

## Autism Spectrum Disorder Knowledge, Training and Experience: Ontario Physicians' Perspectives About What Helps and What Does Not

### Abstract

**Background:** *Many physicians experience barriers such as lack of time and expertise, as well as facilitators such as collaboration with other healthcare professionals, when providing care for individuals with autism spectrum disorder (ASD). This study aimed to identify barriers and facilitators that Ontario physicians encounter when providing care for individuals with ASD.*

**Method:** *Twenty-seven physicians practicing in Ontario participated in a two-phase study. During the first phase, participants completed a questionnaire regarding their demographic information as well as their knowledge, competency and experiences when providing care for individuals with ASD. During the second phase, five participants answered questions about their experiences when providing care for individuals with ASD.*

**Results:** *In this study, physicians expressed their needs for further education and training regarding ASD. Despite physicians' reported lack of comfort and expertise in diagnosing individuals with ASD, they identified working in an interdisciplinary team as a facilitator in helping them to provide care for this population. The findings also revealed that previous work experiences with individuals with ASD, and collaborating with parents of children with ASD enhance physicians' experiences when providing care for this population.*

**Conclusions:** *Findings have implications for raising awareness in healthcare and educational systems regarding the steps need to be taken to enhance Ontario physicians' experiences when providing care for individuals with ASD.*

Despite the high prevalence of autism spectrum disorder (ASD) – 1 in 66 children (Government of Canada, 2018) – many medical practitioners experience barriers (e.g., lack of education and training) in providing care for this population, especially in areas such as diagnosis and treatment (Daniels, Halladay, Shih, Elder, & Dawson, 2014; Fenikilé, Ellerbeck, Filippi, & Daley, 2015). In addition to challenges, researchers have also identified several facilitators (e.g., working in a multidisciplinary team) that enhance the diagnostic and treatment processes for both physicians as well as individuals with ASD (Major, Peacock, Ruben, Thomas, & Weitzman, 2013). Given the importance of physicians' roles in providing care for the ASD population, it is necessary to investigate their

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experiences, both positive and negative, in order to enhance healthcare management for individuals with ASD.

ASD is a pervasive neurodevelopmental disorder that is characterized by deficits in two developmental areas including social-communication as well as behavioural skills (American Psychiatric Association, 2013). Although caregivers often identify early symptoms of ASD (i.e., delay in language and social skills development) as early as 18 months of age, research shows that many children with ASD do not receive a diagnosis until the age of four or five (McMorris, Cox, Hudson, Liu, & Bebko, 2013; Warren, Stone, & Humberd, 2009). Additionally, the literature shows that parents of children with ASD have raised concerns regarding the delay in the diagnosis as well as the lack of direction and support they receive from healthcare professionals throughout this process (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012; Glazaard & Overall, 2012). Even though the diagnosis of ASD often employs a multidisciplinary approach (i.e., collaboration among healthcare professionals as well as families of individuals with ASD), many parents feel left out, as their views are not sufficiently included in the process. These parents must often become self-reliant and gain knowledge regarding the diagnosis of their children on their own (Brookman-Frazee et al., 2012; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Glazzard & Overall, 2012). Research also shows that parents have raised concerns regarding the lengthy ASD diagnostic process, and that they often receive the diagnosis for their children after the fourth visit with a medical professional (Siklos & Kerns, 2007).

### Challenges in Providing Care

Because physicians are the first healthcare professionals who interact with children suspected of having ASD, they play an important role in the early identification of ASD symptoms in the pediatric population (Self, Parham, & Rajagopalan, 2015). A growing body of research has revealed some of the barriers that medical practitioners experience when making a diagnosis of ASD. For instance, a study investigating physicians' experiences in terms of knowledge and preparedness in identification and diagnosis of ASD showed that medical practitioners expressed their need for further

education and training regarding this matter (Fenikilé et al., 2015). Research shows that many physicians in the United States have described the ASD diagnostic tools as time-consuming as well as demanding in terms of knowledge and expertise (Carbone, Behl, Azor, & Murphy, 2010; Fenikilé et al., 2015; Nah, Young, Brewer, & Berlinger, 2014). In line with such findings, Finke, Drager and Ash (2010) investigated general pediatricians' experiences with regard to the diagnosis of ASD, using a qualitative interview methodology. Pediatricians reported a lack of ASD-specific training during medical school. Some pediatricians stated that developmental pediatricians receive more training about ASD, while other participants expressed their lack of comfort with the diagnostic process, and discussed referring individuals with a suspected diagnosis of ASD to more specialized professionals (i.e., developmental pediatricians and psychologists) (Finke et al., 2010). Research also shows that pediatricians in different regions of the United States report screening children for developmental delays, but only 8% screen for ASD (Dosreis, Weiner, Johnson, & Newschaffer, 2006). In the same study, most pediatricians referred children to other clinical specialists, and 20% used a wait-and-watch strategy for children younger than two years of age (Dosreis et al., 2006).

### Facilitators

In addition to the barriers faced by physicians, recent studies have identified factors that enhance medical practitioners' experiences when providing care for individuals with ASD. For instance, Ritzema, Sladeczek, Ghosh, Karagiannakis, and Manay-Quian (2014) recommended collaboration among physicians and psychologists in order to facilitate the delivery of health care services for individuals with developmental disabilities including ASD. Through partnerships with other healthcare professionals, researchers have identified significant benefits for physicians (e.g., consulting with other healthcare professionals), children (e.g., receiving early diagnosis and treatment), and families of individuals with developmental disabilities (e.g., less frustration in terms of obtaining medical support for their children). Such collaborations ultimately promote optimal service delivery for individuals with ASD and other developmental disabilities (Ritzema et al., 2014; Zwaigenbaum et al., 2016).

Researchers in the United States, Australia, and United Kingdom have identified working experience with individuals with ASD and other developmental disabilities as imperative in improving medical practitioners' knowledge, skills, comfort levels and attitudes when providing care for this population (Havercamp et al., 2016; Woodard, Havercamp, Zwygart, & Perkins, 2012). Additionally, Ontario physicians who have been in practice for a longer period of time have reported higher comfort level when providing care for individuals with ASD compared to those who have been practicing, for example, for less than five years (Ghaderi & Watson, 2019). According to Havercamp and colleagues (2016), medical training that provides opportunities for medical students to gain hands-on experience working with individuals with ASD and developmental disabilities has been shown to be effective in enhancing practitioners' knowledge, competencies and attitudes. In other words, medical students who directly worked with patients with developmental disabilities indicated improvements in their knowledge, communication skills, self-efficacy, and attitudes when providing care for this population (Havercamp et al., 2016).

Despite a wealth of research based in the United States, United Kingdom, and Australia investigating the experiences of medical practitioners when providing care for the ASD population, there is little known about these matters in Ontario, Canada. Overall, research illustrates that there are obstacles (i.e., delay in diagnosis, medical practitioners' lack of knowledge and comfort level in providing care for individuals with ASD) and facilitators (i.e., collaboration with other healthcare professionals) that impact physicians' experiences when dealing with individuals with ASD. Furthermore, the results of the study by Ghaderi and Watson (2019), indicated that Ontario physicians reported lack of comfort in providing diagnosis and treatment for this population; therefore, there is a need to explore Ontario physicians' experiences when providing diagnosis and treatment for individuals with ASD. The present study was based on examination of data generated from the two-phase study previously described by Ghaderi and Watson (2019), but it focused on qualitative information pertaining to barriers and facilitators that Ontario physicians experience when providing care for the ASD population. Some data from this study have already been published (Ghaderi & Watson, 2019).

## Methods

As explained by Ghaderi and Watson (2019), "participants in this study were accessed through snowball sampling, social media (e.g., Facebook), as well as conferences in health- and developmental-related areas" (p. 684). The Laurentian University Ethics Board approved this study, and informed consent was obtained from all participants at both phases of the study (i.e., quantitative and qualitative). Participants were assured that they had the freedom to withdraw from the study at any time. All participants are referred to by pseudonyms to protect their identities.

### Participants

As explained by Ghaderi and Watson (2019), participants in this study were comprised of physicians who would encounter individuals with ASD (e.g., family physicians, pediatricians, and developmental pediatricians), and who practiced in the province of Ontario. Twenty seven participants completed a set of quantitative questionnaires, at the end of which they were invited to participate in a semi-structured interview. From 27 participants, five [family physician ( $n = 3$ ), developmental pediatrician ( $n = 1$ ), child and adolescent psychiatrist ( $n = 1$ )] volunteered to partake in a semi-structured interview. The age of participants ( $n = 27$ ) ranged from 28 to 62, with a mean age of 43, and the majority were female (85%). Further information outlining participant demographics can be found in Ghaderi and Watson (2019).

### Materials

For the purpose of this study, participants were first invited to participate in the survey and then some of whom participated in the semi-structured interviews.

**Phase I.** "In this phase, participants completed the Healthcare Professional Questionnaire, which was adapted from the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012). The questionnaire was set up via REDCap, which is an online survey website hosted at Laurentian University. Participants also had the option of filling out a paper copy of the questionnaire. The initial section of the Healthcare Professional Questionnaire was

designed to capture participants' demographic information such as age, gender, areas of speciality, years of practice, as well as the communities that they had practiced in (i.e., rural and urban)" (Ghaderi & Watson, 2019, p. 685).

In addition to the demographic information, the questionnaire was also designed to investigate participants' levels of education and training in regards to providing care (i.e., diagnosis and treatment) to individuals with developmental disabilities, throughout their undergraduate degrees, medical school, as well as professional training (e.g., pediatric residency). For example, participants were asked to rate their opinion about the usefulness of general undergraduate medical training in increasing their knowledge about developmental disabilities on a 3-point Likert scale (i.e., "not helpful" to "very helpful").

**Phase II.** "At the end of the survey, the participants were invited to partake in a semi-structured interview. All the interviews took place over the phone" (Ghaderi & Watson, 2019, p. 685). The semi-structured interview consisted of approximately 14 questions, "which were intended to explore the participants' perceived levels of competency as well as their experiences when dealing with individuals with ASD" (p. 685). Sample interview questions included "What previous experience(s) do you have with people with intellectual or developmental disabilities? ASD?", "How have these previous experiences influenced your perceived self-efficacy (ability) to care for individuals with intellectual or developmental disabilities? ASD?"

## Analysis

As discussed by Ghaderi and Watson (2019), "to analyze the questionnaire responses, data were coded in Statistical Package for the Social Sciences (SPSS; v22)" (p. 685). Using descriptive analyses, the demographic characteristics of the participants, as well as the frequency of their answers with regards to questions such as "How competent do you feel collaborating with different healthcare providers, educators, and other professionals?" were summarized.

As discussed by Ghaderi and Watson (2019), "in order to capture participants' experiences, this paper employed an integrated approach where the interview results that coincided with

findings from the quantitative analyses were analyzed and presented here. Participants' responses to open-ended interview questions, such as "Have you been exposed to ASD during your medical practice," were examined and analyzed using an inductive thematic analysis (Braun & Clarke, 2006). All interviews were digitally recorded and transcribed verbatim. Transcripts were read and reread in order for the researchers to become familiar with the data. Following repeated readings, the researchers gathered detailed notes, and comments were made in the margins of the transcript with regards to the thoughts and statements that were discussed by participants, as well as patterns that occurred in the data. Next, the initial codes were generated based on recurring patterns, and the data were collapsed into labels. Then the codes were combined to create themes that accurately represented the data. The themes were defined based on the aspects of the data that were being captured as well as their meaningfulness in the present study" (p. 686). For the purpose of this paper, the data that were gathered during the interview were integrated with the results of the quantitative analyses.

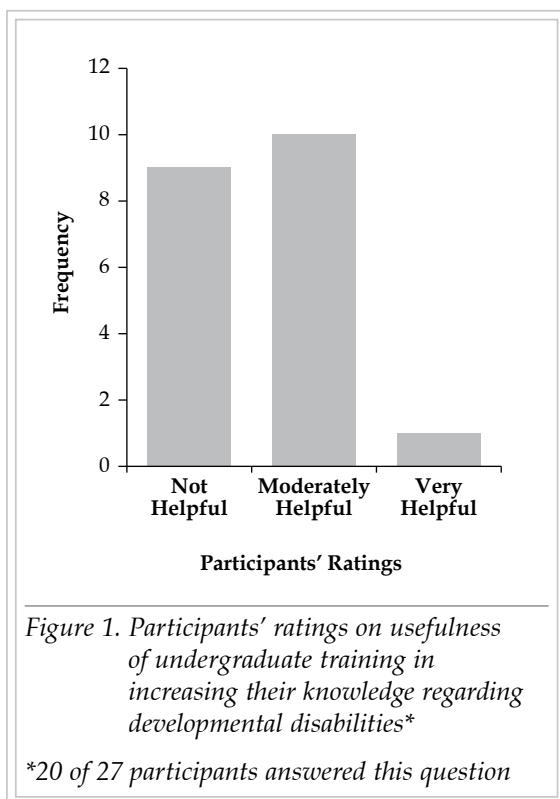
## Results

These sub-sections are based on the main themes identified in the analysis of the interviews and are supported by the questionnaire responses in an integrated approach.

### "There was no particular focus on ASD": Barriers in Providing Care for Individuals With ASD

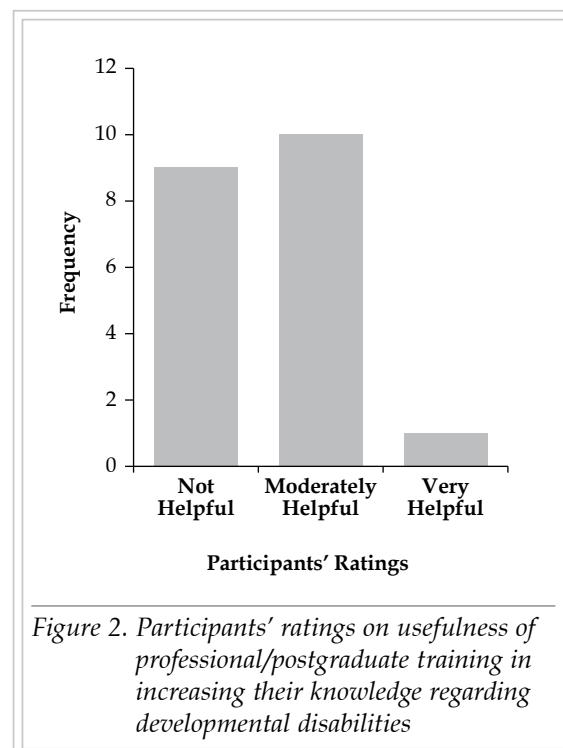
Participants stated that factors such as limited focus on ASD in medical school and professional trainings or workshops, as well as difficulties accessing resources or information about providing services to individuals with ASD, hinder their ability to provide care to individuals with ASD. The results of the questionnaire also revealed that most participants identified insufficient education and training throughout undergraduate medical education and unhelpfulness of resources available to them as barriers impeding their preparedness to meet the needs of patients with ASD.

Participants were asked to rate the usefulness of their general undergraduate training and professional or postgraduate training in increasing their knowledge about developmental disabilities on a 3-point Likert scale. Thirty-three percent of the participants rated their undergraduate training as "not helpful," 37% rated it as "moderately helpful," and 3.7% rated it as "very helpful" (see Figure 1). In addition, 53% of the participants rated their professional or postgraduate training as "moderately helpful," and 42% rated it as "very helpful" (see Figure 2).



These results show that most participants did not feel that they received sufficient knowledge and training with regards to the diagnosis and treatment of developmental disabilities during their undergraduate medical education. Additionally, less than half the participants found their professional training on developmental disabilities as very helpful in providing them with knowledge and training regarding such matters. Similar to these findings, all participants who participated in the interview raised concerns with regard to the lack of education on ASD and developmental disabilities during their undergraduate and post-graduate medical education. For example, when asked

about his medical education and training on ASD, Jason, a family physician, responded that "There was no particular focus on ASD." Monica, a psychiatrist, also stated "I imagine there would have been a lecture, but I can't remember; there would have been a ... pediatric lecture." Other participants with pediatric or developmental psychiatry specialties claimed they obtained most of their education about the diagnosis and treatment of ASD during their professional training, as opposed to their undergraduate training. For instance, Monica, a developmental psychiatrist, stated "after psychiatry, I did an extended fellowship in child and adolescent psychiatry. It's been 20 years, I have been working in developmental disabilities with both children and adults." Based on these results, it appears that physicians who pursue professional or postgraduate medical education are more likely to gain knowledge and training regarding ASD in comparison to other physicians. Overall, all participants expressed the need for more extensive education about ASD throughout their medical education.



Although participants reported high rates of participation in professional trainings and workshops on ASD (85.2%), they did not report these trainings as being helpful in improv-

ing their knowledge about the diagnosis or treatment of autism. This lack of relationship between training and increased knowledge is demonstrated by Sharon, a developmental paediatrician, who when asked about the helpfulness of training sessions, stated “with conferences, yes and no, because sometimes they are very generalized; so, they discuss general things and not very specific like, OK, we have a kid with ASD, and this is what we should do.” Therefore, it is likely that the educational content of the professional opportunities and workshops may not be judged as helpful in enhancing physicians’ knowledge about ASD.

### **“I definitely see a lot of ASD in my practice”: Facilitators in Providing Care for Individuals With ASD**

When asked about factors that enhance their experience and perceived competency when providing care for individuals with ASD, participants reported that clinical exposure and working with this population as well as working as part of an interdisciplinary team facilitated their experiences and improved their perceived comfort level.

The interview analysis showed that participants who have worked with individuals with ASD reported higher knowledge regarding the diagnosis and treatment of autism. For example, Sharon, a developmental paediatrician, stated “I definitely see a lot of ASD in my practice. Prior to residency, not much exposure in medical school, but I definitely see a lot more in my private practice, a lot more diagnosis of ASD.” Additionally, Nina, a family physician, stated “I think the more experience people have, especially in the training, and understanding of what’s going, the easier it becomes, because we learn from our patients; every patient we encounter, we learn. So, one of the critical things to have is exposure as medical students and residents.” These findings reveal that despite the desire for more education and training throughout their medical education, work experiences with this population enhanced their perceived knowledge about the diagnosis and treatment of ASD. The interview findings thus highlight the importance of hands on experience with the ASD population to enhance physicians’ perceived knowledge about the diagnosis and treatment of ASD.

The literature has demonstrated that collaboration among healthcare professionals is one of the leading factors in enhancing the healthcare system for both physicians and individuals with ASD (Swiezy, Stuart, & Korzekwa, 2008). Descriptive analysis was performed in order to investigate the frequency of participants who have had experience working as part of an inter-professional team. The results showed that 89% of the participants ( $n = 24$ ) have worked as part of a professional interdisciplinary team. The analysis of the interview transcripts also revealed that participants working in an interdisciplinary team reported higher levels of comfort and competence in providing care for individuals with ASD. For example, when Monica, a psychiatrist, was asked about her experience working with individuals with developmental disabilities and ASD, she stated

I love it. It’s extremely appealing and rewarding, and part of it is when you have the ability to work as an interdisciplinary team, and I think if you are trying to do it on your own as a healthcare provider, it is rather daunting and very very time consuming. I think, part of the joy is when you feel confident, they know you are gonna do your best to understand them and help them to have a better quality of life, they feel better and is best done in team settings.

These findings illustrate that working as part an interdisciplinary team contributes to physicians’ enhanced experiences and perceived competence when providing care (i.e., making a diagnosis) for individuals with ASD.

## **Discussion**

The present study was conducted to explore the barriers and facilitators physicians experience when providing care for individuals with ASD. Previous studies have shown that lack of education and training regarding ASD throughout medical education is a significant barrier medical practitioners experience when dealing with this population (Carbone et al., 2010; Fenikilé et al., 2015; Nah, Young, Brewer, & Berlinger, 2014). In support of these findings, the results of this study also revealed that most participants rated the usefulness of undergraduate medical training as moderate in increasing their knowledge regarding developmental disabilities and

ASD. Furthermore, a handful of participants expressed their needs for further education and training regarding ASD in medical school. Most participants, who participated in the interviews, stated that they may have received only one lecture regarding ASD during their undergraduate medical education. Due to a perceived lack of ASD training throughout their medical education, participants felt the need to educate themselves by attending conferences, workshops, and training on their own time. While some participants reported such workshops and trainings helpful in providing them with knowledge and skills about dealing with individuals with ASD, other participants found such trainings to be too general and therefore unhelpful.

On the other hand, approximately half of the participants (i.e., 53%) rated the usefulness of postgraduate and professional training as very helpful in increasing their knowledge regarding such disabilities. Participants who obtained their degrees in more specialized programs regarding children and adolescents (e.g., developmental paediatrician and child and adolescent psychiatrist) received more training and education with regard to individuals with developmental disabilities and ASD, compared to family physicians, who felt they did not receive sufficient training with regard to this population, unless they participated in specialized workshops on developmental disabilities due to their personal interests. Overall, the results of this study are in line with previous findings with regards to medical practitioners' concerns about challenges they experience in terms of the time they must spend in order to educate themselves on the diagnosis and treatment of ASD (Carbone et al., 2010; Nah et al., 2014).

According to Haverkamp and colleagues (2016), in order to improve the quality of care for individuals with ASD, there is a need for healthcare providers to receive ASD-specific training. However, the findings of this study revealed that participants often do not find the educational content helpful in increasing their knowledge regarding ASD in approaching the needs of this population. Specifically, professional trainings and workshops may focus on the general topic of developmental disabilities rather than being specific to ASD and its diagnostic and treatment approach. In line with previous research (e.g.,

Haverkamp et al., 2016; Major et al., 2013), the findings of this study shed light on physicians' needs for more specific training, through which they learn about ASD, its symptomology, identification, diagnosis, and treatment, rather than education or workshops focused on the general topic of developmental disabilities. Therefore, it is imperative to implement ASD-specific training in medical curricula and residency programs in order to provide physicians with clinical exposure to the ASD population.

The findings of this study also identified a few facilitators reported by participants related to their training and experiences when providing care for this population. As discussed by Haverkamp and colleagues (2016), clinical experience working with individuals with ASD improved medical students' attitudes, knowledge and skills in providing care for this population. Similar to such findings, participants in this study also identified hands-on clinical experience working with individuals with ASD as helpful in enhancing their knowledge and comfort level in meeting the needs of this population. Research shows, receiving education and training with regards to ASD has proven to be imperative in physicians' preparedness and comfort level providing care (i.e., diagnosis and treatment) for individuals with ASD (Finke et al., 2010). Therefore, implementing clinical placements and residency programs that are focused on ASD will provide physicians with opportunities to enhance their competency in meeting the needs of patients with ASD.

Finally, collaboration among healthcare professionals (e.g., physicians and psychologists) has demonstrated to enhance the ASD diagnostic process as well as medical practitioners' experiences when providing care for individuals with autism and developmental disabilities (Ritzema et al., 2014). In line with these findings, participants in this study reported higher comfort levels and perceived competence providing care for individuals with ASD when they work with other healthcare professionals. Therefore, promoting and improving communication and collaboration between medical practitioners and other health care professionals such as psychologists as well as speech and language pathologists is a critical step towards enhancing the primary care for individuals with ASD and their families.

## Limitations

Even though this study addressed the gap in the literature with regards to Ontario medical practitioners' experiences when providing care for individuals with ASD, a number of limitations are present. This study investigated the experiences of medical practitioners in limited geographic areas in Ontario, and therefore results may not be generalized to other communities in this province. For the purpose of this study, information regarding physicians' past trainings (i.e., where and when they received trainings) were not gathered. This information may have better explained their perceptions of the trainings that they have had received. Furthermore, given the nature of the medical profession, physicians are often considered the busiest professionals (Cunningham et al., 2015; Flanigan & McFarlane, 2008). More than 50 participants, whose contact information was gathered through the College of Physicians and Surgeons of Ontario (CPSO) website, social media, and snowball sampling, were invited (i.e., via emails, phone calls, etc) to participate in the study, but only 27 participants filled out the questionnaires and five participated in the interviews. Consequently, the current participants may have different experiences working with individuals with ASD than practitioners practicing in other regions of Ontario due to their interest in terms of obtaining education and training in this area.

Finally, in order to facilitate medical practitioners' participation in this study, a significant number of participants were recruited at conferences (i.e., the Health and Wellbeing Conference and Child Development Update conference). These conferences were in the areas of physical and developmental disabilities, where participants were exposed to education and training about developmental disabilities. Therefore, due to the educational setting, the possibility exists that these participants may have had biased perceptions of their own knowledge and competency. Participants recruited at the conferences may have higher levels of interest in acquiring knowledge and training with regards to developmental disabilities, as well as ASD. In addition, due to the educational nature of the conferences, some participants may have experienced a heightened perception of their knowledge about the

diagnosis and treatment of ASD, and therefore, may have rated their perceived knowledge higher in comparison to other developmental disabilities.

## Conclusion and Implications

This study investigated the barriers and facilitators that Ontario physicians experience when providing care to individuals with ASD. The findings illustrate a number of challenges that physicians often encounter when dealing with individuals with ASD. Most participants expressed their needs for further ASD-specific education and training throughout their undergraduate medical education. Physicians would benefit from professional development opportunities that are focused specifically on ASD and would provide them with knowledge and hands-on experience with regard to providing care for the ASD population.

The current study supports the findings of existing research that those who have had clinical and experiential experience working with individuals with ASD reported higher levels of comfort and competence in meeting the needs of this population. Furthermore, the findings of this study revealed that collaboration among physicians and other healthcare professionals have been found to play a significant role in their knowledge and comfort level when dealing with this population.

In conclusion, the findings of this study point to the importance of increasing discussion of ASD in medical school curricula and professional development. In addition to providing more ASD education and training throughout medical education, it is imperative for medical students and practitioners to gain hands-on clinical experiences working with individuals with ASD throughout their medical education and residency programs. Finally, even though lack of education and training are identified as some of the significant barriers medical practitioners experience when dealing with this population, other facilitators such as collaboration with other healthcare professionals can be promoted in order to enhance the experiences and perceived competence of physicians, ultimately improving the care for patients with ASD and their families.



## Key Messages From This Article

**Professionals.** Physicians have a desire to learn more about autism diagnosis and treatment of individual with ASD. However, they do not feel prepared to meet the needs of their patients with autism. Therefore, experience working with individuals who have autism increases the perceived competence of physicians working with this population. Additionally, working in an interdisciplinary team enhances physician competence when they have a patient with autism.

**Policymakers.** Policy to promote more extensive education and clinical trainings regarding ASD is crucial in medical schools, in order to better prepare future medical practitioners to feel competent to provide care for this population.

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I would like to thank the physicians who took the time out of their busy schedules to participate in this study. I am grateful to have had the opportunity to meet such incredible and caring professionals who shared their experiences in order to contribute in the field, and ultimately make a difference in the lives of individuals with ASD.

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