
Southern	26 (57.8%)	57 (37.0%)
Northern	2 (4.4%)	4 (2.6%)

chose to focus our analyses on data from the Central and Southern regions, yielding a final sample of 175.

Measures

Data were gathered using a paper questionnaire, designed by Autism Ontario, that was distributed to attendees during the conference. First, respondents were asked to identify their role in relation to the autism community, and the region in which they lived. The remainder of the questions asked participants to evaluate the following 11 programs & services: clinical supports; a range of school support; respite services; support groups for families, siblings, and the individual with ASD; transition planning and support; day programs; vocational training & support; housing options; advocacy, public awareness and information about ASD; special services at home (SSAH) funds; and an integrated system of support. This list of services was

generated based on the results of a 2006 Autism Ontario survey, in which 300 respondents identified and prioritized the most important supports for adults with ASD. Participants were asked whether each service was available in their region ("yes," "no," or "partially"). They then rated on a 5-point scale the accessibility and the effectiveness (defined as the degree to which the service meets the needs of individuals with ASD) of each item listed. The final two open-ended questions asked participants to discuss any additional services they felt were needed, and for any other comments.

Procedure

During the course of the conference, attendees were asked to complete the paper questionnaire and return it to Autism Ontario staff prior to leaving. As an incentive to participate, each respondent was entered into a draw for monetary prizes.

Table 2. Service Availability for Central and Southern Regions

Service	Central			Southern		
	Parents (%) [†]	Professionals (%) [†]	χ^2	Parents (%) [†]	Professionals (%) [†]	χ^2
Clinical supports	42.6	73.0	4.27	56.5	81.8	5.92
School support	85.7	72.7	1.26	32.0	67.3	9.82**
Respite services	78.6	75.0	0.58	69.6	68.5	0.04
Support groups	78.6	66.2	1.60	50.0	64.8	4.25
Transition planning & support	46.2	53.2	0.83	31.8	46.3	7.18*
Day programs	38.5	61.8	5.18	28.0	64.2	9.37**
Vocational training	38.5	55.6	1.44	28.6	48.0	11.68**
Housing options	30.8	56.3	5.03	19.0	45.1	8.90*
Advocacy/public awareness/information	69.2	71.8	2.16	43.5	62.7	3.44
Special services at home funds	92.9	76.4	1.95	82.6	75.5	6.75*
Integrated system of support	38.5	42.5	2.19	18.2	56.3	13.62***

[†] Percent of respondents who indicated "yes" when asked about existence of services

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

Results

Chi square analyses revealed that the distribution of parents and professionals in the Central and Southern regions was significantly different ($\chi^2(1) = 6.42, p = 0.01$). In order to eliminate the confoundment created by this difference, we independently analysed trends in the Central and Southern regions.

Central Region

Service Availability. Data were analysed using a chi-square test of independence to determine if there was a difference in the proportion of parents and professionals in the Central region who rated each service as “available.” Though the proportion of professionals who indicated that each service was “available” was greater than the proportion of parents for 7 of the 11 programs listed, none of these proportions differed significantly (see Table 2).

Service Accessibility and Effectiveness. A Multivariate Analysis of Variance (MANOVA) was used to compare the mean “accessibility” ratings given by parents and professionals with regard to each service type. The overall MANOVA was significant, $F(11,38) = 2.30, p = 0.03$. Subsequent ANOVAs examining the mean differences between respondent groups for each service type revealed that professionals rated clinical supports, $F(1,38) = 5.43, p = 0.02$, day programs, $F(1,38) = 17.55, p = 0.000$, transition planning and support, $F(1,38) = 6.87, p = 0.01$, vocational training, $F(1,38) = 11.70, p = 0.001$, and housing options, $F(1,38) = 4.80, p = 0.03$, as more accessible than did parents.

A second MANOVA comparing the mean “effectiveness” ratings across service types was not significant, $F(11,36) = 1.51, p = 0.17$. However, individual ANOVAs revealed that professionals rated day programs, $F(1,36) = 5.69, p = 0.02$, transition planning and support, $F(1,36) = 4.46, p = 0.04$, and vocational training, $F(1,36) = 5.60, p = 0.02$ as more effective than did parents.

Southern Region

Service Availability. A second chi square analysis was calculated to examine the “availability” ratings given by parents and professionals for each service type in the Southern region.

Contrary to the Central region, a significantly greater proportion of professionals indicated that school supports, day supports, transition planning, vocational training, housing options and an integrated system of support were “available” in their community, compared to parents. Also, in contrast to the other services listed, a significantly greater proportion of parents endorsed the “availability” of SSAH funds, compared to professionals (see Table 2).

Service Accessibility and Effectiveness. The overall MANOVA comparing mean “accessibility” ratings was statistically significant, $F(11,26) = 2.22, p = 0.05$, indicating that overall, professionals rated services as more “accessible” than did parents. None of the ANOVAs analyzing differences in specific services were significant, though the accessibility of housing options approached significance, $F(1,26) = 3.87, p = 0.06$.

To compare the mean “effectiveness” scores for parents and professionals, a final MANOVA was conducted. There were no significant differences between the scores given by parents and professionals with regard to specific services. Overall, however, professionals rated most services as more “effective” than did parents, $F(11,24) = 2.41, p = 0.04$.

Discussion

These analyses suggest that a disparity may exist in the perceptions of parents and professionals on the availability, accessibility, and effectiveness of some services for adults and adolescents with ASD in Ontario. Although ratings assigned by both respondent groups were generally low, in many cases professionals assigned higher ratings than did parents. In the Central region, parents and professionals were largely in agreement concerning the availability of services; professionals, however, felt that clinical supports, day programs, transition planning and support, vocational training and appropriate housing options were more accessible and/or effective than did parents. In the Southern region, a greater proportion of professionals noted that services were available in their communities (for 6 out of 11 services) when compared to parents, but for the most part did not differ from parents in their mean ratings of service accessibility or effectiveness.

There are several possible explanations for the trends reflected in these findings. For instance, the perceived differences in program availability and accessibility may in part be due to a disconnect between the methods used by providers to disseminate information about services and the avenues used by parents to get this information. Wesley, Buysse, and Tyndall (1997) found that parents cited "informal methods" (such as seeking information from friends) as the most frequent way of gaining information and access to services, while professionals highlighted the importance of agency outreach, public information systems, and other "formal" methods. If it is easier for professionals to find information about resources, it may also be easier for them to gain access to the resources than it is for parents, who are, naturally, less integrated into the service sector.

Discrepancies in parent and professional opinions on the ability of available services to meet client needs (i.e., effectiveness) may be reflective of key issues in the service evaluation process, as it is possible that parents and professionals use very different criteria when assessing this aspect of programs. For example, a service may be deemed "effective" from a professional point of view if it is sufficiently staffed, if clients are actively using the service, and/or if predetermined service goals are met. Conversely, for parents, the effectiveness of a program may be largely based on the extent to which the intended benefit of the program is relevant and useful in natural settings, or if service use results in direct benefits to the client and family in their daily lives. Also, a lack of consensus regarding the roles of each party can lead to dissatisfaction, particularly on the part of parents, when expectations are not met (see Wesley, Buysse, & Tyndall, 1997). It is, therefore, crucial for parents and professionals to consider each others' goals, needs and responsibilities (as well as those of the client) when determining whether programs are indeed effective.

It is also interesting to note that although professionals generally had more favourable ratings than did parents, either in terms of availability, accessibility, or effectiveness, there is some indication that these differences might be regionally based. For the Southern region, differences were related to the availability of services, while for the Central region, differ-

ences were related to service accessibility and effectiveness. These findings further highlight the complexity of evaluating service quality, as aspects of services may be influenced by variability across the geographical area.

Limitations and Future Research

Because no random selection was possible, this study's sample may not be representative of Ontario's autism community. Respondents consisted solely of attendees at an Autism Ontario conference, and therefore likely included the most actively involved and informed members of the ASD community. Future research into this topic should include a larger and more representative sample of parents and professionals from across the province, recruited from a variety of agencies and organizations. Also, the data gathered were based on loosely defined criteria and subjective assessment of service availability, accessibility, and effectiveness. Additional examination of these variables should include a more operational definition of the constructs measured, and perhaps collection of more detailed data. Despite these limitations, however, these analyses provide an important preliminary look at an area of increasing focus.

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