SAAAC

TOWARDS CULTURAL COMPETENCE

Communication for Diagnosticians When Working with South Asian and Black Families of Children/Youth on the Autism Spectrum

Sureka. *Flowers*. 2021, watercolour on paper. SAAAC art commission.

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Introduction

We live in an ever-increasingly globalized society and technology is bridging the gaps at an ever-faster pace. In our pluralistic society, culture often defines belonging and identity, which means that being culturally literate or competent is vital to the way we form and maintain relationships. Furthermore, discrimination and bias have serious consequences, and cultural competence can often mitigate some of these harmful interactions.

Children who require services may not access them in a timely manner because of a lack of cultural competence within the diagnostic journey. As well, the way the diagnostic journey is designed may be preventing families from accessing services and/or marginalizing them in the process.

Autism needs to be viewed through an **intersectional** approach along with various identities such as race, class, gender, sexual orientation, etc.

To read more about an intersectional approach, please **click here**.

Read more: **Appendix 1: Autism Spectrum Disorders**

Purpose of the Tool Kit

This resource was created to provide cultural competence training for diagnosticians specifically in the context of South Asian and Black[1] families, as these communities are under-represented in literature. Through this training, diagnosticians will have a better understanding of the barriers these communities face, the concerns with the current screening/diagnostic tools used, and strategies to more effectively communicate with families to improve retention during the diagnostic and treatment pathways.

Goals

1) To help equip diagnosticians with better understanding of South Asian and Black families and the barriers they face
2) To highlight strategies on how to effectively communicate with South Asian and Black families
3) To review some of the concerns around screening and diagnostic tools currently used for Autism Spectrum Disorders
4) To highlight strategies to help create a more inclusive environment for families during the diagnostic and treatment pathways

Definition of Culture:

> According to UNESCO, "[Culture] is that complex whole which includes knowledge, beliefs, arts, morals, laws, customs, and any other capabilities and habits acquired by [a human] as a member of society" (2014, p.1). Simply put, culture is defined as a system of collectively held values, beliefs and practises of a group that guides thinking and actions in patterned ways.

Read more: **Appendix 2: Cultural Competence**

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[1] Within the African diaspora, individuals have varying preferences regarding self-identification as "Black", "African-American," or other terms (Cross 1991). Although we recognize this diversity, we have chosen to use the term "Black" throughout this resource to refer to any individuals of African descent, for purposes of inclusivity and consistency (from Shaia et al, 2019, p. 1841).

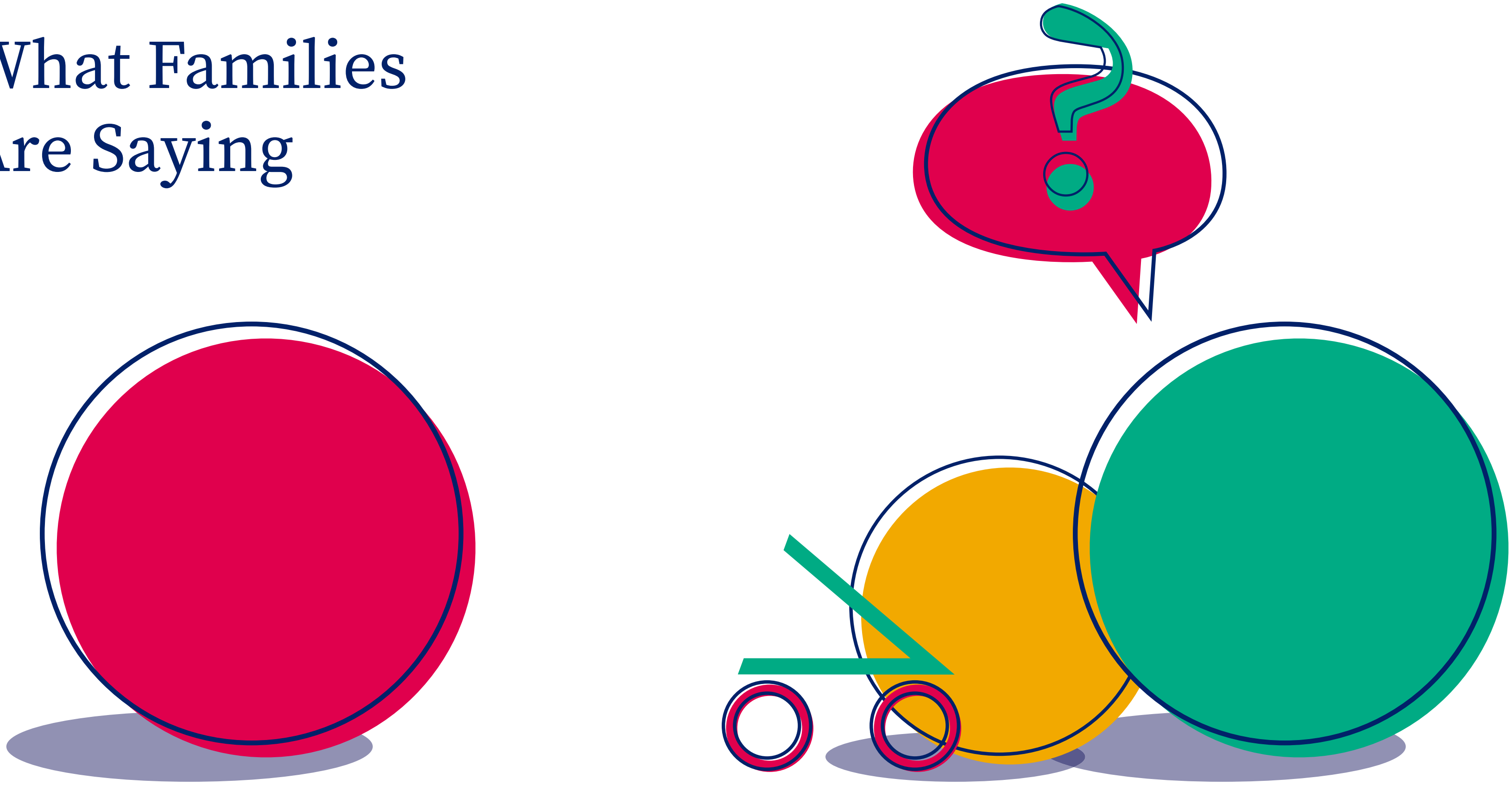
Methods

For this project, we designed a questionnaire to better understand the diagnostic journey in three parts: pre-diagnostic appointment, assessment appointment, and post-assessment appointment (i.e., after a child receives a diagnosis), along with a demographics section to capture data about the cultural and socio-economic profiles of the respondents. Community agencies including the Thorncliffe Collaborative for Muslim Families, Sawubona Africentric Circle of Support, SOCH Mental Health, and SAAAC Autism Centre (SAAAC) reached out to the families they serve to ascertain whether they would participate in this project. Community liaisons met one-on-one with caregivers who voluntarily consented and used the questionnaire to guide conversations with families with children on the Autism Spectrum.

The community agencies already had relationships of trust and familiarity with families, which made respondents comfortable sharing their stories in vulnerable and honest ways, and allowed for robust responses to the questions. The conversations were culturally and linguistically appropriate, as the agencies had the skills and knowledge. This exercise highlights the need for a grassroots, culturally responsive approach to the diagnostic journey.

SECTION 1:

What Families Are Saying



Key Themes

The community agencies recorded the responses from families on the questionnaires and returned completed questionnaires to the SAAAC project co-leads. The project team then reviewed the data and collated the themes based on keywords and phrases. Direct quotes from respondents are interwoven to highlight themes in the words of the families. While theme reporting is separated by South Asian families and Black families, you will see crossover from both communities; this informs the recommendations at the end of this report. Based on the principles of Universal Design for Learning, the recommendations can be good practice for all families going through diagnostic screening or assessment, while other suggestions are more culturally specific. More information is needed from diverse, racialized family compositions, and further research is recommended.

Read more: **Appendix 3: Role of Caregivers**

Parent Experience: Aparna Sanwalka

THEMES: South Asian Families

Theme 1: Transparent Process

- Families expressed not knowing how to navigate the diagnostic process in terms of what questions to ask at appointments. In other words—you don't know what you don't know.
- Families felt overwhelmed with information at appointments, especially when heightened emotions were involved.
- Assessments need to be explained to families in a way that they can understand:

  > *"They don't tell you everything in this one appointment."*

  > *"[It wasn't] easy to understand. The videos always showed very severe [situations], I would get demoralized and close the videos."*

- The purpose of appointments should be clarified, so families know what to expect.
  - What happens at each appointment?
  - Who will be there?
  - What will happen?
  - What preparation is necessary for assessment appointments?

As one parent said:

> *"I didn't know that the assessment was for Autism. The word Autism was only used when [the] diagnosis was given."*

Theme 2: Accessible Process

- Language can be a barrier, even if the listener is comfortable with English.
- There is a lot of jargon. It would be helpful to have support at the meetings, such as a translator or, more specifically, support from someone who understands the cultural context of the caregivers.
- Accessible information is required. Everything should be communicated in text. Avoid use of acronyms, and translate information so that it can be shared with other family members
- Some families did not even know the diagnosis was Autism, as the diagnosis letter was not explained to them

Theme 3: Parental Intuition/Parent Advocacy

- Some doctors don't take parent concerns seriously.
- There is a lack of credibility around the parenting skills in South Asian families.
- Some diagnosticians do not validate the knowledge brought by the families about their own children.
- Parents are left to research things on their own.

> *"They told me [my child] is a level three. I asked what levels one and two are, [and] I was told to search online."*

- There are a lot of concerns around gaps in the system once the diagnosis is made. The initial two weeks after getting the diagnosis appeared to be a very hard time for families. This is where support is needed the most.

Theme 4: Assumed Class Privilege

Families struggled with navigating further therapy after the diagnosis.

- Suggested activities for children are not always feasible due to cost.
- How to access funding for therapy is confusing or not shared.
- Families struggled with funding for therapy.

> *"Concerns [were] expressed about how [organizations] manage funding and put the financial burden on families to pay upfront."*

Theme 5: Cultural Competence and Bias

- Resources are needed to share with South Asian families—such as videos created with the linguistic and cultural contexts in mind—so a family's support network can better understand what Autism is.
- There is a lack of representation and cultural competence among diagnosticians

> *Culture never came up. [The doctor] was not of the same culture. I was asking myself, being Indian, how do you incorporate this?*

> *"How do you deal with this? I didn't even know how to explain this to my mom in Punjabi."*

> *"I told them myself that, in my culture, men can't look at women. When I got married, my husband always looked at the floor. We thought my son got this from my husband. My friend from Canada who is white said that because your husband doesn't make eye contact, that's why your son doesn't. I want him to stand with me when I am talking to a female doctor."*

> *No one understood [the] culture. When I come and ask for help, that is way out of my comfort zone. As a South Asian woman, I will do a million things for a million people but I won't ask for help. Getting the diagnosis was great but afterward, I felt abandoned.*

> *"I still had to find my own OT, deal with school, community living, Kerry's Place...it was such a disjointed thing back then. 'The service navigation sucks' is what I hear from a lot of families. I teach my staff basics through my own business. I send my families a list of funding. Families need to know how to navigate education for their children. Kids who have higher functioning and lower behaviour—there is a systematic problem with these children being left behind. Being a South Asian single woman, I fought hard. I had to ask five, six, seven times. Not having a husband, I wasn't being heard as much. We are taught to do our best. For me to ask for help was very hard."*

Read more: **Appendix 4: Potential Barriers to Diagnosis**

Parent Experience: Nellie Michel

THEMES: Black Families

Theme 1: Accessible and Transparent Process

- Give step-by-step instructions for the assessment process.
- Explain what to expect at the appointments.
- Give reminders regarding appointments.
- Eliminate jargon when communicating with families.

Theme 2: Multimodal Approaches to Communication of Information

- Given the heightened state of stress that parents sometimes experience during the diagnostic pathway, important information can sometimes be missed when verbally communicated. Language can also be a barrier.

> *“With English being my first language, there were no communication difficulties. [But] perhaps a bit more of a breakdown of the professional/medical terms into everyday language so that the layperson can understand [would be useful]. [Then there’s no need] to ask for something to be clarified or explained in “simpler terms” and then feeling “dumb” or inferior for asking. Having someone who looked like me and understood my culture, my upbringing and the possible fears and anxiety that were brewing up in me would have been helpful as well in making the entire experience a more positive and supportive one.”*

- A multimodal approach be used to communicate the diagnostic process through a combination of video, transcripts, written, verbal, graphics, etc. would be helpful.

Theme 3: Time

- Give step-by-step instructions regarding the assessment process.
- Minimize wait times for initial and follow-up appointments to be scheduled until diagnosis.
- Offer programs or general strategies that families can employ to address their child’s language and general behavioural challenges while waiting for follow-up appointments.
- Early intervention matters, so determine how to support families through this timely process when intervention is time-sensitive.
- Avoid making families feel rushed during appointments and not heard or validated.

> *“[Offer] ore warmth, more inclusion in the conversation. Don’t get annoyed when I ask questions. We don’t know what we don’t know. They see so many people, [so] do the professionals just become desensitized to the process and to the feelings and humanity of the families and just try to get the job done?”*

> *“I didn’t always feel that I had a platform to talk. I felt pushed out of the conversation. I was happy when our time...was finished.”*

Theme 4: Lack of Representation/Cultural Competence

- Lack of representation among diagnosticians, support workers, health care team, and in the tools used as well as the process results in a feeling of alienation and discomfort. The following quotes are from different Black families with a child on the Autism Spectrum.

> *“None of the staff...looked like me and so we couldn’t relate to each other.”*

> *“Maybe we could have been more...set at ease. Who wouldn’t feel or [be] comfortable being with someone who ‘gets’ the culture and possible emotions associated with that cultural lens and upbringing and how this diagnosis may impact and be felt by the individual, their family and friends? Even if they don’t understand Autism, there is like-mindedness. To have someone who looked like me, even just to understand the daily struggle in this skin, would have helped relieve some of my emotional challenges at the time.”*

> *“I think it would have been a more valuable experience if the physician and/or OT had been Black. The physician was South Asian, so I was glad that it was a woman of colour that would be assessing my son. The OT was a white woman, which is what I was expecting.”*

> *“No one on the assessment team looked like me or my child. In fact, over the years, we [had] never met a specialist in this field who look[ed] like us or [could] relate to our cultural background until he became an adult and his current GP, who specializes in IDD and health, [became] his doctor. Would it have impacted? Absolutely. There were so many questions that I had that I couldn’t ask the attending specialists because they wouldn’t understand or may provide me with a ‘clinical’ response. I didn’t even want to ask for fear of looking “dumb or uneducated.”*

> ***These are the unspoken feelings of marginalization and inferiority that are bred into those who don’t look like or live like those who hold ‘power’ and social capital.** So, we end up researching on our own or suffering in silence. Even unspoken or unwritten types of information for dealing and coping with the eventual diagnosis could have been shared with someone who may already know exactly what I may be feeling or thinking as this process.”*

Theme 5: Community

- One of the first places many families turned to after the diagnosis was a church or trusted friends. It was challenging to discuss a diagnosis with families because of perceived stigmas. They also didn’t know other Black families who had children with Autism.
- For many, the parent support groups were often white, and while they had Autism in common, they did not have a shared feeling of culture.
- Culturally responsive health care workers and support groups were deemed necessities for families.

Perhaps have a social worker, or a representative from an agency or even a parent representative on staff to support. And in saying that, ensure that the person can relate to the family and understand the cultural, religious etc., nuances that this type of news may bring through their own lived experience. Maybe make it a part of the entire process to bring the family back for a couple of sessions to see how things are going for the parent/caregiver, the child and the family, and help them create an initial plan going forward with some…next steps to get them going. If I were a different person, not raised in Canada, perhaps having multiple children diagnosed, being a single parent, relatively new to the country and leaving the rest of my family behind in my place of origin, etc., I might have locked myself away from the world for a lot longer than the three months that it took me to stop crying and get proactive where my child [was] concerned. There is no easy way to give the diagnosis, but some added compassion could have helped ease me into not only accepting the diagnosis, but in developing a plan and becoming more realistic but also hopeful as to the potential outcomes for my child.

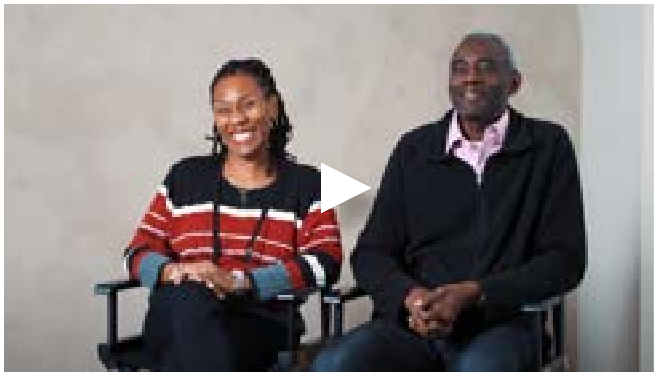
Theme 6: Self-Advocacy/Education

- In keeping with the previous two research articles from the environmental scan, the feeling of being your child's advocate was a resonating theme for the Black families who participated in this project.
- Families often felt it was all on them to advocate for their child to even be considered for assessments.

> *"The most difficult part was getting the referral from the family doctor. They can be the 'gatekeeper' in this process and if my relationship with my GP was different [or] strained, or [if] I didn't have the knowledge and confidence that I did to push the matter, perhaps I wouldn't have gotten the referral and diagnosis when I did, if at all. Once the referral was made, we were automatically put on the waitlist and things just went like clockwork from there. I think we were lucky we didn't have to wait too long."*

- Families reported that they would often Google words used by diagnosticians, as the terms were not explained well. They would be given a list of resources to research and with which to connect. No part of the process was made family friendly, or considered the shock and stress families experience after the diagnosis.

> *"We did not feel uncomfortable. We are educated and understand the system, but it was not entirely supportive. When we got the diagnosis, we were told one of the most important things was to get onto waitlists, which we did. We were provided with some contacts and starting points...[but] no other support was provided. It was helpful having a partner who could help and support the process..."*



Parent Experience: Sherron Grant and Clovis Grant

Summary

Three of the main points resonating from the testimonials of families are supported by research:

1) "Culture, language, ethnic background, and religion, among other family characteristics that shape a child and his or her family, are important to take into consideration at any point during a diagnosis of the disability" (Barrio et al. 2019, p. 5).
2) "Diverse cultural and ethnic backgrounds could add to the perplexity of what individuals with ASD experience, especially how practitioners from a dominant culture could perceive or misunderstand cultural differences due to the lack of cultural competency" (Barrio et al. 2019, p. 1).
3) "Need for practitioners and educators to be culturally competent regarding their treatments and practices for children and youth with ASD continues to exist" (Ravindran & Myers, 2012 cited in Barrio et al. 2019, p. 1).

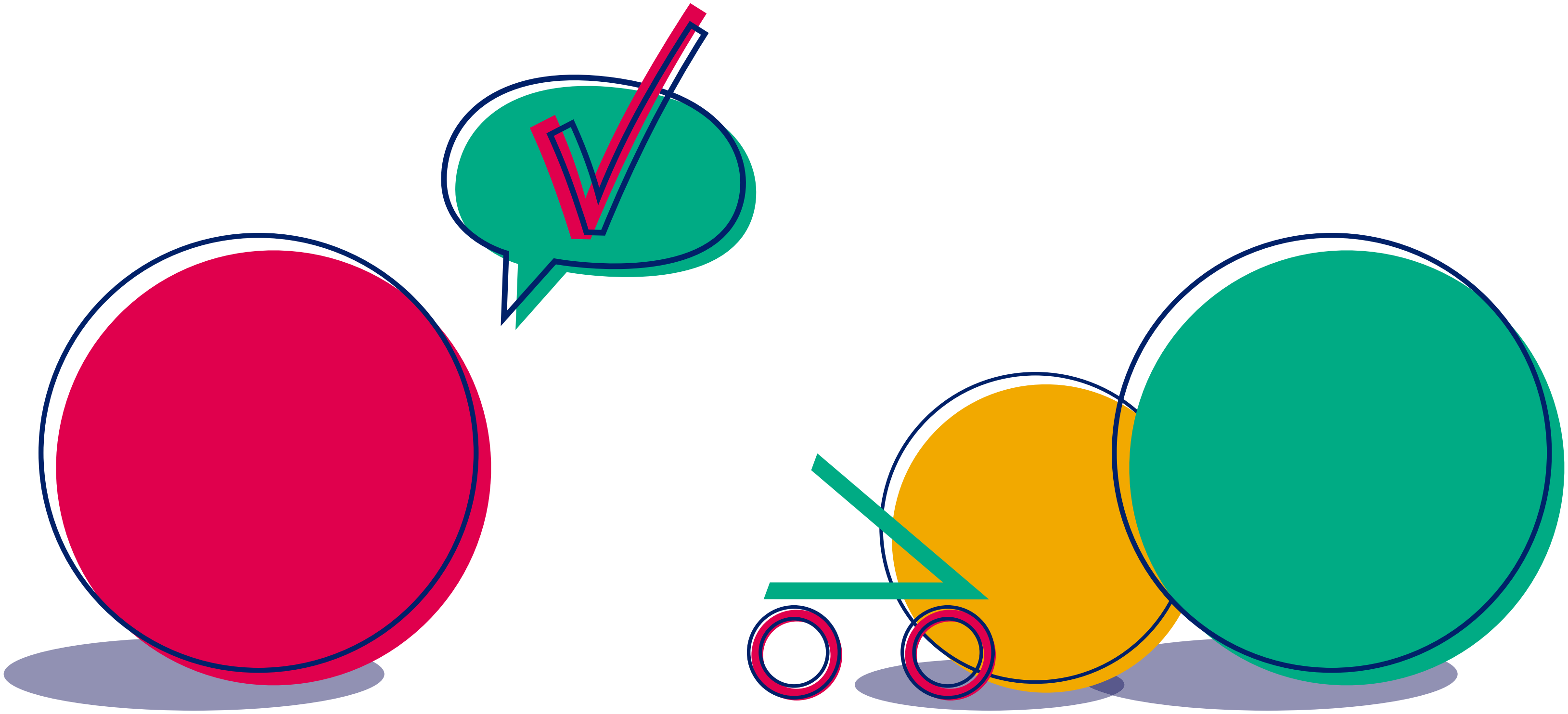
With this in mind, there needs to be a culturally competent process from pre-appointments through to diagnosis with a mechanism for families to follow up.

Diagnosticians need to keep the following principles in mind (Karatas, 2020):

- To be aware of explicit biased thoughts and prejudices
- To learn about the cultural backgrounds of families/caregivers
- To understand the social, economic, and political status of patients/clients
- To administer assessments that are culturally responsive
- To demonstrate a commitment to culturally responsive pedagogy

SECTION 2:

What You Can Do



Cultural Competence and You

The following continuum is a guiding framework to support diagnostic hubs in creating a sustainable, culturally competent approach to the diagnostic journey. The purpose of this continuum is to help you to understand where you are in your journey and where we want to be for equity. The ultimate goal in transformative equity is to be culturally proficient; cultural competence is the competency that precedes proficiency.

Read more: **Appendix 5: Cultural Norms**

Read more: **Appendix 6: Cultural Context for Screening and Diagnostic Tools**

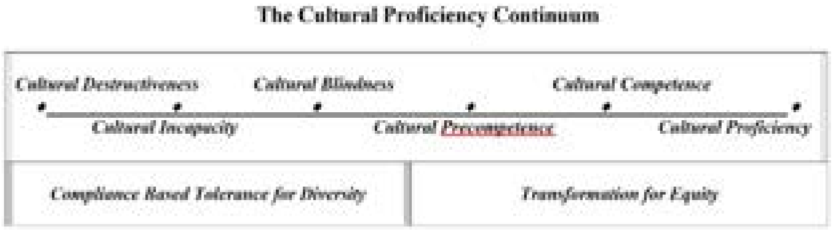


Image source: https://ccpep.org/home/what-is-cultural-proficiency/the-continuum/

Reflection Exercise

1. Watch the Video

a) Learn the key themes regarding the importance of cultural competence in the diagnostic journey.

Parent Experience: Baljit Ghuman

2. Try This Task

a) Examine the dos and don’ts chart on the next pages.

b) How would you sort the suggestions provided onto the Cultural Proficiency Continuum? Where are you in the journey?

Cultural Destructiveness	**Cultural Incapacity**	**Cultural Blindness**	**Cultural Pre-Competence**	**Cultural Competence**	**Cultural Proficiency**

DOs ✓

PRE-APPOINTMENT

- ✓ Learn the name of your patient(s) and their caregivers, and how to pronounce them.
- ✓ Provide alternative routes to arrive at the centre (e.g., public transit, low-cost parking options, etc.)
- ✓ Ask families to repeat key instructions to ensure retention and understanding.
- ✓ Provide reminder calls, emails and/or texts one to two days prior to the appointment as well as the day of the appointment.
- ✓ Ask the family if there are any specific types of toys their child likes.
- ✓ Ensure front staff are aware of religious holidays when booking appointments. Families may not want their child assessed or have bloodwork done during these holidays.
- ✓ Check with families on any specific arrangements (e.g., physical access, interpreters, parking, work schedules, etc).

DURING THE APPOINTMENT

- ✓ Review in detail what will be happening over the next few appointments (i.e., taking a developmental history by asking questions of parents, followed at the next appointment with an assessment of their child, and then the final appointment where the results will be discussed with the family).
- ✓ Review the timeline for these appointments.
- ✓ Explain to the family the benefits of early identification.
- ✓ Reassure the family that they are taking the right steps.
- ✓ Acknowledge the fears that the family may have about the potential diagnosis.
- ✓ Review how, in the past, omissions of early identification led to children not reaching their full potential.
- ✓ Ask parents how they would like to be referred to and how they want their child referred to during the assessment.
- ✓ Explain to parents why you may be referring to them as “Mama/Mommy” or “Daddy/Dada/Papa” during the interview and the purpose of it (i.e., to make the child more comfortable by using the name the child uses).

DELIVERING THE DIAGNOSIS

- ✓ Start with reminding caregivers what brought them in (i.e., symptoms of concerns).
- ✓ Review the additional information you were able to find during the assessment.
- ✓ Explain to caregivers what their child can do and any milestones they are meeting; then explain where the child may have delays.
- ✓ Explain how the collection/combination of these delays has a specific diagnosis called Autism.
- ✓ Give parents some time at this point to process that information.
- ✓ Ask them if they have any questions at this point before you move onto what the diagnosis means for their child.
- ✓ Explain to them what treatment is, in simplified language.
- ✓ Provide culturally relevant analogies to help families relate to treatment.
- ✓ Explain that there is financial support and how to access it.
- ✓ Explain why you are ordering blood work (some parents may believe that you are testing for Autism just as you would test for diabetes, and if the blood test comes back normal, their child does not have Autism).
- ✓ Book a follow-up appointment for two weeks later to discuss questions.

COPING WITH DIAGNOSIS

- Be sure to provide hope.
- Remind parents that their child is their own person.
- Share how other racialized families are navigating the Autism journey. Make it relatable to caregivers.
- Help families to build a strong support system.
- Help families find relevant resources in their communities.
- Remind families to do activities their child enjoys.
- Help families to set small, reasonable goals.
- Remind caregivers to take care of themselves as well as their partners (if applicable).
- Help them to build on their child's strengths, as well as their strengths as a family.
- Work in collaboration with cultural liaisons and community agencies to be more informed.

DON'Ts

- Do not rush families.
- Don't assume the type of transportation they are using to get to appointments (e.g.. not every family owns a car, may require accessible modes of transportation, etc.).
- Be sure not to chastise families. If parents arrive late, ask them, "Is everything okay, did you have any difficulty finding the clinic?" rather than immediately reminding them of your no-show or late policies.

  Don't make statements like, "I'm so surprised you know this" or "Your wife isn't saying much, do you mind letting her speak?"
- Do not mispronounce names or make dismissive comments about the length or background of names (e.g. "Your name is so long, you must be Sri Lankan, right?")
- Don't assume financial background of families.
- Don't assume linguistic competencies and cultural norms. Avoid comments like, "I'm so impressed by your English," "Your English is so good, when did you come to Canada?" or "It must have been so difficult in your country. You must be so happy to be here in Canada."

Hear from our medical expert, Dr. Zubairi, on cultural competence in the diagnostic journey.

Moving Towards Cultural Competence

ACTIVE Listening

- Be willing to listen with the understanding that you do not nor cannot fully understand the cultures of all the families you will meet.
- As a diagnostician, you can demonstrate respect through your willingness to ask questions and listen to a family's story.

WELCOMING Environment

- Create a safe and welcoming space for families to talk about their concerns and make them feel that their concerns are heard without judgment.
- Be sure families can find themselves represented and reflected in the examples you use.
- Be a space where families understand that all people are treated with respect and dignity.
- Ensure availability of positive and inclusive brochures and pamphlets that represent the experiences of families.
- Ensure you have inclusive posters in the waiting room, as well as inclusive promotional materials for support services.
- Make sure your environment is fully accessible.

Considerations:

> *[If only diagnosticians could] get some more training and support to understand the impact of their ways when they just go about this process as though it is merely a job and forget that they are dealing with human beings and their children...that can't be taken lightly.*
>
> - Black parent from Sawubona Africentric Circle of Support

1) Approach every encounter with the understanding that there is always something to learn.
2) Treat every person with dignity.
3) Hold every person in high regard while being aware of and not allowing unconscious biases to interfere in any interactions.
4) Assess if this practice can be applied to every encounter.
5) Embody the practice of cultural humility to enhance personal resilience and global compassion.
6) Recognize and accept that you are *not* an expert when it comes to another person's culture.
7) Be willing to ask questions with the understanding that you do not, and cannot, fully understand the cultures of all the clients you will meet.
    a) Be willing to ask questions respectfully and listen to a patient's story in order to effectively demonstrate respect.

(Masters et al., 2019)

A culturally competent approach balances the need to convey accurate developmental information with the need to protect the investment of parents in their children. This means the following:

- Understanding our own cultural biases
- Understanding the communities' barriers
- Speaking to them in their language
- Use of cultural brokers/liaisons/community health workers
- Reframing assessment requestions for cultural competence
- Providing adequate time for parents and family to voice their concerns
- Understanding that this is a constant learning process with continued evolution
- Allowing families enough time to process

Clinician Tips and Tricks

Goal: To balance diagnosis with investment by parents.

1) Appointment Day:

a) Learn the names of your patient(s) and their caregivers, and how to pronounce them.

b) Allow some time at the beginning of the appointment for parents to orient themselves.

c) Ensure a comfortable, welcoming waiting space that is inclusive of diverse families.

2) Interviewing Strategies:

a) Use statements such as:

- i. "I would like to understand the concerns that bring you and your child here so I can help you more effectively. I want to know about your experiences and ideas. I will ask some questions about what is going on and how you are coping. Please remember there are no right or wrong answers."
- ii. "What brings you in today?"
- iii. "How would you describe your child's concerns/ behaviours?"
- iv. "If you had to describe your child to someone else, what would you say?"
- v. "How would you describe your concerns about your child to someone else?"
- vi. "Why do you think your child has these concerns?"
- vii. "Has anyone outside if your family had any concerns about your child? If so, what do they think may be causing these concerns?"
- viii. "Who normally spends the most time with your child? It would be great to hear their observations as well, since they may have noticed something that might be important to our assessment today."

3) For Families Who May Be Upset:

a) Allow families to express their frustration (both with the process and the outcome).

b) Try to understand the source of their frustration, which may include the following:

- *i. Worries about the child's future*
- *ii. Worries about telling the child's grandparents or extended family*
- *iii. Feeling that they are the cause of their child's Autism*
- *iv. Feeling that the diagnostic testing was not accurate*
- *v. Mother may feel it is her fault (i.e., "refrigerator mother theory")*

c) If caregivers are worried about the future, remind them that early intervention can significantly impact the developmental trajectory of a child

d) Provide strategies on how they can explain the diagnosis to extended families.

e) Review the myths and causes of Autism Spectrum Disorder.

f) Review what specifically in the diagnostic testing did not accurately reflect their child's abilities.

g) For families upset with wait times, have resources that they can access in a relatively short period of time.

h) Connect them with support groups (ideally culturally specific, if possible).

Hear from our panel of experts

Towards Systemic Change: The Importance of Cultural Liaisons

Dr. Sarah Bauer, a child psychologist, showed that because of cultural differences, "it is crucial to work closely with people from the child's own cultural community, people who intimately understand the expectations within that community for what Autism means to them" (Bauer, 2016, para 10). This highlights the importance of why representation matters. Cultural liaisons are especially vital in gaining a better understanding of the parents' perspective.

A cultural liaison does the following:

a) Stands within a community and is willing to serve as a link between the community/family and the physician

b) Advocates on behalf of another individual or group

c) Can help provide understanding for cultural context

d) Helps overcome gaps, and helps physicians/agencies better understand the barriers families face (this is specifically true for parents living outside of their cultural framework)

Acknowledgments

This tool kit for Culturally Competent Communication was created by the SAAAC Autism Centre Project Team.

SAAAC Project Team

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Video Production: Red Lotus Films	**Video Animation:** By The Booth
Tool Kit Designer: Christien Gilston	**Project Overview:** Kingston Yogendran

South Asian Autism Awareness Centre

SAAAC Autism Centre is a Scarborough-based charity that provides a broad range of services and supports to individuals with Autism Spectrum Disorder (ASD) and their families. Our organization is a lifeline to marginalized populations living in Toronto and the Greater Toronto Area (GTA) that are currently underserved in this sector. SAAAC's mission is in making Autism care equitable for all Canadians. It is principally formed to aid and empower underserved families living with ASD. The Centre engages in a wide range of advocacy and awareness building initiatives, in addition to providing free and subsidized programs.

SAAAC is able to deliver a combination of free and subsidized programming made possible through strong partnerships across federal, provincial, and municipal governments, along with leading Autism agencies in the province.

The SAAAC Autism Centre provides a diverse range of programs that support the development of individuals with ASD at all life stages. These programs include diagnostic support; clinical services; Early Years programming; caregiver support programming; summer and March break camps; arts programming; and adult learning and vocational training.

SAAAC currently serves 400 families annually through 13 unique programming streams. There are 23 full time staff members along with 160 volunteers supporting day-to-day operations at SAAAC. With the support of the City of Toronto, SAAAC was able to open up an 11,000 sq. ft. facility in Scarborough. Ninety percent of families served at SAAAC have come to Canada within the past 15 years and 60 percent of families are identified as low-income (report annual income less then $44K for a family of four). The majority of SAAAC families come from South Asian, East Asian, and Middle Eastern countries and typically face language, financial and cultural barriers to service.

SAAAC grew as an organization to better serve the important needs of marginalized families and to address the gaps in the system.

Project Collaborators

The Thorncliffe Collaborative for Muslim Families – Representative: Munira Khilji

Munira Khilji represents the Thorncliffe Collaborative for Muslim Families. She is also a mother of a child on the Autism Spectrum, and coordinator for the school paediatric clinic based at Thorncliffe Park Public School. She has the unique experience of travelling down the diagnostic pathway herself, becoming a cultural liaison for her community and now is an integral part of the diagnostic pathway at Health Access Thorncliffe Park.

Sikhs for Autism – Founder: Baljit Ghuman

Baljit Ghuman is a father of a daughter on the Autism Spectrum and is the founder of Sikhs for Autism which focuses on advocating and creating awareness around Autism, especially within the Sikh, Punjabi and South Asian communities. The goals are to build an inclusive community that ensures the rights and needs of Autistic people.

Ubuntu FX – Founder: Neeran Kuni

Neeran Kuni is the current Director of Social Enterprise and Adult Services at SAAAC Autism Centre. He is also the founder of Ubuntu FX, a socially-conscious company that designs and implements impactful programs for people with neurodivergent needs with a particular focus on those who identify as being a part of the BIPOC community. Neeran has advocated for change and has led other organisations to strive towards more inclusive, neurodiverse and equitable practices for just over 20 years.

Sawubona Africentric Circle of Support – Co-Founders: Sherron Grant and Clovis Grant

Sherron Grant is a principal with the Toronto District School Board, and Clovis is the CEO of 360°kids, an organization that provides a full complement of programs and services aimed at assisting at-risk and homeless youth in York Region. They are also the founders of the Black Parents Support Group and are now called the Sawubona Africentric Circle of Support. Clovis and Sherron are parents of a son on the Autism Spectrum and have been working to better help support Black communities impacted by Autism. The Grants' experience inspired them to create a support group specifically for Black parents and caregivers of children and adults with disabilities. The organization celebrated its one-year anniversary in November of 2021.

SOCH Mental Health – Co-Founders: Maneet Chahal-Gill and Jasmeet Chagger

Maneet Chahal and Jasmeet Chagger are two registered nurses who are both very passionate mental health change-markers, trailblazing to put South Asian mental health in the spotlight. They have recently started to focus on Autism within the South Asian community with their work with Autism Ontario.

Parent: Nellie Michel

Nellie Michel is the mother of three adult children, one of whom is on the Autism Spectrum, having Asperger's Syndrome. As a personal support worker, Nellie provides compassionate care to seniors and those needing support. With French as her first language, she is a strong advocate for more support services for those in the GTA whose first language is French.

Executive Director, Convergency: Aparna Sanwalka

Aparna is the Executive Director of Convergency. She is also a mother of a child on the Autism Spectrum and, during the past 20 years, has been working to support families with children on the Autism Spectrum. She decided to form Convergency to support these families. Convergency provides ABA/IBI therapeutic support as well as respite, educational advocacy, coaching, and support.

Dr. Mohammad Zubairi

The SAAAC Project Team would also like to thank Dr. Mohammad Zubairi for his editorial review of this tool kit. Dr. Mohammad Zubairi is a Developmental Paediatrician and Associate Professor at McMaster University and currently Medical Director for the McMaster Children's Hospital Autism Program. He is a member of the McMaster Autism Research Team (MacART). He is Chair of the Physicians of Ontario Neurodevelopmental Advocacy (PONDA) network, and a Board member with Empowered Kids Ontario (EKO).

The SAAAC Autism team wishes to thank the Children’s Treatment Network (CTN) for funding and supporting the development of this tool kit.

Children’s Treatment Network

Children’s Treatment Network (CTN) supports more than 23,000 children and youth with disabilities and developmental needs in their homes, communities, and schools. CTN provides intake, service navigation, and coordinated service planning, assessment and diagnostic services, specialized clinics, and rehabilitation services, including physiotherapy, occupational therapy, and speech-language therapy through contracted public and private partner organizations in the education, health, and community sectors. CTN supports families in York Region and Simcoe County for all services, offers school-based rehabilitation services in an expanded catchment area including Central and West Toronto, and also offers assessment and diagnostic services within Dufferin, Halton, Peel, Waterloo, and Wellington. Through its innovative network model, CTN’s commitment to providing family-centred care is anchored by an electronic client record that is shared across its partner organizations and provides the foundation for integrated plans of care and services.

Appendices

Appendix 1: Autism Spectrum Disorders

Autism Spectrum Disorders

The most recent Diagnostic and Statistical Manual for Mental Disorders (DSM-5) defines Autism Spectrum Disorders (ASDs) as neurodevelopmental disorders characterised by impairments in social interaction and communication, and the presence of restrictive and repetitive behaviours (DSM-5). The Centres for Disease Control (CDC) reports that the incidence of Autism in the United States is one in 59 today (Shaw et al., 2020). In a report published by the National Autism Spectrum Disorder Surveillance System, it was found that in Canada, among children and youth 5 to 17 years of age, it is estimated that one in 66 were diagnosed with ASD in 2015.

There is growing evidence that newcomer and low-income families with children on the Autism Spectrum face poorer health outcomes and quality of life. This health inequity can lead to the following:

- Overwhelming parental stress resulting in isolation
- Depression
- An overall sense of powerlessness

The Canadian Autism Spectrum Disorders Alliance (CASDA) National Needs Assessment Survey done in 2014 recommended the need for "targeted outreach to linguistically and culturally diverse communities, facilitating understanding of their service needs and improving their access to service" (National Needs Assessment Survey - CASDA, p. 7).

In several studies from the USA, children of ethnic minorities were on average diagnosed later with ASD than children of white Americans, or remained undiagnosed (Mandel et al., 2002 and Mandel et. al., 2009).

In March 2019, a policy brief from the Canadian ASD Alliance proposed some governing principles when developing a blueprint for a National Autism Spectrum Disorder Strategy (see attached document for the citation). "The Strategy should be culturally responsive and appropriate, especially for vulnerable Canadians, inclusive of pan-Canadian stakeholders and reflective of different regional needs, especially northern, rural and remote communities." (Blueprint for a national autism spectrum disorder strategy, p. 6)

There are a number of barriers that play a role in ethnic minorities receiving a later diagnosis, such as language, geographical, financial, and cultural stigmas, to name a few. Considering these barriers and modifying current approaches can significantly improve access to the diagnostic pathway, as well as ensure that these families follow the pathway into intervention. By utilizing a culturally competent approach, it may help families move from denial to acceptance of an ASD diagnosis for their child.

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Appendix 2: Cultural Competence

Cultural Competence:

> “Cultural competence is the ability to understand, appreciate, and interact with people from cultures or belief systems” different from your own

(DeAngelis, 2015, para.1)

To be a culturally responsive diagnostician, one must be culturally competent.

For the purpose of this tool kit, we define cultural competence in the following ways:

According to Brach and Fraser (2000):

- “Cultural competency goes beyond cultural awareness or sensitivity. It includes not only possession of cultural knowledge and respect for different cultural perspectives but also having skills and being able to use them effectively in cross-cultural situations” (para. 4).
- “Cultural competency has been used to refer to an ongoing commitment or institutionalization of appropriate practice and policies for diverse populations (Denboba et al. 1998; Tervalon and Murray-Garcia 1998, para. 4).
- The concept of cultural competency is also presented as a continuum, in recognition that individuals and institutions can vary in the effectiveness of their responses to cultural diversity (Andrulis, Delbanco, and Shaw-Taylor 1999; Cross et al. 1989, cited in Brach and Fraser, 2000, para. 4).

Source: **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5091811/**

The Need for Cultural Competence

Cultural competency is crucial and there is a need for it within the ASD communities.

- “There is a lack of research focusing on the impact of cultural diversity on the development of programs, diagnostic testing, and services provided to students with ASD” (Barrio et al. 2019, p.2).
- “The original hypothesis of ASD presented by Kanner focused on ‘highly intelligent’ families from an Anglo-Saxon background” (Barrio et al. 2019, p.2).
- “Similarly, Asperger studied only Caucasian children in Austria due to the large population of Anglo-Saxon people in the area. Thus, there is a clear lack of research and understanding of diverse populations and practises that could inform the development of resources and programs to support children with ASD and their families (Tincani, Travers & Boutot, 2010 cited in Barrio et al. 2019, p. 2).

  Based on the (**Community Report on Autism 2018**)
- Autism and Developmental Disabilities Monitoring (ADDM) Network “reports have consistently noted that more white children are identified with ASD than black or Hispanic children” (para. 1).
- “Previous studies have shown that stigma, lack of access to health care services due to non-citizenship or low-income, and non-English primary language are potential barriers to identification of children with ASD especially among Hispanic children” (para.1).
- “A difference in identifying black and Hispanic children with ASD relative to white children means these children may not be getting the services they need to reach their full potential” (para.1).

Appendix 3: Role of Caregivers

Key search terms: ASD, Autism, caregivers, South Asian, Black, cultural competence, health are, culturally relevant, cultural awareness, sensitivity and responsiveness

A search for scholarly articles focusing on South Asian and Black caregivers and ASD, on ERIC **https://eric.ed.gov/**, a peer-reviewed database of scholarly work, yielded no results for South Asian families and limited results for Black families. Additional searches on PubMed did not yield relevant materials for this topic. Ultimately, an article on "Asian"(as an umbrella term) parents' experiences of Autism as well as Black families was retrieved through the Ontario Institute of Studies in Education of the University of Toronto Library database.

An essential component of ASD and cultural competence is the role of caregivers. Families are the primary touchstone for a child's care. Yet many studies indicate that racialized caregivers face significant challenges when dealing with ASD diagnoses and access to services (Boshoff et al 2016, p. 795).

Key messages from Boshoff et al, 2016 study include the following:

- Advocacy provides important personal benefits for parents of a child with ASD.
- Providing opportunities for parents' voices to be heard during service delivery is important.
- Advocacy is described by parents as complex, intensive, and a life-long challenge.
- Encouraging parents to obtain social support will assist parents with their advocacy role.
- Service providers need to be sensitive to parents from different cultural and language backgrounds, low socioeconomic areas, and less articulate parents in order to promote advocacy.
- Incorporating the child's, the parents' and the family's needs in the intervention will promote well-being and a balanced family life.

South Asian Caregivers:

The following were key messages from Shorey et al's 2020 study on Asian caregivers:

Face language and cultural barriers

- "Their inadequacies in the English language made it difficult for them to fully express their concerns and seek help from service providers" (p. 598)
- "Differences in cultural parenting practices also presented clashes in opinions with service providers" (p. 598)
- "In Jegatheesan et al.'s (2010) study, migrant parents were offended by health care providers' advice to "stick to English" to avoid confusing the child and to "keep the child's life simple" by limiting visitors to their homes and avoiding community events (e.g., going to the mosque), which were integral parts of their cultures" (p. 598).

Struggles with acculturation

- "Some parents missed their social lives and family support back in their home countries and expressed desires for their children to connect with their roots" (p. 598).
- "A few parents also struggled with biculturalism and getting their children to adapt to new environments while trying to instil and retain their own cultural values and norms" (p. 598).
- "Asian immigrant parents were less likely to attribute causes of ASD to cultural factors" (p. 598).

The term Asian is too large an umbrella term and thus a significant gap exists in the literature regarding South Asian caregivers' experiences with Autism.

Black Caregivers:

Limited research was available on Black families's experiences with Autism, and the research available was based in an American context. African-Americans tend to be accepting of their role as caregivers to someone with a disability and actually report "lower levels of depression, anger, and hostility in their role as a caregiver for family members with disability" (Pruchno et al., 1997 cited in Dababnah et al 2018).

Dababnah et al's 2018 study raises some key issues:

- "The literature about the unique issues affecting Black families raising children with ASD is only just emerging" (p. 333).
- "Interventions to train primary health care providers to become conversant on matters affecting Black families, especially in cases in which those families are experiencing the multiple effects of poverty, are crucial to reducing racial disparities in ASD screening, and ultimately, diagnosis and intervention." (p. 333)
- "As the main gatekeepers to specialty developmental and ASD-specific services, primary health care providers play a critically important role in delivering culturally relevant care and ensuring all children have an equal opportunity to obtain timely ASD diagnoses and access early interventions." (p. 333)

Refer to the following table (Dababnah et al, 2018) for a summary:

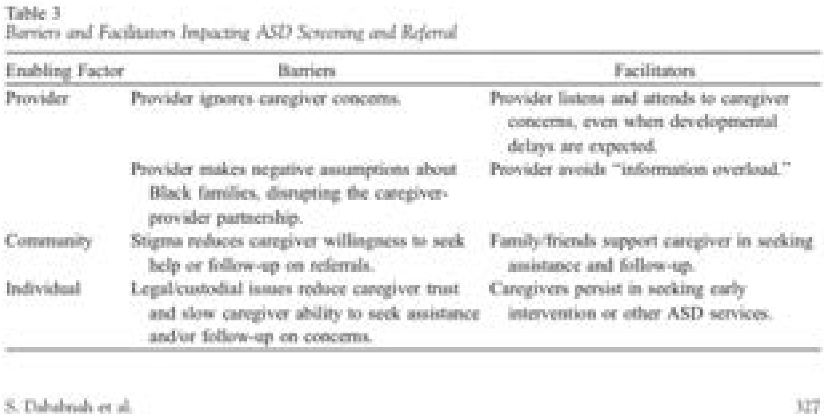

Table 3
Barriers and Facilitators Impacting ASD Screening and Referral

Enabling Factor	Barriers	Facilitators
Provider	Provider ignores caregiver concerns.	Provider listens and attends to caregiver concerns, even when developmental delays are expected.
	Provider makes negative assumptions about Black families, disrupting the caregiver-provider partnership.	Provider avoids "information overload."
Community	Stigma reduces caregiver willingness to seek help or follow-up on referrals.	Family/friends support caregiver in seeking assistance and follow-up.
Individual	Legal/custodial issues reduce caregiver trust and slow caregiver ability to seek assistance and/or follow-up on concerns.	Caregivers persist in seeking early intervention or other ASD services.

S. Dababnah et al. 327

(Dababnah et al, 2018) identify four key themes from their analysis:

Theme 1: Primary Health Care Providers' Attention to Caregiver Concerns

There were two different responses:

- "In the first pathway, participants reported that their primary health care providers listened to their concerns and paid close attention to their needs. These providers referred families to early intervention services for developmental evaluations when either the caregiver or provider was first concerned" (p. 328).
- "The remaining caregivers reported that their primary health care providers did not seem to take their initial concerns seriously and did not provide immediate referrals for ASD screening services" (p. 328).
- "When we looked at potential socioeconomic differences between caregivers who did and did not receive initial referrals from their primary health care providers, there was no discernible pattern of differences" (p. 328).
- "However, there were observable differences within the subgroup who persisted in obtaining early intervention services, despite their initial experiences with their primary health care providers. Overwhelmingly, these caregivers had college or advanced degrees; or, household incomes greater than $100,000" (p. 328).

Theme 2: Perceived Racism and Poor Caregiver-Provider Interactions

- "The majority of caregivers reported unease in their interactions with their child's primary health care providers, which some perceived racism. Other participants were unsure if poor caregiver-provider interactions were related to participants' neighbourhood or socioeconomic status. (p. 329).

Theme 3: Stigma in the Black Community

- "Many caregivers identified ASD stigma within the Black community, which made caregivers reluctant to follow up on, or even acknowledge, early developmental delays expressed by their primary health care providers or others" (p. 329).
- "Several participants asserted that denial or shame related to having a child with special needs is prevalent in the Black community, which reduced awareness of ASD" (p. 329).

- “Some caregivers mentioned they only found out children of family members or friends had special needs after the caregiver’s own child was diagnosed with ASD” (p. 329-330).

Theme 4: Legal and Custodial Issues

- “Changes and disruptions in caregiving and custodial arrangements created a barrier to following up on ASD screening and their primary health care providers’ referrals to developmental evaluations for some caregivers, delaying their child’s ASD Diagnosis” (p. 330).
- “Some caregivers were not their child’s biological parent (e.g., grandparent), and discussed legal challenges that prevented them from making medical and treatment decisions on the child’s behalf for developmental concerns” (p.330).

What we hope to uncover through this study is how culture impacts the Autism journey for caregivers in the Greater Toronto Area.

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Appendix 4: Potential Barriers to Diagnosis

With a better understanding of these terms, it is also important to understand what may play a role in preventing families from wanting to have their child assessed for Autism. There are a number of barriers families face—barriers that may prevent them from wanting to attend an appointment with a diagnostician.

Barriers include but are not limited to the following:

- Distrust of the health care system
- Lack of time or interest
- Fear of diagnosis and implications
- Language barriers
- Caregiver denial
- Cultural stigmas
- Unaware of benefits of early identification

Understanding these barriers is the first step in developing better strategies for approaching families. One of the most common barriers that families face can be language.

Although it is fairly common to think that simply translating materials is the easiest solution, it is actually a bit more complex than that. For many South Asian families, the terms 'developmental delay' or 'Autism' are completely unknown terms, and in a variety of languages there may not be an equivalent word or phrase. Additionally, there may be a word that may have a very negative connotation (i.e., in a certain South Asian language, Autism translates to a word that means "empty mind").

Simply translating materials and handouts is not enough. There needs to be an understanding of the context and meaning behind phrases and terms. It cannot just be a direct translation. The use of structured text and visual representations can make a significant difference. Utilizing images/pictures that represent that diversity of the communities and the communities that a clinic services, can not only make the clinic more welcoming, but also help illustrate to the family that they are not alone.

Caregiver denial is also another significant barrier. This may be one of the most common situations a diagnostician may face. It may be common to encounter caregivers who do not believe that the child has any concerns or delays. This can be more common if this is their first child, where everything in parenthood is new to them.

There can be a number of other factors playing a role in this denial such as cultural stigmas. They may be worried about shame and isolation if their child were to get a diagnosis. For both Black and South Asian communities, which both have a strong foundation in collectivism, being connected to their community is an essential component to a family's well-being. Families may worry that if their child receives a diagnosis, they may be shunned by their community and lose an essential part of their well-being.

They may also feel a sense of blame or fault, which is fairly common for both South Asian and Black families (e.g., similar to the "refrigerator mothers' theory" described by Austrian psychiatrist Leo Kanner who described a mother's cold, uncaring style traumatized a child to the point that they retreated into Autism) (Kanner, 1943). Caregivers from South Asian and Black communities state that they hear similar statements from their extended family who may tell them, "It's because you weren't strict enough with your child, or you allowed your child to watch too much TV." Keeping these comments in mind, and being able to address them, can make families feel more comfortable with the diagnostic process and understand some of the benefits of having their child diagnosed earlier. Reassuring parents that their child's diagnosis is not related to the caregivers' parenting techniques can also bring some much-needed comfort and anxiety reduction for these caregivers.

It is also important to keep in mind that for some caregivers, they may be unaware of the benefits of early identification. They may have misconceptions that their child will improve with time or that their child will "grow out of it." They may be hearing this from family, parents, or friends. It is important that, in this case, diagnosticians must practice patience and have continuous open conversations with these families. Reminding families that delays in early identification can have adverse impact on the long-term development of their child is crucial in helping hesitant families.

Other common barriers are just a general distrust of the health care system and specifically for the Black communities; this is linked to historical and systemic discrimination. Some families may also not be able to attend appointments due to work, lack of access to adequate childcare or are working late hours. This is fairly common for South Asian and Black caregivers.

Another common barrier in both South Asian and Black Communities is the fear of diagnosis and its implications. For these communities, concerns around the future of their child can fuel these fears. They are commonly worried about attending post-secondary education, getting a job and marriage. For some of these caregivers, they may fear that the child will face the same fate as a child diagnosed in their home country, where there may be minimal support. By understanding their fears, a diagnostician may be able to help reassure families that they are taking the right steps and that there are supports available here in Canada that may have not been available in their home countries.

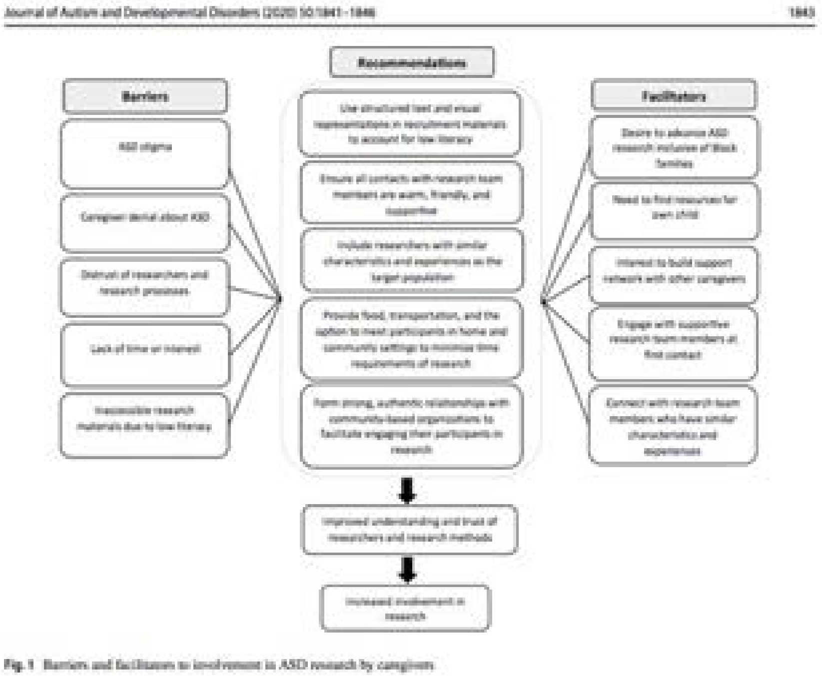
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Fig. 1 Barriers and facilitators to involvement in ASD research by caregivers

Image from Dababnah, et. al, 2018

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Appendix 5: Cultural Norms

Cultural Norms

These are rules or expectations of behaviour and thoughts based on shared beliefs within a specific cultural or social group.

Why is it important to understand cultural norms?

It is important to know that different cultural practices and beliefs about child development may indirectly affect the age at which developmental concerns are being detected by families.

For example, in some cultures:

- Independence is encouraged at an older age when compared to Western cultures
- Interactions with family have a higher importance than playing with toys
- Importance is placed on a child being quiet and obedient
- Have certain gender expectations

For diagnosticians that may be approaching families, it is important to know that the family may be unaware of any concerns with their child. They may feel that their child is developing typically. Approaching families by using examples that they may relate to may better help them to understand their child's development.

A common example seen on many developmental checklists is using a spoon/utensils to eat. It is important to keep in mind that certain utensils, such as chopsticks, may take longer to master, as they take more fine motor and cognitive skill. It is also important to know that in other cultures, families may not encourage children to feed themselves until they are older. It may be more common in certain cultures for the parents to feed the child by hand (e.g., commonly seen in many South Asian cultures). By understanding some of these cultural contexts, it can help with how a diagnostician approaches a family and how they can also build a rapport with them. It may also help diagnosticians modify their assessment, such as by adapting their interview questions or diagnostic tools, so it better reflects the child's development.

Appendix 6: Cultural Context for Screening and Diagnostic Tools

There is growing data to show that immigrant and newcomer families receive a later diagnosis when it comes to Autism. Research has also highlighted a need for an increase in awareness of multicultural and immigrant experiences regarding ASD **(Dyches et al., 2004; Singh et al. 2013).** This will help us to better understand the socio-cultural factors that may play a role leading delays in diagnosis. That is, differences in cultural practices and beliefs about child development may indirectly affect the age of ASD detection.

An example that illustrates this within South Asian communities is a study done in Sri Lanka where the authors noted that the rate of recognizing social impairment and other main characteristics of Autism was low with that population. The authors attributed this to cultural differences where mothers did not perceive social deficits listed in the screening tool **(Perera et. al, 2013)**.

Another study showed that parents of children on the Autism Spectrum in India identify impairments in their children approximately 6 to 10 months later than families in the United States. The authors believe that this is due to a range of cultural differences **(Daley et. al., 2004)**.

To elaborate, in some cultures, certain standard indicators of ASD may not elicit concern at an early age.

Here are a few examples:

1) *Pointing*: This is a common question on screeners. However, it is important to keep in mind that the use of index finger pointing to share interest is not a common practice in some Asian cultures **(Zhang et al., 2006 cited in Tek & Landa, 2012)**.
2) *Eye Contact*: In certain Asian cultures, making direct eye contact with adults or imitating behaviours of parents may be considered disrespectful **(Zhang et al., 2006 cited in Tek & Landa, 2012)**. This has also been observed similarly in rural South Africa.
3) *Difficulties in communication and social skills*: A study done in Goa, India, showed that parents did not notice subtle delays in communication and social milestones until a child starts preschool and has trouble connecting with peers **(Divan et al., 2012)**. It is important to also keep in mind that some families from diverse ethnic backgrounds may view these types of difficulties as temporary (**Danesco, 1997**). This is even more the case when families are living outside their cultural framework. These same families may also struggle to acknowledge a diagnosis of ASD in an attempt to preserve hope for their child's future.

Screening Tools

Cultural context is also extremely important to keep in mind when using screening tools. Keep in mind that almost all of these instruments were developed in high-income countries and were not designed to consider cultural influences **(Varma et al., 2014)**.

1) *M-CHAT-R/F*: A commonly used screening tool is the Modified Autism Checklist for Toddlers (M-CHAT -R/F). However, it has been shown the M-CHAT-R varies significantly in sensitivity and specificity when screening for ASD from community to community, potentially due to socio-cultural influences **(Albores-Gallo et al., 2012)**.
2) *LOOKSEE*: Another commonly used screening tool is the LookSee. However, families at SAAAC have reported that some of the questions on checklists can easily be misinterpreted by parents. An example is questions regarding the child's ability to feed themselves with a spoon/utensil. This may not be relevant in cultures where the use of hands is preferred, such as in many South Asian cultures. In certain cultures, such as South Asian cultures, feeding the child is an inherent part of bonding between child and caregiver. Hence families may not encourage children to feed themselves until they are older. In some cultures, parents may have strong beliefs against putting children on the floor to play until a certain age.

It is important to be aware of some of these beliefs when screening children. Utilizing a diverse set of screening tools or adapting questions on the tool to be more culturally competent will ensure that the screening is more reflective of the child's abilities.

Diagnostic Tools

The gold standard ASD diagnosis is the Autism Diagnostic Observation Schedule (ADOS). However, more recently in the context of differences in social behaviours cross-culturally, it has been shown that the norms and operational definitions used in the ADOS need to be re-evaluated to be more diagnostically accurate in culturally diverse groups. Other studies have shown that there are differences on standardized tests of ASD symptoms from country to country (**Freeth et al. 2013; Matson et al. 2017, 2011)**.

This can cause difficulties with diagnosis as it is still unclear whether there is a true difference in symptoms within the two communities or if it's due to the lack of cultural sensitivity in the diagnostic tools used.

1) *Eye contact*:
    a) Eye contact, as mentioned above in regards to screening tools, can be a very ambiguous sign when not taken within a cultural context. A study in 2013 done by Hall and Knapp suggested that the amount and type of eye contact may be dependent on whether the child's culture is individualistic versus collectivist (i.e. Black and South Asian cultures).
    b) As mentioned above, in certain Asian and African cultures, eye contact may be a sign of disrespect **(Liam et al, 1996, Sue et al., 2008)** and thus discouraged. In other cultures it is more commonly accepted as a form of respect or sign of paying attention (Collett, 1971).
    c) These differences were also noted between white and Black students in the United States. **(Fugita et al.,1974)**

Hence it is important to consider the cross-cultural variability in eye-contact as it may be reflected in the scoring procedures for the ADOS.

2) *Facial Expressions and Recognition*
    a) Research has shown that there is cross-cultural variation in how different groups exhibit non-verbal facial cues when expressing emotions (Harrison et al., 2017). For example, one study showed that Black participants are generally more emotionally expressive than white participants **(Vrana and Rollock, 2002)**. The belief is that these differences in facial expression may rise from different value systems within these cultural groups. Kochman hypothesized that Black culture encourages a greater range of expression than white culture because of a heightened value placed on spontaneous expression of feelings and self-assertion **(Kochman, 1981)**.

3) *Language*:
    a) It is important to note that in certain cultures, children may less frequently sit and talk with adults **(Carter et al., 2005)**. As a result, this may impact how the child performs when asked to interact with an adult examiner such as with the ADOS.
    b) It is also important to keep in mind the language used when assessing a child. Research has shown that a child performs better when the testing language/dialect matches the language spoken at home (Hall et al. 1975). This is especially important for modules three and four in the ADOS that utilize semi-structured interviews.
    c) An example that illustrates this is when a Black parent uses phrases like, "My child won't mind me." Some diagnosticians may interpret this as the parent describing their child as being disobedient and not a socially impaired one (i.e., my child is not interacting with me or responding to when I call their name). This is just one of the examples that may explain why Autism is diagnosed less frequently among Black children.

4) *Play*:
    a) Research has shown that more serious, methodical, and purposeful play seems to be more highly valued in white culture, and unstructured types of play seem to be more highly valued in Black cultures **(Harrison et al., 2017)**
    b) Studies have also shown that compared to Black children, white children are more likely to have an inflexible adherence to non-functional routines and a preoccupation with parts of objects **(Sell et al. 2012)**.
    c) A commonly used activity in the ADOS is the pretend birthday party. But in certain African and South Asian cultures, birthdays often are not celebrated, so even typically developing children might be unfamiliar with it. It may be useful to consider using alternative scenarios of shared excitement.

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16. Immigrant Children with Autism Spectrum Disorder: The Relationship between the Perspective of the Professionals and the Parents’ Point of View **Milena Pereira Pondé**, MD, PhD[1] and Cécile Rousseau, MD[2]
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