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# Community General Pediatricians' Perspectives on Providing Autism Diagnoses in Ontario, Canada: A Qualitative Study

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**ABSTRACT:** *Objective:* Community general pediatricians (CGPs) are a potential resource to increase capacity for autism spectrum disorder (ASD) diagnostic assessments. The objective of this study was to explore factors influencing CGPs' perspectives on and practices of providing ASD diagnoses. *Methods:* This qualitative study used a constructivist modified grounded theory approach. Participants included CGPs who had attended ASD educational events or had referred a child with suspected ASD to a tertiary rehabilitation center. Individual in-depth interviews with CGPs were recorded, transcribed, and coded. An explanatory framework was developed from the data. A summary of the framework was sent to participants, and responses indicated that no changes were needed. *Results:* Eleven CGPs participated. Assessment for ASD consists of 3 stages: (1) determining the diagnosis; (2) communicating the diagnosis; and (3) managing next steps after diagnosis. Each of these stages of ASD diagnostic assessment exists within an ecological context of child/family factors, personal CGP factors, and contextual/systems factors that all influence diagnostic decision making. *Conclusion:* Community general pediatrician ASD diagnostic capacity must be considered within the larger context of ASD care. Suggestions to improve diagnostic capacity include preparing families for the diagnosis, changing CGP perceptions of ASD, providing community-based training, improving financial remuneration, and providing service navigation. Further study is needed to ensure that CGPs are providing accurate, high-quality assessments.

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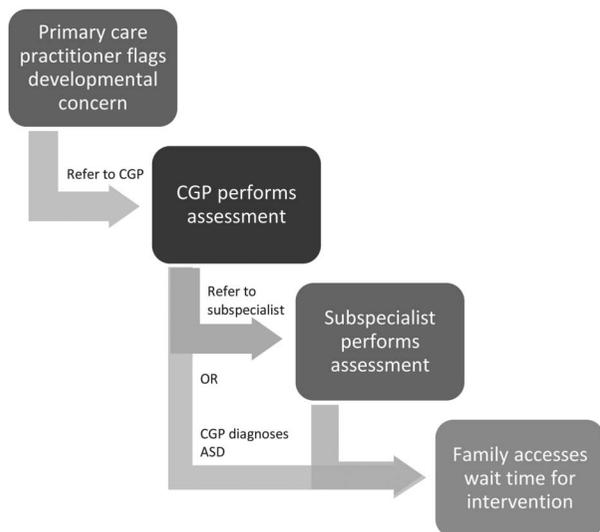
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**A**utism spectrum disorder (ASD) is a neurodevelopmental disorder defined by social communication impairment and restrictive and repetitive behaviors.<sup>1</sup> The diagnosis of ASD is made based on meeting criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition* (DSM-5).<sup>1</sup> Some clinical guidance recommends that the diagnosis should be made only by a team of expert clinicians<sup>2–5</sup> or with the use of standardized tools.<sup>4,5</sup> A recent review by pre-eminent Canadian ASD experts proposed that diagnostic assessment could be conducted by an experienced general pediatrician, provided the assessment satisfies the DSM-5 criteria.<sup>6</sup> In the Canadian context, community general pediatricians (CGPs) are consulted by a child's primary care physician if there are concerns that require more specialized care. If the CGP does not feel that they can provide the necessary expertise, they may refer to a subspecialist, such as a developmental pediatrician or multidisciplinary team (Fig. 1).

The need for increased diagnostic capacity relates both to increasing rates of ASD and the evidence supporting the effectiveness of earlier intervention,<sup>7</sup> necessitating access to timely diagnosis. The reported



**Figure 1.** Process of consultation in Ontario, Canada for cases of suspected autism spectrum disorder (ASD). Children are followed by a primary care practitioner (often a family physician/general practitioner/nurse practitioner). If there is a concern identified that the primary care practitioner does not feel qualified to diagnose or manage, they can refer to a community general pediatrician (CGP), who completes their own assessment and makes a similar decision as to whether to refer to a more specialized provider. In Ontario, any physician or psychologist can diagnose ASD, and all physician services are publicly funded. This study focused on the decisions made at the CGP level as to whether to diagnose and manage ASD themselves or to refer to a subspecialist.

prevalence of ASD in Canada ranges from 1/104 to 1/63 children aged 5 to 9 years in 2012 with an annual increase of between 9.7% and 14.6% in prevalence.<sup>8</sup> The proliferation of ASD cases requiring diagnostic assessment places strain on the systems providing these services. A diagnosis is often necessary before patients can access evidence-based ASD interventions, which are less effective with increasing age.<sup>7,9</sup> Unfortunately, the age at ASD diagnosis in 3 Canadian regions has increased over time, including in Southeastern Ontario, where age at diagnosis increased from 53 months in 2003 to 2006 to 59 months in 2007 to 2010.<sup>8</sup> Improving access to ASD diagnosis can positively affect effectiveness of interventions.

Little is currently known about the roles of CGPs in ASD diagnosis. A recent Canadian qualitative study of ASD screening practices in 11 CGPs found that participants eschewed screening in favor of subspecialist referrals, which they perceived would help the family to accept the diagnosis and provide further resources.<sup>10</sup> There has been no companion work addressing CGPs' views on providing the definitive diagnoses that are often needed to access interventions. The objective of this study was to explore the perspectives of CGPs regarding their perceptions of providing ASD diagnoses and the factors that influence their perceived abilities and desires to do so. Although not generalizable to all health system contexts, this work provides a necessary foundation for the development of educational and health system strategies targeting increased ASD diagnostic capacity among CGPs.

## METHODS

### Qualitative Approach and Research Paradigm

The chosen qualitative approach was constructivist, semi-participatory grounded theory.<sup>11</sup> The constructivist paradigm posits that meaning is socially constructed through interaction and context, which was ideal for exploring perceptions surrounding the ways pediatricians understand their role in diagnosing autism spectrum disorder (ASD).<sup>12</sup> Grounded theory was optimal for this study because it provides a method for developing a robust framework, grounded in the interview data, to explain participants' contextualized experiences of ASD diagnosis.<sup>11,13</sup> Although grounded theory posits that the researcher should not bring in preconceived ideas,<sup>11</sup> this work modified the traditional approach (as per the semi-participatory location), as members of the research team participate in pediatric practice, which directly influenced the undertaking of this research and the resultant interview guides and analyses.

### Researcher Characteristics and Context

MP, a developmental pediatrics fellow, conducted all recruitment and interviews. Interviews occurred in community general pediatrician (CGP) offices in an urban context in Ontario, Canada, from February to June 2014. Residents of Ontario have universal access to health care. There are no restrictions on the ability of CGPs to diagnose ASD in Ontario, but a definitive ASD diagnosis is required to access services,<sup>14</sup> making it an ideal setting to study perceptions about the role of CGPs in the diagnostic process.

### Sampling Strategy and Recruitment

A stratified purposeful sampling method was used to identify potential participants with diverse perspectives.<sup>15</sup> Two populations of CGPs were targeted for sampling: a group who were on a mailing list for Autism Treatment Network<sup>16</sup> educational events and a group who had referred at least 1 patient with suspected ASD for subspecialist assessment at a tertiary rehabilitation center. To ensure that the sample captured general pediatric practice, participants were excluded if their practice was limited to a subspecialty or if they had completed subspecialty training in developmental pediatrics. All potential participants received an information letter about the study in the mail followed by a phone call by MP to ascertain their interest in participation. Data saturation was defined as failure to identify new codes or themes from 2 successive interviews after the research team noted that the data may be approaching saturation.<sup>17</sup> This study obtained research ethics approval from the hospital Research Ethics Board. All participants provided written informed consent to participate in the study. Participants received a \$100 CAD honorarium after interview participation.

### Data Collection Methods

Data were collected using individual, in-depth, semi-structured interviews, which were audio recorded.

Participants first read a fictional case description of a child who meets the *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition* (DSM-5) diagnostic criteria for ASD to frame the discussion within the context of their usual clinical practice for children referred with suspected ASD (Appendix 1, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A144>). Participants were then asked about their approach to the case and about the broader system of ASD diagnosis (see Appendix 2, Supplemental Digital Content 1, <http://links.lww.com/JDBP/A144> for interview guide). Participants also completed a written questionnaire obtaining basic demographic information, information about their wait times, and any additional training in child development.

## Data Processing and Analysis

Audio recordings were transcribed verbatim by a professional transcriptionist and verified by MP. Identifying information was removed on verification of the transcripts. Analysis of the data began on reading the first transcript and proceeded in an iterative fashion.<sup>18</sup> Two investigators (M.P. and G.A.K.) each independently read the first 3 transcripts, extracted codes from the data, and met face to face to discuss the initial codes and codevelop the initial coding guide. MP coded all transcripts, and a second investigator (one of G.A.K., M.S., E.A., or C.M.H.) independently coded each transcript to enhance trustworthiness.

Members of the research team met regularly to group codes into emerging themes, which were compared against newly available data and reconsidered based on these new data. Themes were first connected with relation to the diagnostic process, and then, in accordance with the social constructivist paradigm, analyzed within the broader context. A preliminary explanatory framework was circulated through mail to participants with a request for written feedback as a method of member checking.<sup>18</sup> Input from the member-checking process did not necessitate changes to the framework.

## RESULTS

### Study Participants

Eleven community general pediatricians (CGPs) participated in the study. Participant characteristics are described in Table 1. Among the sampled population, willingness to diagnose autism spectrum disorder (ASD) was not related to participation in ASD education, and instead existed along a continuum between participants. One participant did not do any diagnosis of ASD, and another only provided ASD diagnoses as part of a specialized team. Those who did diagnose ranged from those who would give a diagnosis in rare cases to those who had built a reputation for performing ASD diagnostic assessments.

### Framework

The framework first outlines the stages of ASD diagnosis, including determining whether the child had

**Table 1. Participant Characteristics**

Sex	5 males, 6 females
Years in practice	Median 14 (range 2–40)
Time booked for a new pediatric consult	Median 40 min (range 30–60)
Time booked for a new developmental consult	9 participants: 60 min 1 participant: 45 min 1 participant: 30 min
Wait time for a new pediatric consult	Median 2 mo (range 3 wk to 6 mo)
Wait time for a new developmental consult	Median 3.25 mo (range 3 wk to 9 mo)
Additional training in child development	3 participants: none 3 participants: additional CME 3 participants: additional community practice-focused training during residency or fellowships 2 participants: additional training and CME

CME, continuing medical education.

ASD, communicating the diagnosis to the family, and managing the next steps after the diagnosis. These stages are theorized as occurring within an ecological model<sup>19</sup> of child/family, personal CGP, and contextual/systems factors (Fig. 2). The child/family factors are defined as perceived features, knowledge, and beliefs of the family group that influence diagnostic decision making. Personal CGP factors are interests, perceived roles, training experiences, feelings of satisfaction/certainty, and beliefs of the CGP that influence ASD diagnosis. Contextual/systems factors refer to formal or informal resources, practice patterns, remuneration schedules, and policies affecting ASD diagnosis (Representative quotations for each of the stages and factors are presented in Tables 2–4).

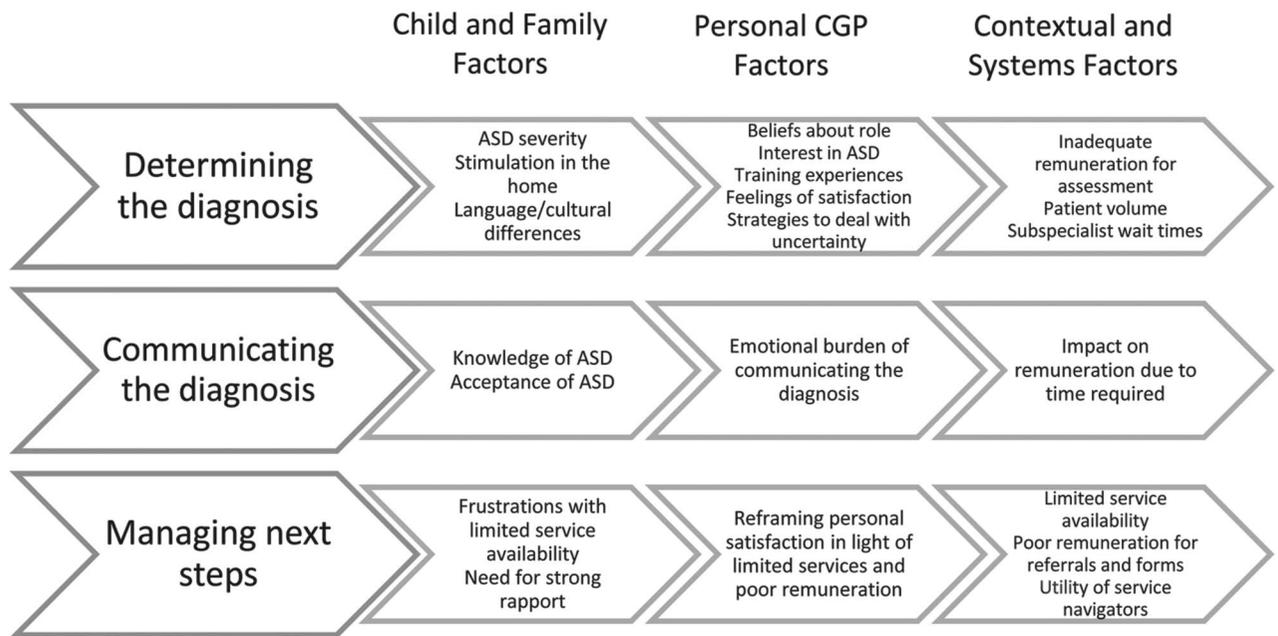
## Determining the Diagnosis

### Child and Family Factors

Child factors that influenced diagnostic determination included the severity of presentation, with a milder presentation being more difficult (P2, P7-8, and P11); age, with both very young children (P5, P8, and P11) and older children (P2 and P7) being more challenging; gender, with girls being more difficult (P9); and co-occurring conditions (P7 and P10-11), the presence of which increased diagnostic difficulty. Language/cultural differences (P2, P4-5, and P9) increased difficulty. A lack of developmental stimulation in the environment (P2-3 and P8-11) was also more challenging; however, it allowed the CGP to suggest modifications that could improve the child's development.

### Personal Community General Pediatrician Factors

All participants noted that an interest in child development was an important factor in choosing to do



**Figure 2.** Explanatory framework for factors influencing community general pediatrician (CGP) autism spectrum disorder (ASD) diagnostic processes. This figure depicts the explanatory framework developed from the interview data. The stages of the diagnostic process are determining the diagnosis, communicating the diagnosis, and managing next steps after the diagnosis. Factors influencing each stage are conceptualized as ecological levels and consist of child/family factors, personal CGP factors, and contextual/systems factors. A list of the factors influencing each stage of the process at each of the 3 levels is provided.

this work. There was an intersection between interest in ASD and systems issues; namely, participants who diagnosed ASD chose this work out of a genuine interest despite the relatively low compensation (P2, P7, and P11). Improved financial remuneration may entice some CGPs to do diagnostic assessments, but it was repeatedly stressed (P5-7 and P9) that the financial reward was not substantial enough to merit undertaking ASD diagnostic practices, and CGPs would likely have to have a personal interest in ASD to do this work.

Autism spectrum disorder was often contrasted against “medical” conditions that were more clearly aligned with the CGP’s medical role, including fever/viral infections (P1 and P9), rash (P1), fracture (P2), constipation (P2 and P10), anemia (P4), pneumonia (P4), umbilical hernia (P8), and Kawasaki disease (P9). There was also an intersection between the medical role and remuneration, with other pediatric health issues being better compensated because they could be seen in shorter intervals.

Regarding training and preparedness for providing diagnoses of ASD, participants were trained to work with developmental issues in tertiary care settings, which did not always translate to the resources and requirements of community practice. Many participants who more regularly diagnosed ASD had sought out additional training in a community setting to prepare themselves to meet the needs of this population (P3-5, P7, and P11).

Many participants struggled with diagnostic uncertainty and used strategies to ameliorate this. Participants benefited from accessing opinions of other staff or professionals particularly due to a concern about incorrectly giving an ASD diagnosis. Some sought out

observations of the child’s behavior by office staff, such as nurses (P1) or clinic administrators (P7). Some participants (P2, P4, and P7) had sought out local subspecialists with whom they had “hallway consultations” regarding unclear cases. Participants also used diagnostic tools to improve certainty. One participant (P5) used a full Autism Diagnostic Observation Schedule (ADOS)<sup>20</sup> and 3 used an abbreviated form of the ADOS (P4, P7, and P11). Two participants (P2 and P7) described using the Modified Checklist for Autism in Toddlers (M-CHAT)<sup>21</sup> to help structure their history, and one (P3) reported having the parents complete the M-CHAT and corroborating M-CHAT results with their clinical impression. All participants described the need for an observation and interaction component of assessment.

#### Contextual/Systems Factors

Remuneration for ASD assessment was described by most participants (P4-7 and P9-10) as inadequate, which intersected with CGP interest and beliefs about the CGP’s medical role, as described in personal CGP factors. The busy CGP office did not always lend itself to the ASD diagnostic assessment, particularly in the amount of time required and the resulting impact on wait times. The increased time required to see these cases could also mean that children with developmental concerns waited longer for an appointment, as developmental cases would be triaged in a different category than other presenting issues (P6 and P9).

Some participants (P4-5 and P9) described that their threshold for referring to a subspecialist varied with fluctuations in wait times for subspecialist assessment. One participant (P9) described a lower threshold to refer

**Table 2. Child and Family Factors Influencing the Diagnostic Process**

Factors	Representative quotations
<p>Determining the diagnosis</p> <p>Presentation clearly consistent with ASD</p> <p>Low degree of developmental stimulation in the home</p> <p>Language and cultural barriers</p>	<p>I guess just using your knowledge about development and expectations for what [the] interaction should be—eye contact, and then the history, what they're saying, and what the kid is doing...the child's making some grunting noises, and gets excited about something and starts flapping, you know what I mean? P8</p> <p>...the kid sits and plays on his iPad all day at age two, so there's sort of a deprivation thing there...It makes the diagnosis less clear, but helps target behaviors that I can work on with the family. P10</p> <p>Because if I have parents that don't speak English it's just very difficult, so I have to very quickly make a decision [about] how far am I going to go, and is this a kid I'm going to refer on... P9</p> <p>I don't have translators in my office, so maybe [I would refer] if there was a language barrier with a family and I didn't think I was going to be able to explain it well enough to them. P2</p>
<p>Communicating the diagnosis</p> <p>Perceived family knowledge of ASD</p> <p>Perceived family readiness for the diagnosis</p> <p>Whether the family has been "primed" for the diagnosis</p>	<p>So it is very difficult to give a diagnosis if the parents have very little understanding of ASD, have never done any research...It's not that I wouldn't give the diagnosis, but that certainly makes you feel like, oh, how am I going to do—as soon as it becomes a how, how am I going to do this well, then you start to feel more hesitant about giving the diagnosis. P5</p> <p>I: Are there any patient factors or family factors that make you more likely to give a diagnosis?</p> <p>P: If the family is saying, "We want to start, we need a diagnostic letter, we've done our research and we want to have him or her assessed through [intervention program]." P3</p> <p>You quickly assess their level of knowledge and expertise, and if they've come in with reams of things from the web—I've looked up this, I've tried the gluten-free diet, I've looked at the multi-vitamins and all of that—then obviously those kinds of parents are going to need certainty and the best possible opinion they can get. I would definitely refer them on. P9</p> <p>If the child is borderline, and the family does not want the diagnosis, I often refer further. P7</p> <p>The vast majority seem to know there's something wrong, they may not know the label...And in a way they seem relieved that they have a diagnosis, even if they don't like the diagnosis, even if they understand the implications. P1</p> <p>I felt my heart drop because I knew that this had never been discussed with the family before and it was just being referred to me as a speech issue. P8</p> <p>When no one has mentioned the word autism to them before...it takes more time. I need to have more appointments with them, because the first appointment I feel I need to prime them for the diagnosis...I also often need a lot more collaborating information...But, I mean, we get there. P11</p>
<p>Managing next steps after diagnosis</p> <p>Dealing with frustration while families wait for services (Intersects with contextual/systems issues)</p>	<p>You send in a referral, and then you wait eight months. Meanwhile, I have this family who is itching to get treatment for their child.</p> <p>P10 People tend to be frustrated in terms of, nothing works quickly. P1</p> <p>Very frustrating for parents because then they leave the office, it's usually with the expectation okay, we have a diagnosis, or we have a suspect diagnosis, so something can be done, right?...And then when they get into the nitty gritty of the actual when is this going to be done and how is this going to be done...it's extremely frustrating for them. P9</p>

*(Table continues)*

**Table 2.** Continued

Factors	Representative quotations
Need for rapport with family because the family is responsible for accessing services (Intersects with contextual/systems issues)	<p>So if it's a family you've never met before, you have to get their buy-in, build a relationship with them so when you do tell them that their child has autism, they're not just going to leave and do nothing. P4</p> <p>They need to go to [regional ASD organizations] and have an introduction to autism lecture...You call them, put yourself on the list and ask for their workshop. And if you do, great. But the parents get a big sheet from me of all the things they have to do, and I would say probably three-quarters don't do that as the first step. P7</p>

ASD, autism spectrum disorder; I, interviewer; P, participant.

with a longer subspecialist wait time, leaving them with the opportunity to continue to monitor the child during that time.

## Communicating the Diagnosis

### Child and Family Factors

These factors could influence whether the CGP performed a diagnostic assessment independent of whether they made an ASD diagnostic determination. All participants described trying to gauge the family's possible reactions to receiving ASD diagnosis throughout the assessment. Participants identified that too little parental knowledge of ASD was a barrier to giving an ASD diagnosis because of the additional time required for explanation (P4-5 and P7-11). More knowledge of ASD was generally viewed as a positive thing by the CGPs; however, some participants (P4 and P9) noted that too much prior knowledge of ASD could indicate that the family would not accept the diagnosis from a CGP.

Perceived parental readiness to receive the diagnosis was closely linked to their knowledge about ASD. CGPs reported that parental resistance to a diagnosis tended to deter the CGP from conducting the diagnostic assessment at all (P2, P4, P7, and P9-10). This was not the only parental reaction, as participants also described parents who suspected ASD and experienced a feeling of relief with confirmation of their suspicion (P1, P3, and P6).

Some participants (P8 and P11) described families that were "primed" for the diagnosis by the referring primary care physician, meaning that the referring physician had mentioned the possibility of ASD. If priming had occurred, it facilitated the communication between the CGP and the family.

### Personal Community General Pediatrician Factors

Most participants (P1-6 and P11) described communicating the diagnosis as a significant emotional burden that could be a barrier to providing the diagnosis themselves. Part of this emotional burden can be linked back to the participants' perceptions of ASD, which was described by participants as "devastating" (P4), "heavy" (P1), "loaded" (P3-4), and "severe" (P2 and P5). One participant (P6) indicated that, even in cases for which

they were certain that the child had ASD, they still referred to a subspecialist because of the impact of the diagnosis on children and families. Participants who provided diagnoses described having empathetic responses to the family's reaction, enhancing their own emotional burden (P1-2 and P11).

### Contextual/Systems Factors

The time spent communicating the diagnosis was often described as a substantial barrier to this work (P1-2, P4, P7, P9, and P11). One participant (P7) used a strategy of allowing families to come in for additional appointments if they needed to discuss the diagnosis further. The time spent communicating the diagnosis intersected with systems factors, as it came at the expense of other, better-remunerated types of pediatric office visits and could extend wait times for other patients.

## Managing the Next Steps After Diagnosis

The relationships among families, CGPs, and systems factors were a key factor at this stage. Contextual/systems factors—specifically, limited access to ASD services—intersected with all identified child/family and CGP factors and will be described under these levels.

### Child and Family Factors

Ongoing clinical visits with families after the diagnosis were described as frustrating for families (P1, P4, and P10), particularly as children now accessed waiting lists for services. Participants felt that they could do little to alleviate this frustration. Because the family is responsible to accessing many of the services after diagnosis, the strength of the CGP's rapport with the family was important at this stage to help ensure that families carried through on postdiagnosis recommendations.

### Community General Pediatrician Factors

Participants noted that managing a new ASD diagnosis involved behind-the-scenes work that did not provide professional satisfaction and intersected with the systems level in its inadequate remuneration (P4, P6, and P9-10). Other participants discussed reframing their definition of satisfaction in managing ASD diagnoses (P2 and P11). All participants discussed the lack of system navigation support for families and emphasized that access to service navigation would support feelings of satisfaction and confidence.

**Table 3. Personal CGP Factors Influencing the Diagnostic Process**

Factor	Representative quotations
Determining the diagnosis	
Interest in ASD (Intersection with contextual/systems issues in remuneration)	<p>I have an interest in development, so it's something I've always wanted to do and I never did. Now that I'm older I can do it and I don't need the money. P7</p> <p>[CGPs should diagnose ASD] only if they have time and the desire to do so...If you don't like what you're doing, or it's difficult in what you're doing, then take an easier path, whatever it is. A path that leads to more satisfaction. P6</p> <p>You have to have a mindset that—number one, I'm interested in this kind of thing. And number two, I want to spend the time that's necessary; it's very time consuming. P9</p>
Views on whether ASD fits in the CGP's medical role (Intersection with contextual/systems issues in remuneration)	<p>Diagnose pneumonia; there's a chest X-ray, there's a very concrete, objective finding. Or anemia; hemoglobin is low, here's your iron—it's sort of easy to fix, right. But with autism...I think it's just that continuum of grayness that makes it a bit of a challenge. P4</p> <p>If I can see a kid with straightforward constipation and follow-up in 15 minutes...It's way less work versus a child who comes in for their follow-up of their major behavioral issues...They're weighted equally in terms of performance reviews and financially. P10</p>
Seeking out additional training in community settings	<p>I spent some time at the child development centre...And it wasn't that it was bad, but it was so high level, and so specific that I don't think it really helped me much going out, sort of doing general peds with a focus on development. I spent two weeks or three weeks with a community-based developmental pediatrician, and that was way more helpful. P5</p>
Strategies to deal with diagnostic uncertainty	<p>I think a lot before I tell the people, I'm really sure. I usually discuss it with [clinic nurse], because I sure as hell don't want to be wrong. P1</p> <p>What I miss obviously is someone to show somebody a letter that I've written and say to them, tell me, how would you have diagnosed this patient?...I have a developmental pediatrician that I talk to on the phone if I really have a problem, and that's a friend, not a mentor. P7</p> <p>[Partial ADOSes have] all confirmed the diagnosis. Which truthfully, I did feel good about because you suspect it. P4</p> <p>The M-CHAT gives me a lot of information, because I use it not as a yes/no questionnaire, but I use it as a discussion tool. P7</p>
Communicating the diagnosis	
Emotional burden	<p>Actually being able to say to a family, "I think your child has autism." Telling a family the diagnosis...it's probably the biggest burden, it's probably the biggest deterrent to making a diagnosis. P2</p> <p>Because I don't think that I want to make a diagnosis—this has a significant effect on parents, and prognosis and so forth, so I'd want to get a specialist to make that diagnosis for me. P6</p> <p>I must say, I've never had anyone tearful when I diagnosed [attention deficit/hyperactivity disorder], but I often have people tearful when I diagnose autism. And that's harder, for sure. P11</p>
Managing next steps after diagnosis Professional satisfaction (Intersects with contextual/systems issues)	<p>You're not really compensated for the time and work. It's a lot of work, it's a lot of frustrating work. At the end of it—and maybe this goes back to why I'm not doing it as much, at the end of it it's not that rewarding. P4</p> <p>I like that relationship that you build with the families, and I find these kids interesting, and I think you can provide support to the parents walking them along that pathway, and I enjoy that. P11</p> <p>It's a different kind of satisfaction...I think back about this one kid who's in my office, he's like 10 or 11 now. And mom's like "He's getting this, this, this, and at school he's doing this, this, and he seems happy." That is success, because he's getting appropriately treated because you have the right resources. P2</p>

*(Table continues)*

**Table 3.** Continued

Factor	Representative quotations
Need for service navigation support (Intersects with contextual/systems issues)	<p>If I could make the diagnosis and say okay, here's some information, go home and read about it. Then you're going to meet with this person who will help you navigate. Truthfully, I think that would make a difference, because that's the part I hate. Truthfully. P4</p> <p>I think, in a way, if there would be a home for autism where there would be a department that deals with school, and a department that deals with skills and speech. At least it would be all under one roof. It would be so much easier, especially for the poorer families. P7</p>

ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder; CGP, community general pediatrician; M-CHAT, Modified Checklist for Autism in Toddlers.

## DISCUSSION

This is the first study to evaluate the perspectives of community general pediatricians (CGPs) regarding providing autism spectrum disorder (ASD) diagnoses. The results show that, although CGPs make diagnostic decisions based on their abilities to diagnose ASD in a given case, these decisions are also influenced by factors in the stages of communicating the diagnosis and managing next steps. Each of these stages of ASD diagnostic assessment exists within an ecological context of child/family factors, personal CGP factors, and contextual/systems factors that all influence diagnostic decision making. These factors intersect in powerful ways, such as the relatively low remuneration for conducting ASD diagnostic assessments compared with other medical issues, which may reinforce feelings of dissatisfaction and beliefs about ASD not fitting within the CGP's scope of practice.

These findings are supported by similar results from studies evaluating the practice of ASD screening and diagnosis. In their study of ASD screening tools, Ip et al.<sup>10</sup> identified that knowledge of available resources and ability to support the family influenced the decision to screen for ASD. A training program aimed at increasing diagnostic capacity among CGPs in Tennessee identified similar areas of need to this study (increasing diagnostic certainty, communicating the diagnosis, understanding intervention pathways, and billing effectively).<sup>22</sup> Their training model based on these common themes has been successful, with an 85% increase in the diagnostic identification of ASD by CGPs.<sup>23</sup>

Our work adds considerably to this literature, suggesting that efforts to improve efficiency in the system by increasing diagnostic capacity among CGPs will have to address not only their ability to determine the diagnosis but also these largely psychosocial elements of the diagnostic process and systematic supports for ASD. Examples of these include addressing CGP perceptions of ASD as a uniformly severe and devastating disorder, remunerating developmental care on a similar level to more medical conditions, and providing access to service navigation. Ontario has recognized the need for improved service navigation, which is a key plank in its new Special Needs Strategy.<sup>24</sup>

Integration of many factors is likely required to ensure that high-quality, timely assessments are provided. For

instance, many participants in this study described that their core pediatric training was not sufficient to perform ASD diagnostic assessments once in practice. Linking more lucrative billing codes with additional training may be one solution to balance efforts to increase diagnostic capacity in this group while also incentivizing high-quality assessment practices. One exciting potential avenue for this training is through the Extension for Community Healthcare Outcomes (ECHO) model, which is currently being studied for use in ASD.<sup>25</sup>

## Limitations

The urban Ontario setting may not be generalizable to all jurisdictions, particularly those with additional regulations on ASD diagnosis, such as the need for a team assessment or standardized tools. In addition, our results may be less generalizable to jurisdictions in which the CGP role is more focused on primary care and less time may be available to perform a thorough assessment. This is an important distinction, as previous work has shown high levels of inaccuracy when trying to detect ASD during a brief assessment.<sup>26</sup> Despite this, the setting allowed us for exploration of factors that influence ASD diagnostic decision making in the absence of external requirements. Although the specific details of the factors may change in a given jurisdiction, our framework can be applied more broadly to ensure that diagnostic capacity strategies reflect the interaction between the diagnostic process and the ecological levels of children/families, CGPs, and the broader system.

The members of the research team are all affiliated with pediatric clinical practice and/or research. In accordance with the semi-participatory location of this work, this experience is acknowledged to have influenced the interview guide and the interpretation of the themes emerging from the data. Although not necessarily a limitation of the work, this is necessary to contextualize the findings.

The study reached saturation with 11 participants, indicating similar themes across a continuum of diagnostic practices. Although small by quantitative standards, similar sample sizes of pediatricians have been reported in studies of ASD-related practice.<sup>10,27</sup>

This study did not assess the ability of CGPs to diagnose ASD; further mixed methods studies evaluating

**Table 4.** Contextual/Systems Factors Influencing the Diagnostic Process

Factor	Representative quotation
Determining the diagnosis Remuneration (Intersects with CGP personal factors)	It's not paid well, I lose money, but it's fun. P7 It's not something that many pediatricians want to do. The financial remuneration is not significant for it, I think either. Unless you had a strong desire in terms of early developmental stuff, then no. P6 I guess there's no money in the whole system, but it's—these are some of the hardest cases, and as pediatricians you—the compensation isn't there to want to deal with it. P10
Wait time considerations for CGP assessment	One of the issues is, if you have a kid who comes in for an 18 month checkup and all of a sudden you think there's a[n ASD] case, you probably have to rebook them...It's not like, "oh I'm worried now, I'm going to spend an extra 45 minutes talking to you about this." It's not going to happen because you've got ten people waiting outside. P2 <i>Interviewer:</i> So [your] waitlist for those types of [developmental] appointments may be a little bit longer? <i>Participant:</i> Yes, only because I can't see them in a ten minute interval. P6
Wait time considerations for subspecialist assessment	I tell them they have the right to go to [tertiary diagnostic centre] if they want, that the waiting list is long...And that if I see them and diagnose them, we can get them plugged into help earlier. Almost all of them say they'll take that alternative. P1 I feel like the [subspecialist] plan of the diagnosis is probably a bit more detailed, and a little bit more comprehensive than what I can offer, and I feel like every child should benefit from that, but then balancing that with well, if I think this is what's really going on, there's no point in having them wait another six, eight months to start the same process that likely would start now. P3 So if I make the referral then, they'll get seen in four or five months and I can bring the kid back in three months and reassess, so we've still got that appointment cooking. P9
Communicating the diagnosis Time needed to communicate the diagnosis	Thirty minutes is still not enough time to do a history, physical and some sort of observation or interaction with the child to diagnose autism. And then the whole problem of giving the diagnosis, I mean, that's even a whole separate visit too. So I think time is a big, big issue. P4 I do quite well with parents who have difficulties accepting the diagnosis because I have three appointments and then I have more. So it's not like after the third appointment the door is closed. Sometimes if they need more time, they need more time. P7 Giving a diagnosis of autism means that you have to spend a lot of time with the family...You want to run a busy primary office, you may not be remunerated the same equally for the same amount of time. There's some of the real life factors of the financial aspects of it as well. P2

Managing next steps after diagnosis—Contextual/systems factors intersected with all identified child/family and personal CGP factors. These will be described in their respective tables. ASD, autism spectrum disorder; CGP, community general pediatrician; I, interviewer; P, participant.

the accuracy of CGP ASD diagnoses and family perceptions are necessary to further inform the role of CGPs in the system of ASD diagnoses. In addition, work quantifying the extent to which CGPs diagnose ASD is necessary to further contextualize their role in ASD diagnosis. The investigators have undertaken additional work address these issues through an ongoing study of diagnostic agreement between CGPs and a subspecialist multidisciplinary team, as well as through a Canadian survey of ASD diagnostic practices.

## CONCLUSIONS

Community general pediatricians' (CGPs') diagnostic decision making for autism spectrum disorder (ASD) is

influenced at all stages of the assessment—determining the diagnosis, communicating the diagnosis, and managing next steps. Efforts to improve ASD diagnostic capacity among CGPs must consider child/family, personal CGP, and contextual/systems factors. Further study is needed to ensure that CGPs are providing accurate, high-quality assessments.

## REFERENCES

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Arlington, VA: American Psychiatric Association; 2013.
2. Volkmar F, Siegel M, Woodbury-Smith M, et al. Practice parameter for the assessment and treatment of children and adolescents with

- autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry* 2014;53:237-257.
3. National Collaborating Centre for Women's and Children's Health. *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum*. London, United Kingdom: RCOG Press; 2011.
  4. The Miriam Foundation. *Canadian Best Practice Guidelines: Screening, Assessment And Diagnosis of Autism Spectrum Disorders in Young Children*. Foundation TM; 2008.
  5. Dua V. Standards and guidelines for the assessment and diagnosis of young children with autism spectrum disorder in British Columbia. An evidence-based report prepared for the British Columbia Ministry of Health Planning. 2003.
  6. Anagnostou E, Zwaigenbaum L, Szatmari P, et al. Autism spectrum disorder: advances in evidence-based practice. *Can Med Assoc J*. 2014;186:509-519.
  7. Eldevik S, Hastings RP, Hughes JC, et al. Meta-analysis of early intensive behavioral intervention for children with autism. *J Clin Child Adolesc Psychol*. 2009;38:439-450.
  8. Ouellette-Kuntz H, Coo H, Lam M, et al. The changing prevalence of autism in three regions of Canada. *J Autism Dev Disord*. 2014;44:120-136.
  9. Perry A, Cummings A, Dunn Geier J, et al. Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Res Autism Spectr Disord*. 2011;5:592-603.
  10. Ip AWS, Zwaigenbaum L, Nicholas D, et al. Factors influencing autism spectrum disorder screening by community paediatricians. *Paediatr Child Health*. 2015;20:e20-24.
  11. Charmaz K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London, United Kingdom: Sage Publications; 2006.
  12. Patton MQ. Two decades of developments in qualitative inquiry: a personal, experiential perspective. *Qual Social Work*. 2002;1:261-282.
  13. Morse JM, Noerager-Stern P, Corbin J, et al. *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press; 2009.
  14. Ontario Ministry of Child and Youth Services. *Autism Intervention Program—Program Guidelines*; 2006.
  15. Patton MQ. *Qualitative Evaluation and Research Methods*. Vol 2. Newbury Park, CA: Sage; 1990.
  16. Autism Speaks. *Autism Treatment Network*. 2015. Available at: <https://www.autismspeaks.org/science/resources-programs/autism-treatment-network>. Accessed October 14, 2015.
  17. Creswell JW. *Qualitative Inquiry and Research Design*. Vol 2. Thousand Oaks, CA: Sage Publications; 2007.
  18. Nicholls D. Qualitative research: part three—methods. *Int J Ther Rehabil*. 2009;16:638-647.
  19. Bronfenbrenner U. Ecological models of human development. In: Husen T, Postlethwaite TN, ed. *International Encyclopedia of Education*. Vol 3. 2 ed. New York, NY: Elsevier; 1994.
  20. Lord C, Rutter M, Dilavore P, et al. *Autism Diagnostic Observation Schedule, Second Edition*. Torrance, CA: WPS; 2012.
  21. Robins D, Fein D, Barton M. Modified checklist for autism in toddlers. 2009.
  22. Warren Z, Stone W, Humberd Q. A training model for the diagnosis of autism in community pediatric practice. *J Develop Behav Pediatr*. 2009;30:442-446.
  23. Swanson AR, Warren ZE, Stone WL, et al. The diagnosis of autism in community pediatric settings: does advanced training facilitate practice change? *Autism*. 2014;18:555-561.
  24. Ontario Ministry of Child and Youth Services. *Ontario's Special Needs Strategy*. 2016. Available at: <http://www.children.gov.on.ca/htdocs/English/professionals/specialneeds/strategy.aspx>. Accessed April 20, 2017.
  25. Mazurek M, Brown R, Curran A, et al. ECHO autism. *Clin Pediatr*. 2017;56:247-256.
  26. Gabrielsen TP, Farley M, Speer L, et al. Identifying autism in a brief observation. *Pediatrics*. 2015;135:e330-338.
  27. Carbone PS, Behl DD, Azor V, et al. The medical home for children with autism spectrum disorders: parent and pediatrician perspectives. *J Autism Dev Disord*. 2010;40:317-324.