

Service utilization in a sample of preschool children with autism spectrum disorder: A Canadian snapshot

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OBJECTIVE: To describe services received by preschool children diagnosed with autism spectrum disorder (ASD) during the five-year period following their diagnosis.

METHOD: An inception cohort of preschoolers diagnosed with ASD from Halifax (Nova Scotia), Montreal (Quebec), Hamilton (Ontario), Edmonton (Alberta) and Vancouver (British Columbia) were invited to participate. Parents/caregivers (n=414) described the services provided to their children at four time points: baseline (T1; within four months of diagnosis; mean age three years); six months later (T2); 12 months later (T3); and at school entry (T4). Data were first coded into 11 service types and subsequently combined into four broader categories (no services, behavioural, developmental and general) for analysis.

RESULTS: More than 80% of children at T1, and almost 95% at T4 received some type of service, with a significant number receiving >1 type of service at each assessment point. At T1, the most common service was developmental (eg, speech-language therapy). Subsequently, the most common services were a combination of behavioural and developmental (eg, intensive therapy based on applied behaviour analysis and speech-language therapy). Service provision varied across provinces and over time.

DISCUSSION: Although most preschool children with ASD residing in urban centres were able to access specialized services shortly after diagnosis, marked variation in services across provinces remains a concern.

Key Words: *Autism spectrum disorder; Intervention; Services*

Few childhood conditions have garnered as much public attention in recent years as autism spectrum disorder (ASD). ASD is a neurodevelopmental disorder, characterized by impaired social communication and by repetitive, stereotyped mannerisms and/or behaviour (1). Within these core dimensions, clinical presentations vary widely (2). Overall, ASD is associated with a high burden of suffering for affected children and their families, as well as with high costs, averaging almost \$2 million per person across their lifespan (3). Furthermore, prevalence estimates have increased steadily over the past decade. Recent estimates from the

L'utilisation des services par un échantillon d'enfants d'âge préscolaire ayant un trouble du spectre autistique : un cliché canadien

OBJECTIF : Décrire les services qu'ont reçus des enfants d'âge préscolaire ayant un trouble du spectre autistique (TSA) pendant la période de cinq ans suivant leur diagnostic.

MÉTHODOLOGIE : Une cohorte initiale d'enfants d'âge préscolaire ayant un TSA diagnostiqué et qui provenaient de Halifax (Nouvelle-Écosse), de Montréal (Québec), de Hamilton (Ontario), d'Edmonton (Alberta) ou de Vancouver (Colombie-Britannique) a été invitée à participer à l'étude. Les parents et les tuteurs (n=414) ont décrit les services fournis à leur enfant à quatre moments : au début (T1; dans les quatre mois suivant le diagnostic, âge moyen de trois ans); six mois plus tard (T2); 12 mois plus tard (T3) et à l'entrée à l'école (T4). Les chercheurs ont d'abord codé les données en 11 types de services, pour ensuite les regrouper en quatre catégories plus vastes (absence de services, comportementaux, développementaux et généraux) en vue de leur analyse.

RÉSULTATS : Plus de 80 % des enfants ont reçu certains services à T1, et près de 95 % à T4, et un nombre significatif a reçu plus d'un type de services à chaque évaluation. À T1, le service le plus courant était de type développemental (p. ex., orthophonie). Par la suite, les services les plus courants étaient un mélange de services comportementaux et développementaux (p. ex., thérapie intensive selon l'analyse de comportement appliquée et orthophonie). La prestation des services variait selon les provinces et au fil du temps.

EXPOSÉ : Même si la plupart des enfants d'âge préscolaire ayant un TSA qui habitaient dans un centre urbain avaient accès à des services spécialisés peu après le diagnostic, les variations marquées des services entre les provinces demeurent préoccupantes.

United Kingdom and the United States indicate that as many as 1.1% of children receive a diagnosis (3). In Canada, as elsewhere, growing awareness and improving access to diagnostic services have increased the demand for early intervention – to provide children with ASD the best chance to achieve their full potential (4).

Over the past decade, following successful parent advocacy and high-profile legal challenges, many Canadian provinces have increased public funding for early intensive intervention for children with ASD (5,6). However, preschool ASD services still vary across provinces along several dimensions: the relative mix of

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TABLE 1
Coding and categorization of service types in the Pathways Autism Services Log

Category	Service type	Description
No services	No services	Not receiving services, still seeking services or waitlisted
Behavioural/structured	Behavioural/structured	Receiving a one-to-one structured behavioural intervention program, such as (early) intensive behavioural intervention, applied behavioural analysis, discrete trial training or pivotal response treatment
Developmental/supported educational	Mainstream group (with support)	Attending an integrated mainstream group program with an aide or other specialized support such as a multidisciplinary team within the group context
	Specialized group	Attending a segregated, specialized group program such as a social skills program, a preschool for children with special needs.
	Language/communication	Receiving speech language communication therapies, including social communication/emotional regulation/transactional support (SCERTS)
	Occupational/physical therapy Mental health	Occupational or physical therapy Receiving community mental health services
General/community	Mainstream group (without support)	Attending an integrated mainstream group program such as a community preschool without an aide or other specialized support
	Other services	Receiving other services such as relationship development intervention, music therapy or therapeutic horseback riding
	Community/recreation (without support)	Attending a mainstream community recreation program such as a community play group without an aide or other specialized support
	Community/recreation (with support)	Attending a mainstream community recreation program with an aide or other specialized support

public and private funding; the degree of integration among services; and the extent of population coverage (7). For instance, Nova Scotia now provides public intervention services to all young children with ASD, albeit with delays between diagnosis and access. Ontario provides public intervention services for 'severely' affected preschool children; however, significant wait lists sometimes preclude timely access. Both British Columbia (BC) and Alberta provide funding directly to families to partially subsidize the cost of private intervention – with BC's program being ASD-specific, while Alberta's is integrated with financial support for all families with developmentally disabled children. Across provinces, families who can afford it seek services from the private sector when publicly funded services are regarded as too limited or are inaccessible. Amid this interprovincial diversity, actual service utilization data have been lacking. In particular, to our knowledge, there are no empirical data regarding the range of services received by preschool children with ASD across Canada.

The Pathways in ASD study (2) provided an opportunity to document service utilization in five provinces. Pathways is a large longitudinal study, relating child, family and contextual factors – including service use – and developmental trajectories in children with ASD. The present article uses descriptions provided by participating families recruited from five regional referral centres about services their children received from time of diagnosis to school entry. These data were coded using the Pathways Autism Services Log (Table 1) and were categorized to provide an overview of services received by Canadian preschoolers with ASD from 2005 to 2012. Specific objectives were to document the proportion of children with ASD receiving services, and the types of services received across sites and over time.

METHOD

Participants

The sample consisted of 414 recently diagnosed children with ASD (348 boys) between two and five years of age (mean [±SD] age at diagnosis was 38.3±8.8 months). For detailed inclusion and exclusion criteria, see Georgiades et al (2). All eligible families from ASD diagnostic centres in Halifax (Nova Scotia), Montreal (Quebec), Hamilton (Ontario), Edmonton (Alberta) and Vancouver (BC) were invited to participate. Families completed assessments at four time points: as soon as possible after diagnosis, but within four months (T1); six months later (T2); 12 months later (T3); and at school entry at six years of age (T4).

Procedure

Informed consent was obtained and the study protocol was approved by human Research Ethics Boards at McMaster University (Hamilton, Ontario), McGill University (Montreal, Quebec), Isak Walton Killam Health Centre (Halifax, Nova Scotia), University of British Columbia (Vancouver, BC) and University of Alberta (Edmonton, Alberta). At each time point, using a written questionnaire, parents/caregivers described the service(s) that their children received. Responses ranged widely from broad categories, such as applied behaviour analysis (ABA) or speech-language therapy (SLP), to the names of specific local service providers/programs.

Instrument

The Pathways in Autism Services Log (PASL) was developed to organize these unstructured data, and to enable meaningful comparisons across sites and over time. Two research staff members from each Pathways site, led by investigator JV, developed the PASL. As summarized in Table 1, an 11-point coding scheme was developed, representing major service types. Codes were tested by having two research team members at each site code samples of data from their location because local personnel could more accurately judge the type of service when respondents gave specific names of providers/programs. In successive cross-site teleconferences, the team refined coding criteria. After the coding scheme was finalized, the same two representatives at each site coded all the data from their location. Overall agreement among raters across all sites was 90.1%.

Preliminary analysis indicated that a significant number of children received >1 type of service. Accordingly, PASL codes were collapsed into four categories: no services; behavioural; developmental or supported educational; and general community services. Behavioural services were defined as those using the principles of ABA, such as the systematic use of reinforcement to teach new skills and reduce challenging behaviours (8). Typically they were delivered in a one-to-one context, in which an interventionist worked several hours per week with the child. The

TABLE 2
Percentage of the sample, overall and at each site, receiving each of the broad categories of service according to time point

Service category	T1	T2	T3	T4
No service provided				
Overall	19.5	16.2	8.0	6.5
Halifax	0	2.9	3.1	9.0
Montreal	39.2	20.5	8.8	5.5
Hamilton	17.0	12.5	4.8	6.7
Edmonton	6.0	0	0	4.0
Vancouver	1.0	0	0	0
Provided alone				
Behavioural				
Overall	0.8	3.7	7.1	2.8
Halifax	0	17.6	12.5	0
Montreal	0.8	4.7	15	5.5
Hamilton	0	0	2.4	6.7
Edmonton	0	0	0	0
Vancouver	2.3	1.3	0	0
Developmental				
Overall	25.5	18.6	14.8	20.3
Halifax	27.3	11.8	18.8	40.0
Montreal	21.6	19.6	11.5	14.3
Hamilton	27.7	30.0	21.4	3.3
Edmonton	50.0	42.2	41.7	45.8
Vancouver	17.0	6.5	3.9	21.4
General				
Overall	8.0	0.3	6.8	6.9
Halifax	4.5	0	18.8	20.0
Montreal	12.8	0.9	7.1	5.5
Hamilton	14.9	0	16.7	16.7
Edmonton	2.0	0	0	0
Vancouver	3.4	0	0	2.9
Provided in combination				
Behavioural and developmental				
Overall	12.9	22.0	21.9	25.6
Halifax	25.0	32.4	21.9	0
Montreal	4.8	10.3	15.9	18.7
Hamilton	4.2	12.5	9.5	23.3
Edmonton	12.0	28.9	27.0	20.8
Vancouver	25.0	41.5	38.2	48.6
Behavioural and general				
Overall	2.5	4.0	3.5	6.8
Halifax	4.5	5.9	9.3	4.0
Montreal	1.6	7.5	11.5	11.0
Hamilton	2.1	0	4.8	10.0
Edmonton	0	0	8.3	0
Vancouver	4.5	3.9	0	2.9
Developmental and general				
Overall	19.0	17.7	12.9	12.2
Halifax	13.6	2.9	3.1	20.0
Montreal	15.2	21.3	15.9	11.0
Hamilton	27.7	35.0	19.0	13.3
Edmonton	24.0	22.2	22.2	8.3
Vancouver	21.6	13.0	6.6	12.9

Table continued in next column

TABLE 2 – CONTINUED
Percentage of the sample, overall and at each site, receiving each of the broad categories of service according to time point

Service category	T1	T2	T3	T4
Behavioural, developmental and general				
Overall	11.8	17.7	25.1	19.1
Halifax	25.0	26.5	12.5	8.0
Montreal	4.0	14.9	20.4	28.6
Hamilton	6.4	10.0	21.4	20.0
Edmonton	4.0	6.7	8.3	20.0
Vancouver	25.0	33.8	51.3	11.4

Data presented as %. Sample size per site per time point: Halifax (Nova Scotia): within four months of diagnosis (T1) n=44, six months after diagnosis (T2) n=34, within 12 months of diagnosis (T3) n=33, at school entry at six years of age (T4) n=25; Montreal (Quebec) n(T1)=125, n(T2)=107, n(T3)=113, n(T4)=91; Hamilton (Ontario) n(T1)=47, n(T2)=40, n(T3)=42, n(T4)=30; Edmonton (Alberta) n(T1)=50, n(T2)=45, n(T3)=36, n(T4)=25; Vancouver (British Columbia) n(T1)=89, n(T2)=77, n(T3)=76, n(T4)=70

behavioural code was retained from the original system to reflect the impact of recent public investments in early intensive intervention, and to inform the ongoing debate in many provinces over the accessibility of services (6). Developmental or supported educational services included five of the original 11 codes: SLP; occupational and/or physical therapy; mental health services; services delivered in an integrated setting, such as a community preschool where the child was provided an aide or professional participation in the classroom was the norm; and services provided in a specialized setting, such as a social group for children with ASD. These five service types were grouped together because they generally used typical developmental milestones as a guide to establish intervention targets, and because one-to-one service was generally limited, with family members or minimally trained aides expected to implement specialists' directions. The final broad category, general community services, included mainstream activities that were not specialized for children with disabilities, such as community daycares, preschools without specialized supports and various recreation programs.

RESULTS

Response rates

Of 414 questionnaires distributed at T1, 364 (88%) were completed and returned. At T2, T3 and T4, respectively, 328 (83.2%), 311 (81.4%) and 246 (73%) questionnaires were completed and returned. Some questionnaires were unreadable and, therefore, not analyzed. The total number of questionnaires coded and analyzed was 354 at T1, 303 at T2, 299 at T3 and 241 at T4. Children whose parents/caregivers did not contribute to all assessments were similar at baseline to children whose services data were completed. Therefore, participant dropout was not attributable to variation in severity of ASD, family socioeconomic status or baseline child characteristics such as developmental level.

Children receiving services

The proportion of children receiving services of any kind was 80.5% of the overall sample at T1, 83.5% at T2, 92% at T3 and 93.5% at T4 (Table 2). Fewer than 10% of children at any time point received general services alone; that is, >90% of children receiving services used ≥1 type(s) of specialized service.

Most children received >1 of the three broad service types. Behavioural services were received, either alone or in

combination, by 28% of participants at T1, but by 57.6% at T3. At T1, 69.2% of children were receiving developmental services, either alone or in combination. At T4, this proportion increased slightly to 77%. Roughly 40% to 50% of children were also participating in general community services at each assessment. Each of the broad categories may encompass >1 service type or provider. For example, even when a child was reported as receiving developmental services alone, they may have been receiving SLP or occupational and/or physical therapy while also attending preschool with the support of an aide.

Different combinations of services appeared at different assessment points. As summarized in Table 2, developmental services were the most common type of service overall at T1; however, at T2, most children were utilizing behavioural as well as developmental services. At T3, the highest proportion of children were receiving all three service types, while at T4, the highest proportion of children were receiving a combination of behavioural and developmental services.

Service provision also varied considerably across the country and within sites over time, as displayed in Table 2. Halifax at T2 and T3, and Montreal at T3 were the only sites to report >10% of the children receiving behavioural services alone. Developmental services alone were the most common service option in Hamilton at T1 and T2, in Halifax at T1 and T4, and in Edmonton across all assessments. The combination of behavioural and developmental services was relatively common across sites, peaking in Halifax at T2, in Hamilton at T4, and in Vancouver at T2 and T4. The combination of all three service types was also widespread, peaking in Vancouver at T3, and in Montreal at T3 and T4.

DISCUSSION

Our objective was to describe the service(s) received by preschool children with ASD, using parent/caregiver reports. Three main findings emerged. First, service provision varied considerably across sites and over time. Second, most children received >1 type of service, with a combination of behavioural and developmental services being the most common. Third, most children in the present study received some type of specialized service, including 84% of the sample utilizing some level of developmental or behavioural services, either alone or in combination within six months of diagnosis.

Developmental services were among the first to be implemented across all sites. This finding was consistent with recent reports about service utilization internationally. Most studies involving ASD service utilization focus on medical services, such as paediatrics and psychiatry (eg, Croen et al [9]). However, a recent survey from the United Kingdom reported that SLP and mainstream nurseries, followed by paediatricians, were the services most frequently used by preschool children with ASD (10). Because these standard health and educational services are commonly available and do not require a formal diagnosis for access, they may be more easily accessed when families begin to have concerns. In our data, use of behavioural services appeared to increase over time. This apparent increase may be due to increased demand for, and availability of, behavioural programming following early reports of positive outcomes from the United States (11), and subsequent parent advocacy, legal challenges and policy changes in Canada. Alternatively, it may represent different utilization patterns according to age within the Pathways cohort, without reflecting broader changes in service delivery models.

Service provision also varied considerably across provinces. For example, at T2 42% of the children in Vancouver were receiving a combination of behavioural and developmental services compared with 32% of the children in Halifax, 29% in Edmonton, and <13% of the children in Montreal and Hamilton. At T3,

service provision in Halifax, Montreal and Hamilton appeared to be distributed more evenly across the three broad service categories; however, in Vancouver, nearly 90% of children were receiving behavioural services in combination with other types. In Edmonton, the highest percentage of children consistently received developmental services alone. The proportion of children utilizing services of any type are most discrepant across sites at T1. Small differences in recruitment context and/or processes across sites likely contributed to this. For example, in Montreal, children were diagnosed, enrolled in the study and assessed at T1 almost immediately because diagnosis occurred at a research clinic. At other sites, diagnosis occurred in a clinical setting, with enrollment in the study shortly thereafter.

Our study does not directly address the reasons for the substantial variation across sites; however, one explanation lies in Canada's federalist governance arrangements – in which provincial governments hold primary responsibility for health, education and social services, and the federal government's role is mainly limited to funding. As a result, interprovincial diversity in service delivery is the norm rather than the exception (12). In the case of ASD, the variation in services may have been increased by interprovincial differences in parent advocacy, expert opinion, legal precedent or fiscal capacity. Although this situation can lead to marked differences in opportunities across the country, it can also be a source of innovation, particularly when provinces are able to respond to local population demands. Nonetheless, an urgent task remains: ensuring reasonable access to basic services for all young children with ASD across the country.

Because these data were collected from parent/caregiver reports in 'real world' environments and not from direct observation or under controlled circumstances, interpretation is limited by a lack of information about whether combined service types were coordinated, and on the precise nature of intervention activities within each category. For example, the specific treatment model and intervention targets of behavioural services may vary across providers and provinces. It is common, even in the research literature, to use 'ABA' as a general term signifying commitment to a broad approach, without specifying how the technique has been modified or used (9). In addition, individual therapists providing developmental services may incorporate techniques derived from ABA. Similarly, ABA practitioners may adopt a developmental perspective. These practices effectively homogenize different intervention programs, making it difficult to isolate the elements of effective intervention or to assess fidelity to treatment models described in the literature (8). In addition, it is important to note that these data were obtained from children diagnosed largely between 2004 and 2006, and enrolled in services shortly thereafter in five urban centres. We are unable to comment on any subsequent changes in service delivery, or on service utilization in rural areas or other provinces. Further limitations include the lack of data on intensity of service, on the sources of funding for services received (public or private) and whether families bore an inordinate proportion of costs. Finally, although publicly funded services may be accessible, they are also often limited and paediatricians frequently struggle to find resources for children with ASD.

CONCLUSION

The present study revealed that most of the largely urban Canadian preschool children with ASD in our sample received specialized services within a few months of diagnosis, although it is unknown to what extent services were publicly versus privately funded. One outstanding concern is the marked inter-provincial variation in services, which may have a differential impact on

children's outcomes and families' burdens. Differences in utilization across sites also reflect the absence of a national consensus about optimal clinical treatment pathways for these children. Other pressing questions include how effective these services are at enabling children with ASD to participate in society, and how we can ensure that affected children receive the right services at the right intensity at the right time – and for the right cost. In the long run, linking type and amount of service provision to symptom profiles and outcomes should provide some answers to these critical questions. Our collection and coding of a comprehensive set of services provided across Canada is an important first step toward achieving that goal.

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