Original Article

Environmental scan of Canadian and UK policies for autism spectrum disorder diagnostic assessment

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Abstract

Objectives: Many jurisdictions across Canada and internationally are grappling with providing diagnostic and intervention services for children with autism spectrum disorder (ASD). The objective was to compare Canadian and United Kingdom (UK) policies governing ASD diagnosis.

Methods: The policy scan extended from January 2000 to December 2017. Canadian federal, provincial/territorial, and UK government publications related to ASD diagnosis were retrieved from official websites by searching for ASD and related terms. Retrieved documents were filtered for relevance, with all relevant documents undergoing full text review. Data extracted included personnel and testing requirements for diagnosis, wait times, and eligibility for ASD services and funding.

Results: The included jurisdictions varied substantially in their approach to ASD diagnosis and eligibility for intervention. Nine of the 13 provinces/territories restrict which clinicians can diagnose ASD by requiring certain documentation for service eligibility. Three provinces require multi-disciplinary team assessment (British Columbia [BC], Quebec, and Nova Scotia [NS]). Three provinces (BC, NS, and Prince Edward Island [PEI]) require specific diagnostic tests for diagnosis. Only two provinces, BC and NS, have target wait times for assessment. Jurisdictions differed in whether they allowed children with a provisional diagnosis of ASD to access services. At a national level, the UK provides more clinical guidance for ASD diagnosis, which can be attributed to its centralized system of national healthcare delivery.

Conclusions: ASD diagnostic assessment policies vary across Canada, and between Canada and the UK. Further evidence supporting ASD diagnostic practices is needed to streamline the journey from identification to intervention.

Keywords: *Autism spectrum disorder; Diagnosis; Health services; Policy.*

The growing prevalence of autism spectrum disorders (ASD) (1) has created an increased demand for ASD diagnostic assessments and many jurisdictions across Canada and internationally are grappling with providing efficient and effective services for children with ASD. There currently is no objective gold-standard test for ASD and the diagnosis is made based on the diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (2). Diagnosis requires impairment in day-to-day functioning as a result

of the ASD symptoms as determined through history and clinical observations. The assessment also measures the child's developmental strengths and weaknesses, which can be used to tailor treatment to the child's needs. In practice, some jurisdictions mandate elements of the diagnostic assessment by linking them to eligibility for publicly funded services (3).

Many clinical guidance documents have been published with varying recommendations for the personnel and tools to be

employed in ASD diagnostic assessments (4). To date, there have been no published environmental scans evaluating how these varying recommendations are operationalized in different jurisdictions. Such an analysis is important to provide a foundation for future study of the effectiveness of ASD diagnostic policy.

Canada's federalist governance structure provides an ideal landscape to compare and contrast ASD diagnostic policies. The federal government provides funding through health and social transfers to the Canadian provinces and territories, which have jurisdictional control over how health and social services are delivered (5). These structures may differ from other single-payer health systems, such as the UK, where service delivery occurs at a national level. The objective of this environmental scan was to compare and contrast Canadian and UK government policies that govern ASD diagnostic clinical practice.

METHODS

Scope and eligibility criteria

The scan followed environmental scan methods related to collection of data from published documents (6) and included Canadian federal and provincial/territorial (hereafter referred to as provincial) and UK government publications related to ASD diagnosis. The UK was chosen as a comparator to facilitate comparison between ASD diagnostic assessment services in Canada's federalist governance structure and the centralized structure in the UK. The UK was also selected because of the availability of a national guideline produced by the National Institute for Health and Care Excellence (NICE [7]). Both Canada and the UK have public and private options for accessing ASD diagnostic assessments.

The scan extended from January 2000 to December 2017. The focus was on diagnosis in children younger than age six. Any government documents, including guidance documents, policies, legislation, application forms for funding or services, websites, and brochures, pertaining to ASD diagnosis as described above were included in order to fully describe ASD diagnosis in each jurisdiction. Documents pertaining only to treatment and other ASD management issues were excluded, unless the eligibility criteria for treatment programs required certain diagnostic tests or assessment models.

Search strategy

The initial search was conducted by MP in July 2015 and repeated by MP and LYA in December 2017 to identify the most recent policies. The 'Grey Matters' grey literature search tool published by the Canadian Agency for Drugs and Technology in Health was used (8). Grey Matters is a checklist for grey literature searches that includes national and international health technology assessment websites, health economic resources, health statistics databases, and drug formulary/regulatory

websites. The checklist is also used as a document to record search terms, availability of each website, and the relevancy of the information retrieved.

Federal/national departments whose jurisdiction includes ASD were included in the policy scan. In Canada, these included Senate/Parliament reports, Health Canada (including the Public Health Agency of Canada) and the Canada Revenue Agency (for tax credits). Relevant documents from the UK were included as an international comparison.

Unlike other health conditions, which are solely managed through services delivered through a ministry of health via health practitioners, a neurodevelopmental condition such as ASD requires a commitment across multiple sectors. Provincial ministries involved with ASD were hypothesized to vary by province, and could include health, education, children and youth, and social and community services. The first step in the provincial policy scan was to determine the ministerial jurisdictions related to ASD diagnosis and intervention. This was accomplished by entering ASD (and related search terms including autism, Asperger's syndrome, and pervasive developmental disorder) into the official provincial website search bar. The jurisdictional responsibilities for ASD were then delineated from the search results based on their roles in diagnosis and intervention. Each responsible ministry's page was searched in the same fashion to produce relevant policy documents. One reviewer (MP) reviewed the search results for relevance. Titles were screened for eligibility based on their applicability to ASD diagnosis. All documents with relevant titles underwent full text review with application of the inclusion and exclusion criteria.

Content analysis

A content analysis of the documents was conducted to describe processes governing diagnostic assessment and eligibility for ASD services and funding in each jurisdiction. One reviewer (MP) extracted relevant information from each document. Items extracted included targeted ages or wait times for diagnosis, required personnel or tools for diagnosis, optional personnel and tools, requirement for multidisciplinary team (MDT) assessment, and eligibility for ASD services and funding.

RESULTS

A summary of the policies for each province, as well as Canadian and UK national policies is included below in Table 1. A summary of provincial/national ministries responsible for providing ASD services is provided in Table 2.

Assessment regulations

Three provinces (BC, Quebec, and Nova Scotia) require MDT assessment to make a diagnosis of ASD. For these three provinces, a psychologist, physician, and a speech-language pathologist are expected to be part of the team. The remaining ten

Table 1. Summary of government policies for ASD diagnostic assessment

Process	Requires MDT	Requires certain professionals	Requires certain tools	Target wait time	Assessment at intervention stage	Provisional diagnosis accepted
BC Assessment provided through the British Columbia Autism Assessment Network (20). Families may pursue a diagnosis privately, although eligibility for government funding requires that the diagnosis include all elements listed in the Standards and Guidelines (3).	Yes	Physician, psychologist, and SLP (3)	ADOS ADI-R	6 weeks	No	No
AB No provincial process for diagnostic assessment. A physician or allied health clinician with expertise in ASD can provide documentation confirming a diagnosis or probable diagnosis (21).	No	'Appropriate healthcare professional' (21)	No	No	No	Yes (21)
SK Children with suspected ASD have access to an ASD consultant who will be their case manager, coordinating screening and assessments. The province's website notes that diagnosis may include a number of professionals (22).	No	No	No	No	No	Yes (22)
MB A five-year plan for ASD services was published in 2011, emphasizing goals of timely diagnosis and province-wide access to ASD experts (23).	No	No	No	No	No	No
ON Ontario funded five diagnostic hubs across the province to provide diagnostic assessments, connect families to services, and train professionals in surrounding regions (24).	No	'Qualified professional' (25) Physician, psychologist, or psychological associate (26)	No	No	Yes	No
QC Quebec's Ministère de la Santé et des Services Sociaux (Ministry of Health and Social Services) released a 5-year ASD action plan in 2017 including a goal of establishing varying diagnostic assessment pathways based on age (27).	Yes	Physician, psychologist, and SLP (28)	No	No	Yes	Yes

Table 1. Continued

	Process	Requires MDT	Requires certain professionals	Requires certain tools	Target wait time	Assessment at intervention stage	Provisional diagnosis accepted
NB	No provincial process for diagnostic assessment. Additional assessment of the child's needs is provided at the intervention stage using the Comprehensive Assessment of Learning and Independence, developed by the province in consultation with the Lovaas Institute Midwest (29).	No	Qualified paediatrician, physician, paediatric neurologist, psychologist, or psychiatrist (29)	No	No	Yes	No
NS	Straightforward cases can have 'core' assessment including medical assessment, interview, observation, and ADOS. Psychology and SLP can occur later. Complex cases require 'further' assessment, including all core elements, psychology, SLP, and ADI-R (30).	Yes	Physician, psychologist, and SLP (30)	ADOS (30)	90 days* (31)	No	Yes (32)
PEI	There is no provincial process for ASD diagnostic assessment. Eligibility for services requires diagnosis by certain professionals using standardized tools, including the ADOS and ADI-R (33). Provisional diagnosis is sufficient to be added to the waitlist for early intensive behavioural intervention services, but the diagnosis must be confirmed before starting intervention (34).	No	Physician, psychologist, or psychiatrist (33)	ADOS ADI-R (33)	No	No	Yes (34)
NL	There is no provincial process for ASD diagnostic assessment. Eligibility for services requires diagnosis by a qualified professional (35).	No	'Qualified professional' (35)	No	No	No	No

Table 1. Continued

	Process	Requires MDT	Requires certain professionals	Requires certain tools	Target wait time	Assessment at intervention stage	Provisional diagnosis accepted
YT	There is no territorial process for ASD diagnostic assessment. Various assessments accepted for service eligibility, including: 'a medical assessment from a doctor; mental health assessment, Child Development Centre report, Department of Education report, etc...' (36).	No	No; examples of accepted assessments are provided (see Process).	No	No	No	Yes (36)
NWT	The child is first referred to the Stanton Child Development Team in Yellowknife and to a paediatrician, who subsequently refers to a diagnostic specialist, most often at the Glenrose Autism Centre in Edmonton, Alberta. MDT evaluation is recommended either before or after the ASD diagnosis (37). Provisional diagnosis is accepted for developmental services (38).	No	Medical professional or diagnostic specialist (e.g., psychologist, psychiatrist, neurologist) (37)	No	No	No	Yes (38)
NU	There is no territorial process for ASD diagnostic assessment.	No	No	No	No	No	No
CN	There is no federal process for ASD diagnostic assessment.	No	No	No	No	N/A	N/A
UK	The NICE guideline for ASD diagnosis requires that a MDT make the diagnosis (7).	Yes	Core team members: Physician (paediatrician or psychiatrist), psychologist, and SLP (7)	No	3 months (7)	N/A	N/A

Each jurisdiction is presented, along with a brief description of their processes for ASD diagnosis, any specific requirements, target wait times, and whether they accept provisional diagnoses for access to services. Canada and the UK both have Not Applicable (N/A) listed for interventions because there is no national provision of intervention for either country.

AB Alberta; ADL-R Autism Diagnostic Interview – Revised; ADOS Autism Diagnostic Observation Schedule; ASD Autism spectrum disorder; BC British Columbia; CN Canada; MB Manitoba; MDT Multidisciplinary team; N/A Not applicable; NB New Brunswick; NICE National Institute for Health and Care Excellence; NL Newfoundland and Labrador; NS Nova Scotia; NV Nunavut; NWT Northwest Territories; ON Ontario; QC Quebec; SK Saskatchewan; SLP Speech language pathologist; UK United Kingdom; YT Yukon Territory.

*A diagnostic impression must be formulated within 90 days of disposition.

Table 2. Government services and funding provided for children with ASD

	Ministry funding intervention	Direct services available	Direct funding available
BC	Ministry of Children and Family Development	No	Up to age 6: \$22,000 of funding per year per child. After age 6: \$6,000 per year per child (39). Families contract providers from a list of registered service providers.
AB	Ministry of Human Services	Documentation of a 'severe' diagnosis allows children access to specialized team-based services (40).	Families choose a service provider with funding provided through the Family Support for Children with Disabilities program (21).
SK	Ministries of Education, Health, and Social Services	Children who screen positive will have access to an ASD Support Worker who will provide direct intervention to the child (22).	No
MB	Ministries of Education, Health, Child and Family Services	Manitoba offers direct services for children with ASD under age 18 through Family Services Manitoba's Children's Disability Services (41).	No
ON	Ontario Ministry of Child and Youth Services	Families can choose a direct service option for ABA (25).	Families can choose a direct funding option for ABA (25). Additional funding for individuals with significant functional impairment is available through the Special Services at Home Funding Program (42) and the Assistance for children with Severe Disabilities Program (43).
QC	Ministère de la Santé et des Services Sociaux (Ministry of Health and Social Services)	Prior to school entry: 20 h/week of ABA (44) with flexibility based on needs (27)	No
NB	Ministry of Education and Early Childhood Development	No	Up to school age: \$33,000 in funding per year per child to purchase ABA from provincially approved providers (29,45).
NS	Ministry of Health and Wellness Ministry of Education and Early Childhood Development	One year of ABA services to children prior to school age. Child must participate 6 months before school entry (32).	Tuition support is available through the Ministry of Education and Early Childhood Development for school age children with ASD to attend designated special education private schools (46).
PEI	Ministry of Education, Early Childhood, and Culture	No	Funds \$13.18 per hour for up to 25 h/week to families to offset the cost of an Autism Assistant who provides the individualized treatment for the child (33).
NL	Ministry of Health and Community Services	Provides ABA for children up to Grade 3 (35).	No

Table 2. Continued

	Ministry funding intervention	Direct services available	Direct funding available
YT	Ministry of Health and Social Services	No	The Family Supports for Children with Disabilities provides funding to families to access developmental resources (36).
NWT	Ministry of Education, Culture, and Employment through the NWT Disabilities Council	The Early Childhood Intervention Program provides 1:1 developmental support with an Early Childhood Intervention worker (38).	No
NV	Ministry of Education	The Healthy Children Initiative provides funding to licensed childcare facilities to support the development of children with special needs (47), including occupational therapy, SLP, and supported childcare.	
CN	Canada Revenue Agency		Federal government provides tax assistance for families with a child with ASD if the child has 'marked restriction' in mental functions necessary for everyday life (48).
UK	Local education authorities provide some funding toward specialist education and training, but the provision of this funding varies from region to region. Families are encouraged to investigate the local publicly funded services available through the National Health Service, social services department, and schools (49).		

Each jurisdiction's services are described. Direct service refers to programs that are run by the government. Direct funding refers to money that is provided to families to contract service providers. AB Alberta; ASD Autism spectrum disorder; BC British Columbia; CN Canada; MB Manitoba; NB New Brunswick; NL Newfoundland and Labrador; NS Nova Scotia; NV Nunavut; NWT Northwest Territories; ON Ontario; QC Québec; SK Saskatchewan; UK United Kingdom; YT Yukon Territory

provinces accept a solo clinician diagnosis. Of those, Ontario, Quebec, New Brunswick, and PEI require either a physician or psychologist to make the diagnosis. Alberta, Newfoundland and Labrador, and Yukon specify that a 'qualified professional' should diagnose ASD. The UK, similar to BC, Quebec, and Nova Scotia, requires MDT assessment which includes a physician (paediatrician or psychiatrist), a psychologist, and a speech-language pathologist.

Three provinces require specific tools to be used during the assessment process. BC and PEI require both the Autism Diagnostic Observation Schedule (ADOS) (9) and the Autism Diagnostic Interview – Revised (ADI-R) (10) to be used. Nova Scotia requires the ADOS to be used in all cases, and the ADI-R for complex cases that warrant 'further assessment'.

Most provinces did not publish target wait times for their assessments. BC's target wait time is 6 weeks and Nova Scotia's is 3 months. The UK has reported target wait times of 3 months.

Eligibility requirements for interventions

Seven provinces/territories, including Alberta, Saskatchewan, Quebec, Nova Scotia, PEI, Yukon, and the Northwest Territories accept provisional diagnoses in order to access intervention. The remaining six provinces/territories require a confirmed diagnosis to access intervention. Ontario, Quebec, and New Brunswick also require an additional assessment to determine eligibility for or intensity of the intervention. Neither Canada nor the UK provides interventions at a national level, and as such, no eligibility guidance was provided for either country.

Government services and funding provided for children with ASD

Five provinces, including BC, New Brunswick, PEI, Nova Scotia, and Yukon provide direct funding for families to choose a service provider. Nova Scotia provides 1 year of direct applied behaviour analysis (ABA) service to children under 6 years of age, and also provides funding through tuition support for school-aged children with ASD to attend special education private schools.

Six provinces including Saskatchewan, Manitoba, Quebec, Newfoundland and Labrador, the Northwest Territories, and Nunavut provide direct services. Ontario gives families an option between direct services or funding to choose their own service provider. Alberta provides direct funding for families to choose a service provider and documentation of a 'severe' diagnosis allows children to access specialized team-based services.

DISCUSSION

This scan of Canadian provincial, Canadian federal, and UK national ASD diagnostic policies showed a high degree of variability between jurisdictions. Variations exist in requirements for MDT assessments and at what point in the diagnostic journey various team members become involved. Three of the

provinces (BC, Nova Scotia, and PEI) required the ADI-R and/or ADOS. There was very little Canadian federal input on ASD diagnosis when compared to the UK, which has published a diagnostic guideline. Documents from some jurisdictions suggest 'ideal' practices, though these may differ from the actual requirements for diagnostic practice, which are operationalized through eligibility requirements for ASD interventions. The variation in policies for ASD diagnosis suggests that the ways in which the diagnostic assessment informs intervention strategies have not been fully elucidated beyond simply determining eligibility for costly interventions. A review of ASD diagnostic guidelines by our group (4) similarly found that many guidelines endorsed MDT assessment in order to inform the treatment strategy; however, there is no current empirical evidence to support this link between diagnostic assessment and treatment. Further, a recent survey of Canadian paediatricians by our group found substantial variability in ASD diagnostic practices, indicating a disconnect between recommendations and actual practice (11).

Only BC, Nova Scotia, and the UK published target wait times for assessments. Many jurisdictions have wait lists to access a definitive ASD diagnosis, which is a prerequisite to accessing behavioural interventions in six of the jurisdictions in this scan. Requirements for MDTs or extensive assessment may place further stress on these waitlists, which may delay access to early intervention. Our recent survey of Canadian paediatricians (11) also showed that ASD diagnostic wait times are over 7 months from referral to diagnosis, with reported provincial median wait times outside the target ranges provided in this scan (e.g., a median reported wait time of 9.5 months in BC), highlighting additional discrepancies between recommendations and actual practice. These wait times occur when the brain is optimized for social learning (12) jeopardizing long-term outcomes by delaying access to early behavioural intervention programs (13). A cost-effectiveness analysis (14) estimates that prioritizing timely access to ASD interventions not only improves long-term independence outcomes, but also saves money at both provincial government (53,000 Canadian dollars per person with ASD over the lifespan) and societal (267,000 Canadian dollars per person with ASD over the lifespan) levels.

The provinces varied greatly in their approach to intervention. Six provided only direct ABA services, four provided only direct funding for ABA, and three had both direct funding or direct service options. Seven provinces permitted children to access ABA services with a provisional ASD diagnosis. There does not appear to be a clear connection between each province's requirements for diagnosis and either the type of service offered (direct provision versus funding) or the acceptance of provisional diagnosis.

When examining regional patterns, there was a tendency toward fewer diagnostic requirements in the Prairie provinces, particularly Saskatchewan and Manitoba, as well as in the territories. Instead of reflecting regional healthcare preferences, this

may be more reflective of challenges accessing MDT or subspecialist assessments in jurisdictions that are less densely populated than other Canadian provinces.

Most of the diagnostic services were provided through medical practitioners and ministries of health; however, the ministries involved in intervention differed according to jurisdiction and included health, education, family or children, or community and social services. This reflects the complexity of ASD and the resulting difficulty in housing ASD within appropriate branch/branches of government. The division of diagnosis and intervention between sectors creates a potential disconnect for resource considerations such as advocating for resource-intensive diagnostic assessments without considering the impact on service delivery, or conversely, implementing lax diagnostic requirements without consideration of the impact of false-positive cases on wait times and costs.

Some ministries provided cross-sectorial services, such as those provinces with combined health and social services ministries (Quebec, Yukon), or those whose ministries partnered to provide services (Manitoba, Saskatchewan). Cross-sectorial service delivery theoretically reduced silos in care delivery, but this model requires further evaluation as there is an accompanying risk that multiple stakeholder interests can hinder policy development.

There was little federal input for ASD diagnosis in Canada when compared with the UK, which is likely due to the differing health-care structures, with more centralized health care policy-making in the UK. In contrast to the provincial policies, the UK guidance document focused predominantly on assessment, as there is no provision of ASD services at a national level in the UK. The 2007 Canadian Senate report called for a national ASD strategy, which led to the formation of the Canadian Autism Spectrum Disorders Alliance (CASDA), who led the Canadian Autism Partnership Project (CAPP) from 2015 to 2017 (15). One of the aims of CAPP is to create ‘an authoritative access point for reliable data to inform policy development, funding decisions, and service delivery’ (15); however, given the provincial control over health, social, and educational service delivery, it remains unclear how a national ASD strategy would effect change without attaching new funding to monitor certain benchmarks or legislating requirements for ASD assessment and intervention.

The results of this policy scan have important implications for families. Parent advocacy groups have paid less attention to the assessment and diagnostic process, with much of the effort going into securing public funding for interventions (16–18). In a recent qualitative study of ASD policy in Canada, parents described that after they received the diagnosis, they quickly shifted to a feeling of ‘panic’ about securing interventions for their child (19). As a result, less energy may be directed toward the process that brought families to the ASD diagnosis. Still, the journey leading to diagnosis should not go unexamined, as a prolonged wait time for diagnosis results in parents paying out-of-pocket for services of their own choosing while waiting

for public sector services, or children seeking intervention at an older age, which only serves to heighten parental anxiety about accessing early intervention.

These results also have significant implications for decision makers. Eligibility-based requirements for ASD diagnosis may have significant implications on assessment and wait times for diagnosis. Further work is needed to determine the necessary elements of accurate ASD diagnostic assessment, research recommended in the UK guideline (7). This information may allow for streamlining of the diagnostic journey and facilitating access to intervention.

This review had some limitations. The scan of Canadian policies produced only one clear guidance document (the BC guideline), and as a result, the remaining descriptions of ASD diagnostic systems and policies were assembled from the grey literature. There may be additional policies relating to ASD diagnosis and intervention that are not published online and were not identified in this policy scan. This scan may not provide a comprehensive view of how these policies function in the real world. This information would be valuable in assessing the potential gap between policy and practice.

In conclusion, ASD diagnostic assessment policies vary considerably, including necessary tools and personnel for assessment, and provision of intervention. This variation has developed within Canada’s federalist system, wherein each province delivers ASD services, in contrast to the UK’s centralized system, which facilitates the development of national standards and processes. Further evidence supporting ASD diagnostic policies is needed to streamline the journey from identification to intervention.

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