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ORIGINAL ARTICLE

Snakes and Ladders: Barriers and Facilitators Experienced by Immigrant Families when Accessing an Autism Spectrum Disorder Diagnosis

Mélina Rivard[1] · **Marie Millau**[1] · **Charlotte Magnan**[1] · **Catherine Mello**[2] · **Mélina Boulé**[1]

Abstract
There presently exists limited information or studies on means to support immigrant families as they attempt to access quality services for children with autism spectrum disorder (ASD). An ASD diagnosis is the gateway to support services and adapted interventions. Yet, studies show that immigrant families typically experience longer delays in obtaining a diagnosis and more challenges in gaining access to services. Twenty-four families who immigrated to Québec (Canada) participated in semi-structured interviews in which they listed the obstacles and facilitators encountered in their service trajectory to obtain a diagnosis for their child. Families' attitudes toward ASD, as a function of native culture, and their advice to other families in a similar situation are were also reported. Obstacles most often mentioned by participants were the waiting period for diagnostic services, feelings of social isolation, and a lack of professionals' knowledge about ASD. Parental advocacy, the competency and expertise of the professionals who conducted the evaluation, and parental education and awareness of ASD were the most frequently named facilitators. Finally, the most common recommendations made to other parents were to be persistent and proactive. In light of these reported experiences and perceptions, a series of clinical recommendations are provided to guide ASD evaluation practices in multicultural communities.

Keywords Obstacles · Facilitators · Immigrant families · Diagnosis trajectory · Autism spectrum disorder

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✉ Mélina Rivard
rivard.melina@uqam.ca

[1] Université du Québec à Montréal, Institut de santé mentale de Montréal, Montréal, QC, Canada

[2] The Pennsylvania State University, Berks, Reading, PA, USA

As cultural diversity increases in Canada and other countries, children and families who receive specialized services for autism spectrum disorder (ASD) often face multiple challenges associated not only with their diagnosis, but with cultural differences (e.g., in communication, values, perceived needs; Khanlou et al. 2017; Millau et al. 2018). The agencies tasked with providing intervention, care, and educational services for ASD must adapt their offerings to meet the needs of individuals with dual integration (i.e., to civil society and to the host culture) concerns. In the Canadian province of Québec, where the present study was conducted, governmental policies stipulate that service providers should attend particularly to persons who present multiple characteristics associated with situations of discrimination (also known as "intersectional discrimination"; Government of Québec 2009). For instance, these policies state that persons diagnosed with ASD who belong to ethnic or cultural minority groups are more liable to prejudice and experience greater difficulty in accessing services, and that their requests for public services should therefore be granted priority.

In general, compared to families of typically developing children or of children with other conditions, families of children with ASD face greater challenges across multiple spheres of life: mental health, employment, social and marital situation (Rivard et al. 2014). These difficulties are magnified in immigrant families (Bailey et al. 2004; Gardiner and French 2011; Liptak et al. 2008; Mandell and Novak 2005; Montes et al. 2009; Thomas et al. 2007; Welterlin and LaRue 2007). They notably encounter additional obstacles in accessing ASD diagnostic evaluation services and, subsequently, obtaining information about the diagnosis and the services available to them (Broder-Fingert et al. 2013; Cho and Gannotti 2005; Samadi et al. 2011; Sontag and Schacht 1994). Although the prevalence rate for ASD, presently estimated at 1 child in 59 (Baio et al. 2018), is regarded as relatively homogeneous across the globe (Durkin et al. 2010), there remain ethnic and cultural disparities (Emerson et al. 2008; Fombonne 2003; Gardiner and French 2011; IASSID SIRG 2012; Jones et al. 2011; Liptak et al. 2008; Montes et al. 2009; Thomas et al. 2007; Welterlin and LaRue 2007). Families' socioeconomic status, ethnic or cultural background, language spoken at home, and other characteristics may influence the age at which ASD is diagnosed. Children from immigrant families are more likely to be diagnosed after the age of 4 than their non-immigrant peers (Manning et al. 2011; Roth et al. 2016; Valicenti-McDermott et al. 2012). The age at which children are diagnosed has important consequences for their access to quality early intervention services, and thus their and their family's prognosis (Rivard et al. 2018). More so than symptom severity, socioeconomic status may be the strongest predictor of the accessibility of diagnostic evaluation and related services for ASD (Durkin et al. 2010; Harstad et al. 2013).

Multiple obstacles may underlie the service accessibility challenges encountered by immigrant families: language barriers; a lack of understanding of the host country's health care system; differences between families' and service providers' values, expectations, and goals; and perceived discrimination from service providers (Dyches et al. 2004; Klingner et al. 2009). For instance, families who speak a different language may find it difficult to understand or express themselves in the language in which services are provided in their host country. This, in turn, may make it more difficult for them to understand the diagnosis and entail additional delays in obtaining information or making use of available services (Harstad et al. 2013; Ryan and Smith 1989).

Families' choice of treatment and participation in the child's interventions are a function of their beliefs relative to the diagnosis and their experiences within the services trajectory (Mandell and Novak 2005). Studies indicate that when immigrant families make use of ASD services, these may be less consistent with best practices than those received by families native to their host country (Klingner et al. 2009). For instance, a study showed that in the United States children with ASD whose parents were born in Latin America were six times more likely to receive treatments for which efficacy has not been empirically supported (Levy et al. 2003). This is particularly problematic inasmuch as children within this population are more likely to experience mental health difficulties, such as more severe autism symptoms (Blacher et al. 2014; Cohen and Miguel 2018; Magaña et al. 2013). Documenting immigrant families' perception of their service trajectory, with a particular attention to what they experienced as helpful or challenging in accessing the appropriate services, could help shed light on how to better reach these families and provide them services that are suited to their situation.

There is presently limited research or information available on the means to facilitate immigrant or ethnic/cultural minority families' access to quality services for ASD (Klingner et al. 2009). Furthermore, the literature indicates a need for increasing the participation of families, particularly of diverse social and economic backgrounds, in ASD research and interventions. Indeed, the inclusion and collaboration of these families in research could be instrumental in building a knowledge base that would inform the development of adapted, socially valid practices and more comprehensive arrays of intervention programs (Cohen and Miguel 2018; Wolery and Garfinkle 2002). As part of a larger project investigating the experiences of immigrant families of children with ASD during the early childhood period, the present study specifically sought to document the obstacles and facilitators encountered in their trajectory leading up to the child's diagnosis.

Objective

The specific objectives of the present study were as follows: to 1) document the obstacles experienced by immigrant families in obtaining an ASD diagnosis for their child, 2) document the factors that facilitated their access to a diagnosis, 3) identify prevailing attitudes toward ASD in participants' culture of origin, and 4) record the advice that participants would give to other immigrant families in their own trajectory to obtain a diagnosis.

Method

Participants

Twenty-four first-generation immigrant families residing in the greater Montréal (Québec, Canada) region participated in the present study. For 11 of these families, both parents acted as respondents; for 10 and 3 families only the mother or father, respectively, participated. Thus, a total of 34 parents (21 mothers and 13 fathers) were involved in data collection. All families were registered with one of the two rehabilitation centers providing free ASD services in the Montréal urban area. In all cases, their child had received a formal ASD diagnosis, which is a prerequisite to receive services dispensed by a rehabilitation center in the province of Québec. At the time of the study, these families had either received or were on a waiting list for treatment for their child. Participants had immigrated to Québec from Africa (41.2%), Latin America (32.4%), Europe (14.7%), and Asia (including Turkey and Russia, 11.8%). On average, they had resided in Québec for 8 years and 7 months (*SD* = 4 years and 9 months). The children for which ASD services were requested by these families were aged 4 years and 1 month on average (*SD* = 2 years and 8 months). Table 1 presents additional information about participants' household income, education, and country of origin.

Measures

Sociodemographic Questionnaire A questionnaire was used to collect information about the family as well as the child's diagnosis (or diagnoses) and participation in treatments outside of the rehabilitation center. This questionnaire included: 1) socio-economic characteristics (income, education, employment), 2) ethnic diversity index (country of birth, language spoken at home), 3) family composition and siblings; 4) diagnosis and co-occurring disorders; and 5) other treatments or therapies; 6) variables related to the family's native culture and immigration history.

Table 1 Families' sociodemographic information

	Mothers ($n = 21$)		Fathers ($n = 13$)	
Family income				
10,000-29,999$	3	(14.3)	3	(23.1)
30,000-49,999$	5	(23.8)	4	(30.8)
50,000-69,999$	6	(28.6)	3	(23.1)
70,000-89,999$	3	(14.3)	1	(7.7)
90,000 or more	2	(9.5)	1	(7.7)
Other or missing information	2	(9.5)	1	(7.7)
Level of education				
Incomplete high school	3	(14.3)	1	(7.7)
High school	0	(0)	1	(7.7)
Post high school and professional	1	(4.8)	0	(0)
College (baccalaureate degree)	12	(57.1)	6	(46.2)
University (graduate degree)	3	(14.3)	3	(23.1)
Other or missing information	2	(9.5)	2	(15.4)
Region of origin				
Latin America and the Caribbean	8	(38.1)	3	(23.1)
Africa	7	(33.3)	7	(53.8)
Europe	3	(14.3)	2	(15.4)
Asia (including Russia and Turkey)	3	(14.3)	1	(7.7)

Semi-Structured Interview about the ASD Diagnosis Parents' perception of the obstacles and facilitators they encountered during their child's diagnostic evaluation process was documented through a semi-structured interview (schedule based on Barelds et al. 2009, 2010; Samadi et al. 2012). During this interview, they were also asked about their native culture and the circumstances under which they had immigrated to Québec (based on Cho and Gannotti 2005). The interview as a whole covered three major themes: perceptions of ASD, the ASD diagnostic trajectory, and immigration history. In the present study, responses to the 15 questions that comprised the second theme (diagnostic trajectory) and two questions included in the third theme (immigration history), were examined.

The first two authors of the present study developed the interview schedule, which was then evaluated by three experts: an expert in qualitative research, an expert on research among families of children with ASD, and a clinician who specialized in ASD. The authors revised the interview schedule as a function of this expert feedback and subsequently conducted a pre-test with one family. No further modifications were needed.

Procedure

The protocol for this study was reviewed and approved by the Joint Research Ethics Board for Public Rehabilitation Centers for Persons with Intellectual Disabilities and ASD in Québec. Families who met the inclusion criteria for the study (i.e., having immigrated to Québec and being registered with a rehabilitation center following a formal ASD diagnosis) were contacted by a research assistant employed by the rehabilitation centers. They were given a brief description of the study. Those who wished to participate scheduled an appointment to carry out the interview. They were able to select the venue (in their own home or at the rehabilitation center) and the date and time that best suited their family. Prior to beginning the interview, parents signed a consent form which clarified the details of their participation.

Three research assistants conducted the interviews. These doctoral-level students in psychology received training to ensure consistency in the interview process. Interviews were carried out in French, English, or Spanish according to participants' stated preference. Each interview was recorded and transcribed by research assistants who were undergraduate students in psychology and were fluent in the language in which the interview had been carried out. Transcripts were translated to French by the bilingual interviewer as needed and verified by an independent bilingual research professional to ensure their accuracy prior to data analysis. It should also be noted that transcript excerpts that were selected for inclusion in this article were translated to English specifically for this purpose.

Data Analysis

Mucchielli's content analysis method (see L'Écuyer 1990) was used to analyze the interview transcripts. According to this method, categories and subcategories of themes are first identified in a thorough reading of the transcripts. Then, each unit of meaning in the transcripts is classified into the relevant category and sub-category. To minimize bias in the content analysis process, a triangulation approach was adopted. Specifically, the first two authors, who were trained in qualitative data analysis, independently produced their preliminary version of a coding grid based on a first transcript. They compared and combined their versions into a single, shared coding grid. A research assistant and the second author independently tested this grid on a second interview transcript, compared their results, and discussed modifications to the coding scheme. The outcome of this iterative test-and-revision process, which was performed three times, was then reviewed by an independent expert in qualitative analysis. The research team produced a final version of the coding grid based on this expert feedback. Three research assistants, who were trained in content analysis by the authors, analyzed all interview transcripts with the final grid. Inter-reliability was computed on 13% of transcripts and attained $\kappa = .81$. The frequencies with which each category or sub-category was mentioned by respondents were computed in order to identify salient themes.

Results

Results of the qualitative analysis are presented in the following order based on the objectives of the study: parents' perceptions of 1) obstacles and 2) facilitators to obtaining an ASD diagnosis, 3) attitudes toward ASD in their native culture, and 4) advice they would give to other families.

Perceived Obstacles to Obtaining an ASD Diagnosis

Four categories of perceived obstacles to obtaining a diagnosis were identified in parents' responses: those pertaining to 1) services, 2) the family and 3) service providers. Several subcategories emerged for each type of obstacle. The frequencies with which these themes were mentioned by parents are listed as a function of gender in Table 2.

Service-Related Obstacles Parents most often described obstacles that had to do with ASD services. Specifically, the most frequently mentioned subcategory was the waiting period to receive a diagnosis: "waiting is the problem", "no, there weren't any obstacles, but it took a long time", "I don't understand why it took this long, why couldn't they have told us so from the beginning?"

The second most frequently mentioned subcategory referred to the lack of a centralized information source or service that could explain the steps that parents needed to obtain a diagnosis for their child and, ultimately, gain access to intervention services. Participants felt that the trajectory leading up to a formal ASD diagnosis lacked organization and coherence, that the process was unclear, and that it was difficult to make sense of the available information. For instance, a father mentioned that "information is very scattered", and a mother said: "We know we will meet several people, but we do not know whom nor when.". Another father said: "It's just... word of mouth, that's it. It takes a long time, sometimes, because you don't know. Or sometimes through the internet, that helps a lot too […] Every time, it's up to us to go… sometimes we don't know all of… It's possible that there are other support groups or places that can help us, but we don't have… We didn't call them because we didn't know." Parents explained that the health and social services system is difficult to understand, such as the father who said: "At this point, we don't understand everything, uh, we always have

Table 2 Categories and subcategories of obstacles reported by each parent

Categories	Fathers (*n* = 13)		Mothers (*n* = 21)		Total (*n* = 34)	
Service-related obstacles						
Delays	9	(69.2)	12	(57.1)	21	(61.8)
Lack of centralized information	3	(23.1)	4	(19)	7	(20.6)
Cost of private services	3	(23.1)	3	(14.3)	6	(17.6)
Lack of continuity between services	2	(15.4)	3	(14.3)	5	(14.7)
Lack of governmental support	1	(7.7)	1	(4.8)	2	(5.9)
Cumbersome administrative procedures	0	(0)	1	(4.8)	1	(2.9)
All subcategories	18	(138.5)	24	(114.3)	42	(123.5)
Family-related obstacles						
Social isolation	1	(7.7)	9	(42.9)	10	(29.4)
Denial	1	(7.7)	9	(28.6)	7	(20.6)
Lack of knowledge/understanding of ASD symptoms	3	(23.1)	3	(14.3)	6	(17.6)
Fear of stigma (culturally-based)	1	(7.7)	2	(9.5)	3	(8.8)
All subcategories	6	(46)	22	(104)	28	(82.4)
Provider-related obstacles						
Professionals' lack of knowledge about ASD	2	(15.4)	7	(33.3)	9	(26.5)
Professionals' lack of knowledge of ASD services	2	(15.4)	5	(23.8)	7	(20.6)
Lack of family physician	0	(0)	1	(4.8)	1	(2.9)
All subcategories	5	(38.5)	14	(66.6)	19	(55.9)
Child-related obstacles						
Mild symptoms (delayed the process)	1	(7.7)	0	(0)	1	(2.9)

difficulty making a medical appointment even though we now have physicians […] we are still learning about the network but we do not know it well enough…" A mother said the following in relation to difficulties in understanding how services operate and can be accessed: "It's not easy to meet them, it's not easy. The first time I learned about the CLSC [community health centers[1]] it was through a neighbor who told me 'Listen, you can try to go to the CLSC.' In the French language courses, they tell us that CLSC exist and we get some basic knowledge, but I think a little more general education on how to reach individuals could help, because this didn't come directly from the CLSC, I didn't see any advertising. I am always picking up flyers wherever I go, at the CLSC the flyers didn't just end up in my hands, this information isn't directly available." Parents also mentioned difficulties in understanding the system, even with access to information, because "it is always changing."

The third subcategory concerned private diagnostic evaluation services, to which some parents resorted due to excessive delays in the public network. Parents perceived that their cost was an obstacle: "or else you have to choose private services, but private is too expensive." The fourth subcategory was the lack of continuity across services:

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[1] In contrast to Québec's rehabilitation centers, which are public agencies that provide specialized services to individuals with ASD or intellectual and developmental disabilities and their families, community health centers are primary care clinics that provide general (non-specialized) health care and social services to any person residing within its territory, at no cost.

"Sometimes we […] cannot access the service directly like this [….] we call, someone tells us 'No, no, it is not me, you need to call this other person'" or "I wanted to know what the entire trajectory would be, what was next but… there was none… it was, like, so closed-up."

The fifth and sixth subcategories of service-related obstacles had to do with a lack of financial support by the government and cumbersome administrative procedures, respectively: "instead of getting subsidies from both governments, we only get the federal subsidy but nothing from Québec", "it's a lot to fill out, making all those requests."

Family-Related Obstacles The second most frequent type of obstacles related to the families themselves, and could be further divided into four distinct subcategories. Among these, the most salient was social isolation, which resulted in a lack of support and sense of loneliness during the process. For instance, a mother explained: "We are isolated, full stop. We are isolated. He (husband), I, our children." Another participant specified that "the whole time, we are left to our own devices. We don't know what to do."

Parents' denial of the diagnosis was the second most commonly noted family obstacle. In several instances, one or both parents' inability or unwillingness to recognize some of their child's symptoms was thought to have delayed the evaluation process. A father explained: "I was not ready for the evaluation, and this created tensions in our relationship as a couple." Similarly, the third subcategory related to families not being aware of the symptoms of ASD, which could also delay their seeking help. One parent said that "it was the first time I heard about this disease." This lack of knowledge could result in confusion within the family, including a poor understanding of the diagnosis and the child's need for adapted services.

Finally, some parents reported having delayed seeking out services out of fear of stigmatizing their child. They also reported the same fear of stigmatizing for themselves. A mother said "we were afraid to go to the hospital because… it's a stigma."

Provider-Related Obstacles The third category of obstacles related to the professionals who dispense health and social services to families, and could be further refined into three subcategories. Most often, parents mentioned that some of the professionals who worked with their child (e.g., pediatrician, educator) seemed insufficiently informed about the symptoms of ASD. For instance, parents who had noted symptoms in their child felt that the professionals with whom they initially consulted about these concerns lacked the knowledge to counsel them appropriately. For instance, one mother said "I said so to the pediatrician, and she told me that… I was seeing things that, uh… that weren't there." Another mother said: "I cried so much over the phone, I was astounded, like… she's been her pediatrician since birth… how could she not know… the baby, what does she need… like that, and all the while she [the pediatrician] told me let's wait, let's wait, let's wait…" A third mother mentioned that "the physician, she said let's wait until age 3, because there are children who develop, like… differently, and 3 years old is a… safer age to get a true diagnosis, but I said, I said… that after 18 months, or 2 years, we can get a diagnosis. She said but… yes but it's difficult, with the little ones, we should… give him a chance."

Similarly, several participants mentioned a lack of knowledge of ASD-related services among professionals who worked with the family: "even among professionals, there seemed to be a lack of understanding of this system, how diagnoses are made." Finally, a participant mentioned that not having a family physician represented an obstacle to her obtaining a diagnosis for her child.

Perceived Facilitators for Obtaining an ASD Diagnosis

Three categories of facilitators emerged from the content analysis; these were associated with 1) the family, 2) service providers, and 3) services, respectively. The frequencies associated with each type of facilitator and its subcategories are presented in Table 3.

Family-Related Facilitators Parents most often mentioned strengths present in the family as facilitators in the diagnostic process. Four subcategories were identified. Half of participants mentioned parental advocacy, that is, their own determination and proactive stance. For instance, a mother said "we took the initiative; I would go over there to complain." Another mother said that "he [the child] received a lot of services compared to other children, because I fought for them." Another participant said "I decided to act, so I… I went to see my family physician and I said… I said I will make a request for the developmental clinic."

Table 3 Categories and subcategories of facilitators reported by each parent

Categories	Fathers (*n* = 13)		Mothers (*n* = 21)		Total (*n* = 34)	
Family-related facilitators						
Proactive, determined, persistent parents	4	(30.8)	13	(61.9)	17	(50)
Access to information: classes, training, scientific literature, level of education	3	(23.1)	10	(47.6)	13	(38.2)
Immigration	2	(15.4)	3	(14.3)	5	(14.7)
Support from family members	1	(7.7)	1	(4.8)	2	(5.9)
All subcategories	10	(76.9)	27	(128.6)	37	(108.8)
Provider-related facilitators						
Competent and persistent professionals	5	(38.5)	12	(57.1)	17	(50)
Human qualities of professionals	3	(23.1)	5	(23.8)	8	(23.5)
All subcategories	8	(61.5)	17	(81)	25	(73.5)
Service-related facilitators						
Receiving services	1	(7.7)	7	(33.3)	8	(23.5)
Availability of information on services and resources	1	(7.7)	3	(14.3)	4	(11.8)
Specialists in school/ day care setting	1	(7.7)	2	(9.5)	3	(8.8)
Subsidy	0	(0)	2	(9.5)	2	(5.9)
Access to interpreter	0	(0)	1	(4.8)	1	(2.9)
All subcategories	3	(23.1)	15	(71.4)	18	(52.9)
Other facilitators						
Children with ASD in social network	0	(0)	2	(9.5)	2	(5.88)
No facilitator	0	(0)	1	(4.8)	1	(2.9)

The second subcategory referred to ways in which parents facilitated their child's diagnosis through their own expertise, experience, or information acquisition process (e.g., consulting the scientific literature, participating in training sessions or workshops). They explained "my wife works in health care, I am a journalist, so we… were somewhat equipped to do our own research" or "we went to the meetings [workshops provided by the rehabilitation center] for three months, but we also learned a lot through direct experience." The third subcategory had to do with families' immigration to another country. In some cases, parents' suspicion that their child might have ASD influenced their decision to relocate to another country. This was a case for a father, who said "we left for this [access to services] notably". A mother said the diagnosis was facilitated by "immigrating to Québec, because in France he [referring to her son with ASD] would not have had access to the same services". In other cases, the decision to immigrate preceded the detection of ASD symptoms, but parents nevertheless felt that relocating to Québec facilitated their trajectory. For instance, one mother considered what would have happened if she had not emigrated while pregnant with her son: "No one there would have said 'oh let us try to understand how this child functions so we can help him', nobody would have. To be sure, if he had been born in Africa, maybe today we would not even be… he would not have developed. Maybe we would have taken him to a psychiatrist, who would have said yes he has ASD but there would not have been any services. We might not even have known, we would have never even known it was ASD." Finally, participants mentioned receiving support from within the family, whether from their spouse or members of the extended family. A father said "Me, of course if I had been alone, I would not have gotten there [referring to his wife's role in obtaining the diagnosis]."

Provider-Related Facilitators The second type of facilitator most often cited by parents pertained to the help they received from professionals throughout the diagnostic trajectory. The first subcategory of facilitators specifically referred to their professional qualities, such as competence and persistence: "the psychoeducator did everything for us", "she was determined, she pushed us." In contrast, the second subcategory acknowledged the facilitative effect of their human qualities, such as their supportive attitude. For instance, one mother mentioned the personal qualities of a psychoeducator who worked with the family: "the psychoeducator who came here. Very kind, very nice."

Service-Related Facilitators The third type of facilitator related to organization of services themselves. Most often within this category, participants mentioned having had access to services, whether through private providers or public organizations (rehabilitation centers or community health centers), prior to obtaining a diagnosis. These initial contacts were seen as facilitators to obtaining a diagnosis inasmuch as they enabled them to enter the health care system: "already being in the [community health center] system." Another facilitator referred to the availability of information on services and procedures, and was mentioned by several participants: "the Autism Montréal association got us started on the right foot." Some participants said that the presence of ASD specialists in school or day care had been helpful. For instance, one mother explained that the psychoeducator on staff at the school "had previous experience with children with ASD. She did not make the diagnosis, but she said 'he has symptoms'." A few participants mentioned receiving subsidies that enabled them to afford private services. Finally, one participant indicated that access to an interpreter, provided by the community health center, had facilitated the diagnostic process.

Other Facilitators The remainder of facilitating factors mentioned by participants did not fall under a specific category. In some cases, the presence of a child with ASD in the family's social network helped them navigate the diagnostic process. Indeed, the mother explained "Our social network; by chance I had a friend whose son had ASD." Finally, one mother said there had not been any facilitators to the process.

Attitudes toward ASD in Parents' Native Culture

Parents' account of the attitudes toward ASD that prevailed in their native culture generally fell under three categories: a lack of knowledge of ASD, social exclusion, and fear.

Lack of Knowledge of ASD More than three quarters ($N = 26$, 76.5%) of participants said there was a lack of knowledge or understanding of ASD in their native country. This type of attitude could be divided into three distinct subcategories. The first was the lack distinction between diagnoses ($N = 12$, 35.3%), that is, that all mental health problems were perceived similarly. One mother explained that in her country "we are still at the stage of practically considering a child with autism as being 'retarded'", whereas another said "the idea exists but is not known under this label. We say the child is handicapped, that's all." The second subcategory, mentioned by 26.5% of parents ($N = 9$), described how a lack of awareness of ASD resulted in the absence of adapted and specialized services in their native country. One participant explained: "But over there, they do not know what is autism, there isn't really support or follow-up for them [people with ASD]." Finally, the third subcategory ($N = 5$, 14.7%) described ways in which the prevailing attitude in the native country was to ignore the problem, or act as though ASD did not exist, for instance "it is very much an ignored disease", or "we don't even speak about it."

Social Exclusion The second most frequent attitude noted in families' native cultures was rejection ($N = 11$, 32.4%), and could be further divided into three subcategories. The first ($N = 5$, 14.7%) referred to the fact that children or adults disabilities or mental health problems were socially excluded. During the interview, a mother explained that "we pull them out of schools and institutionalize them"; another parent said that "over there, handicapped people aren't… they are at home." The presence of a stigma on ASD or disability more generally was the second most mentioned subcategory ($N = 4$, 11.8%), with participants expressing thoughts such as "when we still lived in our country, if a person had a diagnosis, that was a stigma." Finally, one participant (2.9%) mentioned a lack of confidentiality of information in their native country. He explained that "For instance, if you go to the hospital and get an evaluation, you cannot keep it to yourself. It becomes available to the whole system, and that's it."

Fear The third type of attitude described by three parents (8.8%) was a fear of ASD or disability in general in the native culture. One participant explained that "Maybe they are scared. Because there is no information, they don't know. Maybe they think he [person with ASD] is dangerous, maybe he can't control himself."

Function of Social Classes Finally, one father (2.9%) mentioned that attitudes toward ASD in his culture are related to differences as a function of social standing. He explained that attitudes and knowledge in his native country vary as a function of social class: "it also depends on class […] it's true that my parents came from lower-middle class. Whereas in N.'s [the child's mother] family, they're more middle-class, so they were better prepared. They studied a lot, so their perception is different."

Advice Parents Would Give to Others in a Similar Situation

Participants were asked what advice they would give to other immigrant families who suspected their child may have ASD. Four general categories that emerged from their responses. The first recommendation, made by 13 parents (38.2%), was to develop personal qualities that would facilitate their services trajectory. This first category could be divided into three subcategories. The first ($N = 7$, 20.6%) referred to persistence and proactivity. For example, participants said: "You need to knock on every door"; "it's about fighting, being ready to put up a fight." According to five participants (14.7%) the second skill to develop is fluency in the language(s) of their host country. For instance, participants said: "You either speak English or you speak French. Otherwise, if you don't speak either of those two languages, well […] you can't." Finally, one participant (2.9%) mentioned the necessity to adapt to this new situation (immigration and child diagnosis), she said: "you must adapt, everything is about adaptation."

The second category of recommendations concerns contacting services. Nine participants (26.5%) said they would also encourage other families to contact service providers such community health centers, rehabilitation centers, community organizations, or even pediatricians. A mother said that families should "call the community health center to get a little help." Acting quickly, as soon as the first suspicions of ASD arise, was the third major category ($N = 4$; 11.8%) of advice given: "timing is very important." The last category ($N = 4$; 11.8%) involved the suggestion that parents seek out information about the ASD diagnosis and available services. For instance, one participant explained "I would tell them to ask a lot of questions, not to be shy, it's your child, if you do not seek information it will not be given to you."

Finally, three recommendations (8.8%) could not be classified into the previously listed categories. One parent (2.9%) recommended that parents stay present in their child's life. Another parent addressed the importance of feeling supported and understood. Specifically, he said that "generally, I think parents of children with ASD need to feel understood. Understanding brings us great solace." The final recommendation, made by one parent (2.9%), was to use private services: "Unfortunately, my cynical advice is, yeah, to set $1000 aside and have the diagnosis done in the private system."

Discussion

As the ethnic and linguistic diversity of the populations requesting assistance from various providers of specialized ASD services grows in Western countries, it is becoming increasingly important to examine ways of supporting individuals with ASD that are sensitive to cultural differences (Gardiner and French 2011). Indeed, immigrant families of children with ASD or other disabilities face intensified challenges in gaining access to services to support the optimal development of their child and their family's quality of life (Broder-Fingert et al. 2013; Rivard et al. 2018). The present study focused on the perceptions of 24 families who had immigrated to the Canadian province of Québec with respect to their trajectory leading up to a diagnosis of ASD for their child. It also documented what these families perceived as the prevailing attitudes toward ASD in their respective countries of origin, as well as the recommendations they would make to other families in a similar situation. In doing so, this investigation sought to highlight their experiences and identify factors that could influence their search for, or access to, services. This type of endeavor could ultimately inform improvements to the diagnostic evaluation process and provide additional guidance to the professionals and staff who support them throughout this period. This approach, which stresses the participation of families in ASD research and program development, ensures that the services they receive are culturally sensitive and socially valid (Cohen and Miguel 2018; Wolery and Garfinkle 2002).

Previous research has indicated that the major obstacles faced by immigrant families in gaining access to services stem from language barriers, a lack of understanding of host country's health care system, differences in cultural values, divergences between families' and service providers' expectations and goals, and perceived discrimination from service providers (Barrio 2000; Cho and Gannotti 2005; Dyches et al. 2004; Gardiner and French 2011; Klingner et al. 2009; Liptak et al. 2008; Magaña et al. 2013; Ravindran and Myers 2012. Of these challenges, our participants mostly reported difficulties in understanding how to access services and how those services worked. They indicated that some programs (e.g. cultural orientation programs, language and cultural integration workshops) at their arrival in Québec helped them to encompass the langage barriers and to better understand the host culture but theur would have appreciated more information about the health care system. They also mentioned that their fear of bieng rejected from their community was related to the delay in their actions for asking an evaluation of their child.

Surprisingly, most of the other challenges were not mentioned by our participants as the most salient barriers they had faced. The discrepancy between our findings and the literature on immigrant families to date may be accounted for, in part, by the level of education of parents in present study's sample. Indeed, their level of education exceeded that of Québec families with a comparable income. We have noted this phenomenon in two studies of parenting stress and family quality of life (Millau et al. 2016; Millau, et al. Quality of Life in Immigrant Parents of Children With Autism Spectrum Disorder: A Comparison With Parents From the Host Culture, in revision). Where, when matched on the basis of income, immigrant families had higher levels of education than their Canadian counterparts. The high level of education of participating families may have contributed to which obstacles they experienced and how they overcame them. The issues frequently reported in the literature may be less problematic for families who may, for instance, have greater personal (e.g., the ability to gather information and seek out educational resources and programs on their own) or external (e.g., more knowledge of available supports) resources to help overcome them. For instance, although many families reported a lack of knowledge or understanding of ASD and negative attitudes toward it in their native country, participants in the present sample were able to learn about their child's condition and overcame misgivings about seeking out a diagnosis (although, as some families mentioned, these concerns may have delayed the process).

It should also be noted that this study's participants were recruited within the network of specialized ASD services. Thus, they had gained access to diagnostic evaluation and, subsequently, interventions, for their child. Their reality and experiences may not be representative of the most vulnerable families, those who have not sought or have not been able to gain access to these same services. Additionally, the present study focused on access to diagnostic evaluation rather than early childhood intervention services that are obtained following the diagnosis. Our team is presently investigating barriers and facilitators to accessing and using early intensive behavioral intervention services for immigrant families (EIBI). It is possible that a different pattern of results and manifestations of challenges related to cultural differences or the immigration process will be more salient in relation to intervention practices in this portion of the services trajectory. Additionally, although language barriers are frequently reported in the literature, families in the present sample were fluent in either French or English. Indeed, French language courses are offered to families who immigrate to Québec and do not speak the official language of the province. This may have helped families in the sample gain a better understanding of the services infrastructure, even though one part noted that these language acquisition and acculturation workshops should include more information on health and social services. Finally, it is also possible that families in our sample had developed effective coping and adjustment strategies, which helped them overcome some of the barriers in the literature.

Families pointed out that certain obstacles that they experienced related to feelings of isolation, a lack of resources and support from members of their culture and social network, the stigma associated with ASD, and a lack of knowledge about ASD in their community. These elements are also reported by non-immigrant families whose has ASD but, in the case of families in the present study, prevailing perceptions and attitudes on ASD in their culture of origin could have magnified or exacerbated some of these difficulties. As the participant discussed, this could have have an impact on their search for evaluation services (p.ex.: denial, fear of stigma).

Synthesis and Recommendations for Services

Based upon the obstacles and facilitators to obtaining an ASD diagnosis that were noted in the present study, some pathways for improvements in this process can be identified within three major areas: 1) the organization of services, 2) supports for families, and 3) increased awareness and training among providers.

Organization of Services

Support during the Period Leading up to a Diagnosis One of the most salient obstacles raised by parents was the delay in gaining access to the diagnostic evaluation. Indeed, more than 60% of families felt that this waiting period was excessive. As they waited for a formal diagnosis, families reported feeling isolated and powerless. Additionally, to the extent that a formal ASD diagnosis is required to gain access to specialized early intervention services dispensed by Québec's rehabilitation centers, families also felt deprived of the opportunity to provide their child with evidence-based treatment as early as possible. One parent explained why it was important to act quickly because "the thing with the diagnosis is that the sooner you get it, the better things are. Because then you can work with specialists, because you can ask for certain things at day care if he [the child] has a diagnosis. Even at […] the community health center, we could request certain things. But before that, before the evaluation, we couldn't. So all this was very difficult in that we needed help but we couldn't get it." Families could potentially avoid delays by opting for private diagnostic services, but many families could not afford to pay for this option out of pocket.

A few recommendations arise out of the reported experiences of immigrant families in this study. In particular, their diagnostic trajectory could be improved by facilitating access to information about ASD, parent associations, and parent coaching workshops as soon as parents or health care providers raise concerns that the child may have ASD. These community-based resources would equip families with additional knowledge and psychosocial tools to cope with the waiting period that precedes a formal diagnosis. In the case of immigrant families who often present additional vulnerabilities due their minority status, social isolation, and financial difficulties, this type of assistance may be especially helpful in closing the gap in access to services compared to families native to the host country (Bilgin and Kucuk 2010; Renty and Roeyers 2006; Samadi et al. 2011).

Centralized Information and Service Coordinators Several families expressed the need for a central source of information. Indeed, up-to-date and accurate information should be made available to families (e.g., in a single document) upon their first meeting with a primary care provider to discuss concerns about their child having ASD. At this point, parents should obtain not only a referral for diagnostic evaluation services, but also to a service coordinator. This person would accompany the family from this first contact up to the point when they obtain specialized ASD services (specifically, early intervention). This would help to streamline the diagnostic process as well as provide support and continuity of care for families they navigate the ASD services trajectory. Again, while this approach would benefit all families of children with ASD, it may be particularly helpful to immigrant families, who often report being confused by the health care system of their new country (Mandell and Novak 2005).

Supports for Families

In a previous study on immigrant families in Québec, approximately half of participating parents reported that they did not have access to social support in overcoming the difficulties associated with having a child with special needs and with the isolation they experienced after departing from their native country and thus leaving behind members of their family and their familiar surroundings (Millau, et al. Quality of Life in Immigrant Parents of Children With Autism Spectrum Disorder: A Comparison With Parents From the Host Culture, in revision). Similarly, in the present study, parents spontaneously reported that feelings of isolation, loneliness, and powerlessness had been an obstacle in accessing an ASD diagnosis for their child.

Acknowledging the Need for Social Support It is critical that parents be offered psychological support by first-line providers (e.g., psychologists, social workers) in order to help them cope with stressors and feelings of distress or isolation. Information on community organizations, parent groups (e.g., that bring together parents of children with ASD, or parents from the same culture), and other ways of participating in activities within the community as a family, should be made available to parents. Indeed, belonging to a group that shares a similar background or that is experiencing similar situations, can be an invaluable asset. A study participant explicitly mentioned that knowing another parent of a child with ASD had facilitated their own search for services. Implementing a small-scale, “sponsorship” model among parents belonging to the same culture could help alleviate feelings of isolation and promote the development of their social support network. As an example, a study examining a parenting skills support group dedicated to cultural minority families, all participating families had listed being able to meet and relate to families who experienced similar challenges (having a child with ASD and also being an immigrant) as one of their expectations for (pre-intervention interview), and as a strength (post-intervention interview) of, the program (Millau, et al., Évaluation d'un programme de coaching parental basé sur le Positive Behavior Support pour des familles originaires d'amérique latine suite au diagnostic de trouble du spectre de l'autisme, in preparation). Furthermore, follow-up interviews indicated that families had retained the friendships that had formed within the group after the program had ended. These observations suggest that the sponsorship approach could effectively capitalize on families’ strengths and ability to mutually support each other.

Awareness Campaigns in Parents’ Community Raising awareness about ASD in the circles frequented by immigrant families, such as community organizations, parent groups, churches, etc. or in the media (e.g., television) could reduce the stigma and fear associated with the condition. In turn, parents may be less apprehensive of seeking out professional help if they suspect their child has ASD. Indeed, denial and lack of knowledge of the symptoms of ASD, which many parents noted existed in their native country or culture, were among the reasons for parents’ delayed access to diagnostic evaluation services. Improving the dissemination of information and promoting discourse about ASD in the community may also encourage parents’ acceptance of their child’s condition. This could also help them realize they are not alone in their situation and impress upon them the importance of consulting a health care provider as soon as possible. Additionally, parents who possess factual information about ASD (e.g., its symptoms, its prevalence, established treatments) would thus have tools with which to address any misinformation, stigma, or rejection they may encounter in their community, and would be empowered to change cultural attitudes toward ASD or disability from within (Cohen and Miguel 2018; Samadi et al. 2011, 2012).

Promoting Parental Advocacy Several families mentioned their own strengths and competencies as facilitators in the diagnostic process. They expressed the importance of proactively, even combatively (“fight for it”), demanding access to services; and of educating themselves on the steps to take toward a diagnosis. For several parents, this also meant refusing to settle, for instance by accepting excessive waiting times or inadequate services. Developing and evaluating programs that seek to foster parental efficacy would be valuable steps in recognizing parents’ expertise and empowering them to be active participants in the ASD trajectory (Burke et al. 2016). For instance, professionals could guide families’ search for information, encourage them to seek recognition of their and their child’s rights, and help them assert themselves as advocates for their child.

Increasing Awareness and Training in Providers

Several families indicated that their access to diagnostic evaluation had been delayed by a lack of knowledge of the symptoms of ASD, or of how ASD services operate, in front-line health care and education providers (i.e., day care centers, community health centers, pediatricians, family physicians). These professionals are typically the first points of contact for parents who suspect their child may have ASD.

Training in Screening for ASD References from primary health care professionals or educators are needed to begin the diagnostic evaluation process. It is therefore crucial that these providers be trained to rapidly detect ASD symptoms. It may be possible to avoid further delays in families' access to diagnostic services through focused training on ASD screening and symptom recognition

Information on Diagnostic Evaluation Services According to parents, staff in day care centers and other community services sometimes did not seem to know how to orient them toward appropriate services when ASD was suspected. Providing these professional with clear information on the diagnostic process and giving them documentation to share with families would facilitate their role as first point of contact.

Recognition of Specialized Care Providers' and Professionals' Competences Many parents mentioned that the competence and experience of the professionals who performed the diagnostic evaluation or helped them during their trajectory had had a facilitating influence on the process. They also appreciated the personal qualities displayed by these individuals, such as their kindness, compassion, and ability to listen. In a previous study on early intervention (Rivard et al. 2015), providers' personal qualities were a crucial determinant in how parents perceived and experienced the quality of services they received. It is therefore important that these attributes be promoted in the training dispensed to these professionals' and within the values of the organizations that employ them.

Limitations of the Study

The results of the present study must be interpreted within the constraints imposed by its methodology. First, although the number of participants is relatively high for a qualitative study, the experience of 24 immigrant families cannot be considered an accurate and comprehensive representation of the experiences of all immigrants to the province of Québec who have a child with ASD. Their experience of the ASD diagnostic trajectory may in some respects be specific to Québec, where service offerings differ from those of other host countries. In particular, diagnostic evaluation and early intervention services are provided free of charge by the public network of health and social services, with the caveat that families may wait for extended periods to receive these services. Additionally, the number of participants who had immigrated from each country or region was insufficient to support in-depth comparisons across cultures or between genders. Also, the experiences and perceptions highlighted in this study were those of families who were already registered in the specialized ASD services system. Their experiences may thus not reflect those of families who had yet to gain access to these services and presumably face greater obstacles. We had attempted to contact families prior to their entry into the system through community organizations and churches; this approach to recruitment proved unsuccessful. It nevertheless remains a priority to investigate the situation of families before they register for public services in order to obtain a more complete and accurate overview of the obstacles and facilitators they encounter.

Conclusion

Professional organizations such as the American Psychological Association (APA 2017) are increasingly emphasizing the importance to account for cultural differences in both research and professional practices. At the same time, research on families often paints a pessimistic portrait of their experience without suggesting possible solutions. The present study therefore sought to examine families' experiences of the service trajectory in a culturally responsive and solution-driven manner. In particular, the findings of this study supported recommendations to capitalize on the existing strengths of families, services, and professionals, and to address some weaknesses or obstacles present among these as they were encountered by immigrant families.

This study invites a reflection on services for families during their diagnostic trajectory as a multi-tiered sequence of supports. Specifically, practices may be implemented at the first tier, within universal services available to all families whose child is suspected of having ASD; at the second tier, for families who are at risk of experiencing greater challenges during this period (in the present case, immigrant families); and at the third tier, as individualized and more intensive interventions for families facing specific challenges (e.g., members of a specific cultural group). Any recommendations to yield more culturally-sensitive practices stemming from research must take into account what organizations can realistically achieve in terms of additional service offerings, staff training, and adjustments to existing practices. With these constraints in mind, it is preferable to propose simple, efficient measures that minimize the need for program diversification. The present study identified some of the concerns of families from diverse backgrounds who shared a common experience: having immigrated to a new country and encountering a system of services that differed from their native country's own as they attempt to help their child with ASD. Some of the experiences reported by these families were similar to those encountered by all families of children with ASD (e.g., delays of access) and should be addressed within universal services (i.e., first tier). However, the majority of the recommendation stemming from this research would be implemented at the second tier, where service providers would be trained to anticipate and identify potential obstacles and prepared to propose solutions to these.

Compliance with Ethical Standards

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The protocol for this study was reviewed and approved by the Joint Research Ethics Board for Public Rehabilitation Centers for Persons with

Intellectual Disabilities and ASD in Québec and by the Research Ethics Board of the Université du Québec à Montréal.

Informed Consent All the participants were clearly informed and consent to participate to the project.

Conflict of Interest The other authors do not report any conflicts of interest of any kind.

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