

Perspectives of Canadian Rural Consultant Pediatricians on Diagnosing Autism Spectrum Disorder: A Qualitative Study

Jennifer Das, MD, FRCP(C),* Laura Hartman, PhD,† Gillian King, PhD,†‡ Nicola Jones-Stokreef, MD, FRCP(C),§ Charlotte Moore Hepburn, MD, FRCP(C),|| Melanie Penner, MSc, MD, FRCP(C)*†

ABSTRACT: *Background:* Consultant pediatricians represent a potential resource for increasing autism spectrum disorder (ASD) diagnostic capacity; however, little is known about how they perceive their roles in ASD diagnosis. *Objective:* The objective of this study was to examine the perspectives of rural consultant pediatricians regarding their perceived roles, facilitators, and barriers in ASD diagnosis. *Methods:* We performed a qualitative study using thematic analysis. Consultant pediatricians from 3 small-sized and medium-sized Ontario communities were recruited. Semistructured interviews were conducted, transcribed, coded, and analyzed. *Results:* Fourteen pediatricians participated in this study. Participants all considered ASD diagnosis to be in their scope of practice. The major theme identified was the process of diagnosing ASD, which occurred in 3 stages: preassessment (gathering information before the first clinic visit), diagnosis, and service access. All these stages are influenced by ecological factors consisting of characteristics of the child, family, individual physician, pediatric group practice, and the broader system of ASD care. *Conclusion:* Consultant pediatricians practicing in nonurban Ontario communities see ASD diagnosis as part of their scope of practice and collaboratively work within groups to address the needs of their communities. Strategies aimed at increasing diagnostic capacity should target salaried group practices and improve the efficiency of assessments through preclinic information gathering.

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Autism spectrum disorder (ASD) refers to a group of neurodevelopmental disorders comprising difficulties with social communication skills and restricted and/or

From the *Division of Developmental Pediatrics, Department of Pediatrics, University of Toronto, Toronto, ON, Canada; †Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada; ‡Department of Occupational Science and Occupational Therapy, University of Toronto, Toronto, ON, Canada; §Developmental Pediatrics, Orillia Soldiers Memorial Hospital, Orillia, ON, Canada; ||Pediatric Medicine, Hospital for Sick Children, Toronto, ON, Canada.

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Address for reprints: Melanie Penner, MD, Holland Bloorview Kids Rehabilitation Hospital, 150 Kilgour Rd, Toronto, ON M4G 1R8, Canada; e-mail: mpenner@hollandbloorview.ca.

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repetitive behaviors.¹ In 2015, the reported prevalence of ASD among children and youth aged 5 to 17 years in Canada was 1 in 66 children.² The most recent US data estimate a prevalence of 1 in 54 children.³ Both countries have noted a continued increase in prevalence when compared with previous years. Receiving a diagnosis of ASD is a pivotal point in a child's care pathway; in many jurisdictions, it is required before a child can receive interventions.⁴ Evidence shows that intervention at young ages improves outcomes for children with ASD,⁵ emphasizing the importance of timely access to diagnosis.

There has been some debate about which clinicians can diagnose ASD. Although some clinical guidelines recommend that only a team of clinicians should diagnose ASD,^{6,7} recent guidelines from both Canada⁸ and Australia⁹ propose that streamlined diagnostic assessments can be conducted by an experienced solo practitioner, such as a pediatrician, in more straightforward cases. In many jurisdictions, pediatricians are authorized to provide a diagnosis of ASD; however, many refer most, if not all, patients to subspecialty assessment to confirm their suspicions,¹⁰ increasing demand for subspecialist assessments and contributing to wait times.

When examining ways to increase diagnostic capacity, researchers have begun to explore the role that pediatricians play in the diagnostic process. Specifically, consultant pediatricians, who see children referred to

them by a primary care provider after a pediatric concern has been identified, might be well positioned to incorporate ASD diagnosis into their scope of practice. Consultant pediatricians are in higher supply than subspecialists and could help to alleviate wait times for ASD diagnosis for families.¹¹ A recent study using pediatricians as initial diagnosticians in a tertiary clinic reported high diagnostic agreement (93% for ASD-positive cases and 100% for ASD-negative cases), a 44% reduction in wait time, and 33% lower costs than their traditional multidisciplinary model.¹²

Involvement of consultant pediatricians in ASD diagnosis holds promise to improve diagnostic access; however, relatively little work has explored their perceptions of providing ASD diagnoses. In 2017, Penner et al.¹³ published a qualitative study involving in-depth interviews with consultant pediatricians practicing in an urban Ontario setting regarding their perspectives of the ASD diagnostic process. The 11 participants in this study expressed a range of comfort levels with ASD diagnosis and discussed 3 stages of the assessment process: determining the diagnosis, communicating the diagnosis, and service navigation after diagnosis. Importantly, the decision of whether to provide a diagnosis could be determined by facilitators or barriers at any of these stages. These stages occurred in a broader ecosystem of factors at levels of the child and family, the pediatrician, and the system of care. To improve diagnostic capacity, the authors suggested several strategies including increasing ASD-specific training, improving remuneration, and assisting in service navigation. An important limitation of this work was that the study interviewees all practiced in a large urban center with subspecialist availability.

Little is known about whether the results of the 2017 study are relevant to consultant pediatricians practicing outside of urban settings. There is good reason to focus on access to diagnostic services in rural communities. Children living in rural environments are diagnosed at later ages than their urban counterparts.¹⁴ Authors have hypothesized that limited access to services (including pediatrics and subspecialty care) and lower socioeconomic status could explain this discrepancy in age at diagnosis between urban and rural children. Indeed, a recent US study on geographic access to ASD care found that diagnostic resources were sparsely and unevenly distributed, which may contribute to long wait times and the need to travel long distances for a diagnosis.¹⁵ A survey of parents of children with ASD in Kentucky found that parents in nonmetropolitan counties reported significantly more difficulty seeing a physician or trained professional with ASD expertise compared with urban participants.¹⁶ In communities where availability of subspecialists is limited, community providers such as consultant pediatricians may be expected to take on additional responsibilities in ASD care, including diagnosis. However, to date, no studies have explicitly asked rural consultant pediatricians about their role in

ASD diagnosis, leaving little evidence upon which to build diagnostic access strategies for rural regions. The objective of this study was to examine the perspectives of rural consultant pediatricians regarding their perceived roles, facilitators, and barriers in ASD diagnosis so that we may propose improvements to diagnostic practices in rural regions.

METHODS

Research Paradigm and Qualitative Approach

This study used thematic analysis within a social constructivist paradigm. We selected this paradigm because it theorizes that knowledge and meaning are derived from social interactions and context.¹⁷ This was the ideal paradigm for this work because of our desire to understand how a number of social and contextual factors can interact and influence the pediatrician's decision of whether to conduct autism spectrum disorder (ASD) diagnostic assessment for a particular patient and family. Our research team also has considerable ASD experience, and we recognize that we are active participants in the creation of knowledge in this study. We selected thematic analysis for this study because it provided a means for developing a framework based on the participants' experiences.¹⁸ Thematic analysis does not rely on a pre-existing theoretical framework but instead attempts to capture the patterned responses within the data and how they relate back to the original research question. Our research objective and approach were informed by Penner et al.¹³ and the desire to determine whether those results could be transferred outside of an urban environment. Although informed by this study, we did not predetermine the framework, themes, or the coding guide and instead applied an iterative approach to developing these.

Researcher Characteristics

J.D., a developmental pediatrics fellow in Ontario, Canada, completed the recruitment and interviews for this study. The other members of the research team have all previously conducted qualitative research. Other members of the research team include a developmental pediatrician, 2 consultant pediatricians, an occupational therapist, and a scientist focusing on psychosocial aspects of childhood disabilities.

Context

All Canadian residents have access to universal health care that covers all physician visits. Most primary care in the province is provided by family physicians, general practitioners, or nurse practitioners with pediatricians often serving in a consultant role. This consulting pediatrician role also exists in Australia¹⁹ and the United Kingdom.²⁰ Canadian pediatricians complete at least 4 years of residency training, including at least one rotation in developmental pediatrics.²¹ In Ontario, funding for ASD-specific therapies is covered for eligible children;

however, children must receive an ASD diagnosis before they are able to receive these funds.²² Any type of physician in Ontario is permitted to provide a diagnosis of ASD (in addition to psychologists, psychological associates, and nurse practitioners), with no requirements for standardized testing.

To balance breadth of experiences and depth of understanding, we selected 3 rural communities in Ontario of varying size and distance to the nearest tertiary center. For the purposes of this work, our inclusion criteria for communities were small-sized (population between 1000 and 29,999) and medium-sized (population between 30,000 and 99,999) communities that were at least 100 km from the nearest tertiary care center. We focused on small-sized and medium-sized communities because these were large enough to have a pediatric group practice but did not have the same access to tertiary resources as a large urban center. The centers in this study also serve the less densely populated communities in their surrounding areas. Orillia has a population of 31,000 people and is located just over 100 km from Toronto, the nearest tertiary care center. North Bay has a population of 51,000 people and is nearly 300 km from Toronto. Sault Ste. Marie has a population of 73,000 people and is approximately 500 km from Toronto.

Participants and Recruitment

All consultant pediatricians in these communities were potentially eligible for participation. Contact information for potential participants in each community was first collected using an Ontario public directory. A recruitment letter was then sent to all potential participants introducing the study. This was followed by a telephone call by J.D. to assess the pediatrician's eligibility and willingness to participate. Potential participants were excluded if they did not have an outpatient practice in which they saw children with possible ASD or if their primary practice was located outside of one of the selected communities. The research team decided a priori to start with 3 communities and to then assess for data saturation, which was defined as 3 successive interviews that failed to add new codes or themes to the data set as determined by the research team.²³ In the event that saturation was not reached, further communities would have been added. An honorarium of \$150 Canadian dollars was sent to participants on completion of their interview.

Compliance with Ethical Standards

Research Ethics Board approval was obtained before initiation of the study. Interested participants were sent a copy of the study consent form for their review before their interview. Verbal consent from each participant was obtained before the initiation of each interview and audio-recorded in a separate file.

Data Collection

Participants underwent individual, in-depth, semi-structured telephone interviews with J.D. between De-

ember 2016 and January 2017. At the beginning of each interview, participants were given a case description of a child who met Diagnostic and Statistical Manual of Mental Disorders, 5th edition criteria for ASD. This case was also used in a previous qualitative study of pediatrician perceptions of ASD diagnosis.¹³ This study built off the interview guide from Penner et al.'s study of urban pediatricians, which was also constructed from a social constructivist perspective based on the reflections of the ASD diagnosticians (including consultant pediatricians) on the research team. Interview questions for this study were refined in consultation with a rural developmental pediatrician to further capture relevant experiences unique to rural practice (Supplemental Digital Content 1, <http://links.lww.com/JDBP/A323>). These questions focused on the participant's experiences within the current ASD diagnostic system in Ontario, their thoughts regarding diagnostic capacity, and their views regarding potential differences between their practices and those in urban environments. At the end of each interview, participants were asked for their demographic information (sex and years in practice), additional training in child development, and average wait times in their practices for medical, developmental, and ASD-specific consults.

Data Analysis

Audio-recordings were transcribed using a professional transcription service and then verified by J.D. for completeness and correctness. Any identifying information was removed at this stage. Analysis started after reading the first transcript and continued in an iterative fashion.²⁴ Investigators J.D. and M.P. read and conducted open coding on the first 3 transcripts independently, after which an in-person meeting was held to develop the coding guide. To enhance trustworthiness, J.D. coded all the interviews, after which a second investigator (M.P., G.K., C.M.H., or L.H.) was provided with the initial coding guide and conducted their own independent coding for comparison and to add to the coding guide. The research team met periodically to discuss the codes and the emerging data, discuss ongoing impressions of the interviews, and generate new codes. As part of our iterative analysis process, discussions about the transcripts led not only to codes but also to questions and impressions. For example, because of our process, questions regarding new changes to the province's funding model were added to the interview guide, and earlier transcripts were reviewed more closely for discussion on the topic. Through these ongoing meetings and guided by the lead author, the team began to develop categories of codes that highlighted the perspectives of rural consultant pediatricians regarding their perceived roles, facilitators, and barriers in ASD diagnosis.

After all interviews were coded and categorized, the research team then met to explore how the categories that had emerged from the data could be further

Table 1. Participant Characteristics

Characteristic	N
Sex	5 male, 9 female
Years in practice	Median 10 (range 0.25–40)
Time allotted for new pediatric consults	Median 60 min (range 60–90)
Time allotted for developmental consult	Median 90 min (range 60–120)
Wait time for new consult	Mean 3.3 mo (range 1–12)
Wait time for new developmental consult	Mean 4.6 mo (range 1–2)
Wait time for new ASD consult	Mean 3.9 mo (range 1–12)
Additional ASD training	No extra training outside of residency: n = 5 Formal ADOS training: n = 4 “Mini” ADOS ^a training: n = 3 Worked with mentors after residency: n = 2

^aMini ADOS refers to an abbreviated form of the ADOS that is taught regionally. ADOS, Autism Diagnostic Observation Schedule (Lord et al., 2012); ASD, autism spectrum disorder.

interpreted into themes and factors that related to perceived roles, facilitators, and barriers in ASD diagnosis. These themes were organized into a framework to describe our understanding of rural pediatricians’ experiences of ASD diagnosis based on the interview data.

To improve the trustworthiness of the qualitative analysis and credibility of the findings, the constructed framework and themes were distributed back to participants with a request for written feedback as a form of member checking.²⁵ Participants were welcomed to provide feedback on the constructed framework, and feedback would be incorporated and resent for further member checking. Feedback received from 11 participants showed general endorsement and did not necessitate any changes to the framework or resubmission to participants for further feedback.

RESULTS

Participants

Fourteen consultant pediatricians participated in this study. Participating pediatricians’ communities are not named to maintain anonymity. The overall response rate was 14 of 22 eligible participants (64%). For community A, 7 of potential 10 eligible consultant pediatricians participated in this study. Community B had 4 of 7 eligible consultant pediatricians participate, and community C had 3 of 5 eligible pediatricians. Participant demographic information is described in Table 1. All participants provided autism spectrum disorder (ASD) diagnoses within their practices, and all 3 communities had developed strategies to address the need for local ASD diagnostic assessments.

An Ecological Framework of Factors Influencing the Autism Spectrum Disorder Diagnostic Process

We identified one overarching theme: Consultant pediatricians move through a process of making an ASD diagnosis. The constructed diagnostic process consisted of 3 stages. The first is the preassessment stage, in which

the pediatrician’s office reaches out to a variety of sources for more information regarding the patient. The second stage, diagnosis, concerns the diagnostic assessment undertaken by the consultant pediatrician, including communicating the diagnosis to the family. The final stage, service access, occurs after the diagnosis is communicated and patients/families are connected to ASD-specific services.

The research team reflected on the perceived roles, barriers, and facilitators communicated by participants in each stage and constructed an ecological framework to represent the multiple levels at which the diagnostic process is experienced and enacted.²⁶ Exploration of factors at the level of the child includes the child’s age, sex, signs and symptoms of ASD, and other medical history. The next level is the family, which includes pre-existing views, beliefs, and knowledge that families have about ASD. The subsequent level of the consultant pediatrician includes the consultant pediatrician’s perceived role in the ASD diagnostic process, their individual approach to ASD diagnostic assessment, any ASD-specific training they have undergone, their previous experiences with diagnosing ASD, and their general interest in ASD. The pediatric group level refers to how the group of pediatricians in the region has organized itself to serve the needs of their community for ASD diagnosis and other developmental care. Systems-level exploration includes resource allocation, remuneration, wait times for publicly funded therapies, and how these factors influence the diagnostic process.

All factors presented in the following Results subsections are organized within our ecological framework of factors influencing the ASD diagnostic process. Supporting quotations for the framework elements are provided in Table 2 along with a participant identifier (e.g., A3 is the third participant interviewed in community A).

Preassessment Stage

The preassessment stage involves information seeking on the part of the consultant pediatrician’s office. Although this stage consumes resources, it adds efficiency to subsequent stages; for instance, less face-to-face time is needed for information gathering, and parents are more prepared for the assessment. Participants commented on how standard referral processes prioritize children who have “medical” issues, thereby resulting in increased wait times for developmental assessments (A2 and A6). For many physicians, appointments could not be scheduled until the family provided required documents containing information about the child. Thus, for families who have difficulty organizing these documents, wait times for an appointment could be longer (A2 and A3). It was also felt that the preassessment process could be used to help prime families to start thinking about the possibility of ASD in their child, thereby decreasing some of the time clinicians had to spend explaining signs/symptoms of ASD and possibly easing the communication of the ASD diagnosis (A2 and C2).

Table 2. Representative Quotations

Preassessment Stage	
Levels	Representative Quotation
<p>Child</p> <p>Children with medical issues are triaged more urgently, leading to longer development wait times</p> <p><i>Intersects with systems themes</i></p>	<p>“School, learning problems and behavior problems; those types of referrals tended to get sort of a second priority when they were being triaged because they weren’t acute medical problems.” A2</p>
<p>Family</p> <p>Family required to provide information in order for an appointment to be booked</p> <p>Preassessment process may help to prime family for ASD diagnosis</p>	<p>“If everybody has the wheels on and the parents are reachable when we—because we contact them right away, so if they were reachable and could do their interview the next day ... then booking to see me is about 3 mo” A3</p> <p>“They’re being issued these rating scales that are designed to look at autism ... So by the time they get to us there’s—a seed has already been planted. So they know they’re coming in to settle that question.” C2</p>
<p>Consultant pediatrician</p> <p>Information gained helps to improve diagnostic efficiency</p> <p><i>Intersects with pediatric group themes</i></p>	<p>“So it moves diagnosis forward. So in the first visit, you can actually have all of that information rather than sending it out to the parent and the school for a return at the subsequent visit. So that way we can fit a few more patients in.” C2</p>
<p>Systems</p> <p>General developmental services can be accessed</p>	<p>“We’ve also now added a box to our packages that says, you know, if the child’s not already involved with early intervention services locally here can we send your information to them.” A2</p>
Diagnosis Stage	
<p>Child</p> <p>Individual child factors determine the amount of testing required in the diagnostic process</p>	<p>“So there’s 3 buckets; there’s the kids that are clear and straightforward and I can label on the first visit or a second visit if the parents aren’t ready. There’s kids that are kind of grey, in the middle, but that I can sort out by some testing and repeat assessment. And then there’s a third bucket of kids where I do everything that I can and I think “I don’t really know” and I refer them on to a speech therapy ADOS and then I bring them back and see them myself.” A6</p>
<p>Family</p> <p>Parental beliefs about ASD affect the diagnostic process</p> <p>Conveying the diagnosis to the family is influenced by the family’s views of ASD</p>	<p>“In that case scenario where parents are, you know, one party is believing the child is autistic, other is not, in order for them to come to terms to a diagnosis, it’s better to do it through (the multidisciplinary) developmental clinic.” B2</p> <p>“A lot of the time the direct observation of the child doesn’t really line up with what you’re hearing from the parent. And in those cases I would say, okay, it’s really difficult for me to arrive at a diagnosis in 90 min.” C2</p> <p>“I just try and point out where their strengths and weaknesses are and how we can help them best and that’s how I kind of sell it ... I do have the occasional family where they’re like “Yeah, he doesn’t have that” and I’m okay to work with them on that, you know, because everybody’s an individual and everybody’s different.” A7</p>
<p>Consultant pediatrician</p> <p>Mentors help pediatricians to start doing ASD diagnostic assessment</p> <p>Residency training did not provide adequate exposure to developmental pediatricians</p> <p>Conflicting views regarding whether ASD diagnosis should be a core competency for consultant pediatricians</p>	<p>“I did work with [community developmental pediatrician] as sort of a mentor where I certainly went and worked in her clinic, directly with her and then for a period of about a year and a half, I reviewed cases with her monthly to make sure that we’re happy about how things were going and we continued to meet monthly to review difficult things.” A3</p> <p>“So as a resident you don’t get a ton of training in this, all your training really is in acute care medicine and then a little bit of the developmental stuff on the side ... you just don’t feel they get enough of it and yet it’s like 90% of community pediatricians do.” A2</p> <p>“So I do think that it’s very possible, but I think it’s a big ask of general pediatricians in their current model because I think they’ve got a lot on their plate ... until you develop some expertise and confidence and whatever, I think that’s hard to really change and I think it’s hard to do it well.” A3</p> <p>“I think general pediatricians outside of northern Ontario should also be making diagnoses ... And not just kind of early detection and then shipping them off to a subspecialist. They should be familiar with making those referrals to community services ... and being able to kind of screen for comorbid medical and mental health disorders.” C2</p>

(Table continues)

Table 2. Continued

Diagnosis Stage	
Consultant pediatricians may reassess after a period of time to help improve diagnostic certainty	"So they're hooked up with developmental services and I'll see them in about 6 months and reassess things. And sometimes things become more clear or less clear at that time and then we can make a diagnosis, or sometimes the problems seem to dissipate, and then, you know, maybe it's just a transient kind of thing." A7
Consultant pediatricians discuss with each other to improve diagnostic certainty	"I was fortunate enough to join a group where some of them were already doing (ASD diagnosis). And so, having that mentorship was really valuable." A5
Pediatric group	
Group determines expectations of their scope of practice re: ASD	"And part of the philosophy of our group is that everybody does everything. So everybody has to do these assessments . . . And so I'd go to them and say "Well, how do I do this and should I refer?" and they look at me like I had 7 heads "You don't have to refer. You do this." I'm like "Oh, we do that." "Yeah, you do that. Of course you do that. Here's how you do it." . . . So there's a lot of mentoring and support that went on that way, and the culture of the group was such that we sort of shared that culture with each other." A6
Designating one of the consultant pediatricians to address more developmental issues than the others in the group	"And I think that part of the reason that we switched to a model in our group where we have one designated person who's doing of the majority of this now, is because we were drowning in wait lists." A1
Group collectively determines the standard of care for ASD diagnostic assessments	"But there's variability among the pediatricians but we always talk about it as a group." A4
Systems	
Diagnostic fee codes influence the assessment process	"So there's these developmental fee codes right where you kind of have to spend an allotted amount of time with them . . . I'd rather see them for a shorter time and then book them back for a follow-up than, you know, book them in purposely for that long so I can bill the code." A2
Ability to perform ASD assessments is influenced by funding models	"I'm also not sure, like, how this would even work in a non-[salaried] model . . . I see the codes I kind of just mentally add things up, I'm like, Jeez that's—I'm doing a ton of work for, you know . . . it just seems like it doesn't really pay very well." A2
Responsibility to ensure that referrals for further care are appropriate	"I think that my role is really to see and diagnose and get on the pathway towards therapy and support as much as I can in order to take the burden off of the more specialist people, like developmental pediatricians, who are more to see the kids who are trickier." A1
Relationships with allied health care providers increase diagnostic comfort and improve patient care	"We feel better now because we have a cohort of people with skills, training and understanding of autistic kids even if they're coming at it from a different perspective . . . Take the time to develop good working relationships with all the auxiliary colleagues because they support you and help you to feel better about your decisions." B4
Service Access Stage	
Family	
Self-referral requirements delay access for families who struggle with system navigation	"There's (a) delay in accessing services from the family's part afterward and sometimes it's, you know, 3 or 4 mo later I see them, and they haven't contacted anyone." A5 "So, the families that seem capable, I don't (bring them back to my clinic); the families where I really worry that they're not going to connect with anything, sometimes I do." A5
Consultant pediatrician	
Responsibility to provide continuing care for patients postdiagnosis	"First initially after the diagnosis I will see them every 4 mo and then I will stretch it to 6 mo and if they are doing well then I will do an annual visit. Just see where they are at school, what programming they're getting, whether they need my help to advocate for them." B2
Responsibility to advocate for patients in their communities	"I think the overall (role for children with ASD) would be advocacy . . . educating them and the people that work with them and linking them up with community resources." A7
Systems	
Definitive diagnosis required to access certain services	"The children that I offer (diagnostic assessment in my office) to, are the ones that I think have the most classic symptoms of autism, with the highest degree of severity, that I would like to provide a diagnosis, so that they can access appropriate intensive services early." B1
The benefits of needs-based service eligibility	"I think we should be focusing more on being able to obtain services without the diagnosis—so more symptom-specific services rather than diagnosis-specific services." C1

(Table continues)

Table 2. Continued

Service Access Stage

Lack of services available for older children	"The challenge for the adolescent one that comes in, you do an ADOS and it's sufficient to provide a supportive diagnosis for the older kids but then there's no services." B3
System navigation is facilitated by the physician's personal relationship with allied health care providers	"I walked across the corridor to where the program manager was and I spoke to her and said, "I believe that this patient is eligible for your program." She agreed and took the referral and said, "We will deal with it." So that was the end of that." B4
Consultant pediatricians feel pressure to make a diagnosis before the child ages out of publicly funded intensive behavioural services.	"There's some urgency to try and get some services in place especially before school age, and maybe more likely to label that kid a little sooner rather than later." A6

ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder.

The individual physician belief that all patients should have timely access to ASD assessments influences the design of the preassessment phase because it was felt to improve overall efficiency of the diagnostic process (A2, A6, B2, and C2). This belief occurred at both the individual pediatrician and pediatric group levels. At the systems level, many of the preassessment descriptions focused on assisting patients to receive general developmental services that are available without a diagnosis (i.e., speech therapy and early intervention) before seeing the pediatrician for a developmental assessment (A2, B3, and C1). Many participants found the preassessment time valuable in streamlining the in-person diagnostic assessment; however, this time is not remunerated in a fee-for-service model (A1 and A5).

Diagnosis Stage

The diagnosis stage was by far the most commonly discussed and deeply explored subtheme. This stage includes the assessments conducted by the consultant pediatrician, deciding on a diagnosis, and communication of the diagnosis to the patient and family. All ecological levels of the framework of factors influencing the ASD diagnostic process were deeply considered and explored by participants.

All participants reported that they tailor their diagnostic process based on the child's presentation to determine what testing is required. Children who have clearer symptoms of ASD may not require as many elements of assessment compared with those whose presentations are more subtle. The Autism Diagnostic Observation Schedule²⁷ was an identified additional element of assessment for some children that participants could perform themselves (B1-2, B4, and C1), ask a pediatric colleague to perform (B3 and C2-3), or refer to a trained allied health care provider, such as a speech-language pathologist, to perform (A1-7 and B3). All participants could refer more complex cases to subspecialty clinics but noted long wait times for these assessments.

At the family level, parental knowledge and preconceived ideas about ASD affected the diagnostic process. The diagnostic assessment relies on information from parents and is influenced by their reporting, and as such,

participants reported a need to be keenly aware of how a family's beliefs may affect the accuracy of the diagnostic process (A7 and C2). After a diagnosis has been determined, conveying that information to families is also affected by their beliefs about ASD, whether positively or negatively (A6-7 and C2). For example, if a parent was unwilling to accept a diagnosis of ASD, this may prompt the pediatrician to refer to a subspecialist to gain further information, or they may continue to follow the patient themselves (A1-4, A7, B1-2, and C2-3). Thus, family factors influence the time needed with the patient and determine the approach that the pediatrician takes to ascertain and disclose the diagnosis.

Participants' comfort level with making a diagnosis was influenced by both their training and access to physician mentors, who were either experts in development or more experienced colleagues (A2, A5-6, and C2). Many participants had to personally seek out additional training after residency at their own expense to feel knowledgeable enough to complete diagnostic assessments (A3, A5, A7, B1-2, B4, and C2). Many also did not feel that the developmental training received in residency was adequate for their community practices (A2, A5, and B2-3). Participants had conflicting views as to whether ASD diagnosis should be a core competency for consultant pediatricians, expressing that consultant pediatricians are already asked to do a lot and require some expertise to take on this work.

When participants encountered uncertainty in the diagnostic process, many would see those patients back in their clinic after a period of time rather than referring to another provider. This reassessment approach developed out of a pediatrician's individual ownership of the case, difficulty obtaining access to subspecialists, and occasionally out of family factors (i.e., willingness to accept a diagnosis) (A1-3, A6-7, B1, B4, and C1-3). Participants also collaborated with the members of their group to help increase diagnostic certainty (A5, A7, B4, and C2).

The pediatric group sets the expectations and norms regarding services/expertise their members are to provide in relation to developmental care (A3, A6, B2, and

C2), including identifying certain physicians with more expertise in assessing for ASD (A1-2 and C2). In one community, the pediatrician who took on more developmental care was compensated for this by being excused from doing acute care on-call work (A2). Some groups also collectively discussed what their standard of care would be for diagnostic assessments (A4, A6, and C2), such as whether standardized testing must be used.

At the systems level, participants noted that finding time in their schedule to complete an ASD assessment is challenging (A1-3 and B1-3). All the participants interviewed practiced in a salaried funding model, and most felt that a fee-for-service model would negatively affect their ability to see patients with possible ASD (A1-3, A6-7, and B1-4). All participants also practiced consultative pediatrics, in which they only see children who are referred to them and not primary care. Many participants commented on this consultative model of practice influencing their comfort level in making definitive diagnoses in many health and developmental conditions (not only ASD). Some felt that a primary care model could make it more difficult to diagnose ASD because the practice model is set up for shorter visits and pediatricians would be used to referring patients more frequently (A1-2, A4, A6-7, B2, and B4).

Participants were keenly aware of the scarcity of further diagnostic input (i.e., from subspecialists) and felt pressure to reserve their referrals for cases where they truly needed further expertise if this option was even available (A1-2, A6-7, and C2). Many noted their relationship with allied health care providers as a factor that increased their diagnostic comfort and ability to provide comprehensive assessments (A5-7, B1-4, and C2-3). Some even noted that by practicing in a smaller community, their relationships with allied health care providers were fostered and led to an open line of communication and improved patient care (A6, B4, and C2).

At the time of the interviews, most of the participants felt increased pressure to make a diagnosis before a child aged out of publicly funded intensive behavioral intervention services (A2-3, A6-7, B1-4, and C2), although this policy subsequently changed.

Service Access Stage

After communication of the diagnosis to the family, the consultant pediatrician's office will connect them to available services. This theme was mentioned by only 8 participants, with a heavy focus on the systems-level factors. Child- and pediatric group-level factors were not discussed at all. Participants observed that less savvy families had delayed access to services when compared with families who were more capable of navigating the systems of care (A3 and A5). All participants felt responsible for providing continuing care for patients after providing an ASD diagnosis. Several participants also felt responsible for advocating for these patients, particularly in their local communities (A7 and B4). Participants

remarked on how the system is set up to promote diagnostic assessments because services cannot be accessed until a definitive diagnosis had been made (A3, B1, and C1). Some queried whether a needs-based model, rather than the current diagnosis-based model, may be more efficient in delivering services (A3 and C1). Many participants felt frustrated with the lack of services available to older children (A5, A7, B1, B3, and C1). System navigation in smaller communities was felt to be facilitated by a physician's personal relationships with allied health care providers (A6, B1, and B4).

DISCUSSION

Our study shows the important role that consultant pediatricians can play in diagnosing autism spectrum disorder (ASD) in rural communities. This sample of rural consultant pediatricians regularly diagnoses ASD, and their practices have been organized to help facilitate the ASD diagnostic process through the stages of preassessment, diagnosis, and service access. Within these stages, factors relating to the child, family, individual pediatrician, pediatric group, and health care systems all influence the diagnostic process. Although these communities are underserved compared with urban environments,¹⁶ our results also highlight many strengths and efficiencies in the ASD diagnostic care provided that could be adopted in other settings.

An ecological framework was also used in the study by Penner et al.¹³ on urban pediatricians, with identified themes at the levels of the child and family, the pediatrician, and the system of care. The themes in this study were developed iteratively and as such differ from the urban pediatrician study. In comparison with urban centers, the ASD diagnostic process in rural communities is adapted to include a stronger emphasis on the pre-assessment phase. This phase, developed to help streamline the assessment process and assist families in receiving support sooner, requires participation by clinic staff and uses nonremunerated time by consultant pediatricians. Notably, all the participants were paid on a salaried model with additional volume-based premiums based on "shadow billing." They felt that a fee-for-service model would limit their ability to complete ASD assessments because of the emphasis on higher volume care with shorter clinic appointments.

Rural consultant pediatricians were also noted to organize themselves within groups that worked together to develop strategies to meet the ASD diagnostic needs of their respective communities. These strategies included incentivizing individuals who provided more developmental care for their group, developing consensus regarding how the group should conduct their assessments, and collaborating with local allied health teams to help increase diagnostic certainty. Notably, this sense of pediatric group organization and responsibility to one's community was not emphasized in the 2017 study of urban pediatricians. The enhanced emphasis on community in rural contexts aligns with family descriptions

of an enhanced sense of inclusion and reduced social isolation that is present in these environments.²⁸ The feeling of belonging to a group with a shared responsibility to the community facilitated the development of systems of care for ASD diagnosis and is an important potential export to other settings aiming to expand diagnostic capacity.

The service access stage did not include child or pediatric group themes. The fact that child factors did not influence the service access stage is notable because it indicates the degree to which service access is driven by diagnosis, instead of the child's individual functional needs. In this stage, participants identified that they performed advocacy for families at an individual level; however, participants did not mention that the pediatric group played a role in service access, indicating a possible avenue for more organized advocacy efforts.

Our participants are not the only practitioners who have implemented various aspects of these strategies to increase diagnostic access. A 2016 review of novel strategies used throughout the United States describes assessment programs that have increased diagnostic capacity using similar approaches.²⁹ Authors have described a Connecticut center that has reduced wait times by implementing a model whereby patients provide information before their diagnostic assessment and are referred to early intervention before seeing a physician. They also describe a trial in Arkansas that created teams of pediatricians working with speech and language pathologists to conduct developmental assessments, with a focus on networking with regional service providers. A group in Tennessee has published their work on a telemedicine-based diagnostic consultation, wherein a clinical psychologist with ASD expertise remotely interviewed parents and observed the child undergo a standardized screening tool.³⁰ The availability of this service was associated with a decrease in referrals to the tertiary center and a shorter wait time compared with that of the tertiary center.

The results of this study provide further insight into possible strategies for increasing ASD diagnostic capacity, including exporting ideas from rural communities to larger centers. In addition to modifying remuneration for developmental care, the results from our study suggest that influencing the practice of a group of consultant pediatricians, such as those sharing an office or on-call responsibilities, may be more effective than targeting individuals. Incentivizing the creation of a preassessment time period could also increase the efficiency of the diagnostic process. In addition, providing access to input from allied health professionals could also aid consultant pediatricians in making a diagnosis themselves, thereby decreasing the need for further subspecialty referral.

Limitations

The 3 communities sampled may not be generalizable to all rural communities in Ontario and elsewhere. In

particular, jurisdictions that require team assessments and/or use of standardized tools require different strategies to increase diagnostic capacity. Generalizing our results of consultation-based pediatrics to a primary care-based model could also prove problematic because there is likely less time available for developmental assessments. In addition, all our participants were remunerated based on a salaried model. Although many hypothesized the challenges that would occur should their practice be based on a fee-for-service model, few had previous experience with this model. Despite these factors, the general diagnostic framework outlined in our study can be applicable to a wide variety of settings that are considering how to increase diagnostic capacity, particularly outside of urban settings. In fact, some of the limitations in generalizability to other settings with different funding models or pediatrician roles may themselves be instructive when considering how these structures and roles could be adopted to further incorporate ASD diagnosis into the consultant pediatrician's scope of practice.

Research is needed to evaluate the accuracy of assessments conducted by consultant pediatricians. There are aspects of a multidisciplinary ASD diagnostic assessment, such as standardized testing to further describe the child's strengths and challenges, that could not be provided by a solo consultant pediatrician diagnostic assessment. As such, this assessment model needs to be supplemented with an additional and ongoing assessment by allied health professionals. In addition, examining families' viewpoints regarding their experience with the diagnostic process are of utmost importance in understanding how to increase diagnostic capacity while still providing family-centered care.

Conclusions

Rural consultant pediatricians in our sample considered ASD diagnosis as part of their pediatric practice. They emphasize a strong sense of group organization and responsibility to provide diagnostic services to their communities. Strategies aimed at increasing diagnostic capacity should target group practices, increase availability of and proximity to allied health support, and improve efficiency of clinic visits through preclinic information gathering. Further research regarding accuracy of consultant pediatrician assessments and family perspectives is required.

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