SAAAC

TOWARDS CULTURAL COMPETENCE

Cultivating Effective Communication with Cantonese-, Mandarin-, and Tagalog-Speaking Caregivers throughout the Autism Journey

Who this toolkit is for

While the primary focus of this toolkit is to support diagnosticians, it also aims to assist allied health professionals, educators, frontline support staff, and community members in effectively communicating with caregivers of autistic children and youth. The information provided in this toolkit is designed to offer culturally competent guidance for improved communication.

Citation Information

Suggested citation: Shanmugathasan, U. Sivapalan, S. , Nguyen. L., and Lee, J.(2023). *Towards Cultural Competence: Supporting Diagnosticians in Communicating with Cantonese-, Mandarin-, and Tagalog-Speaking Caregivers*. SAAAC Autism Centre (SAAAC). Toronto, ON.

Acknowledgments

SAAAC Toolkit Project Team

This toolkit for culturally competent communication was created by the SAAAC Autism Centre Project Team.

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We wish to thank the following individuals for their immense contributions to this toolkit.

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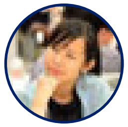
Linda is currently a postdoctoral fellow in the School of Physical and Occupational Therapy at McGill University. She completed her PhD in Rehabilitation Science at McMaster University in 2022. Her dissertation was focused on understanding the experiences of young adult siblings of youth with a disability during the transition to adulthood and synthesizing resources to support them. During her PhD studies, she established and continued to partner with the Sibling Youth Advisory Council (SibYAC) through Canchild through McMaster University, which is composed of young adult siblings of individuals with a disability and/or chronic health condition. Her postdoctoral fellowship is focused on the co-development of a sibling toolkit, as well as improving the engagement of youth, siblings, and families in human rights disability policies in Canada.

James D. Lee (PhD, BCBA-D)

James is an Assistant Professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington and the Seattle Children's Autism Center. His research focuses on developing, adapting, and implementing evidence-based practices (EBP) among underserved families of young autistic children who live in low-resourced communities both domestically and internationally. James has conducted several studies examining the feasibility, effectiveness, and social validity of interventions for caregivers of young autistic children, and he is the lead developer of the **Cultural Adaptation Checklist.** His primary interest is using implementation science to enhance access to EBP for marginalized families.

Carman (Ka-Man) Chu (MS, BCBA), Community Support Worker



Carman was born in Hong Kong and moved to Canada when she was 11 years old. She completed her Master of Science degree, specializing in Applied Behaviour Analysis (ABA) and Autism Spectrum Disorder (ASD). Currently, she is working as a clinical supervisor at a local agency, supporting children and youth with a diagnosis of ASD and their families. It is her passion to increase public awareness and reduce stigma toward autism.

Kyoko Leung (RSW, BSW, MSc), Executive Director

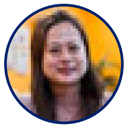
Kyoko is a registered social worker with a Bachelor of Social Work from Hong Kong; she also holds a Master of Science in Marketing from Ireland. With more than 20 years of social work experience, she is fully committed to serving persons with developmental disabilities and children with special needs. Her expertise includes operating adult and children services for various abilities and ages, including adult day activity centres, adult hostels, shelter workshops, supportive employment for those with disabilities, special childcare centres for pre-schoolers, and self-financed social services projects.

In Canada, Kyoko joined Cherish Integrated Services in 2018, as a program officer. She then was promoted to the position of program director, which involved overseeing new projects and service coordination. After a short break from work, Kyoko re-joined Cherish in 2021, replacing our late founder, Annie Leung, as the executive director. Kyoko's dedication and commitment to serving persons with developmental disabilities allows her to be profoundly knowledgeable about and a visionary towards the needs of persons with disabilities, their families, and the community. Her passion is to enhance quality of life by giving each unique person choices and opportunities, helping them to realize their limitless potential.

Esther Ching (RSW, MSW, BSW), Service Manager

Esther graduated with a Bachelor of Social Work and Master of Social Work degrees in Canada. She brings to Cherish more than five years of experience in directing children's summer camps and more than three years of experience in youth work, as well as professional counselling experience. Esther uses her passion for social justice and community development to support the growth of Cherish. She has worked with the Cherish team since 2018, initially working directly in the children's and adult programs, then taking on increasing management responsibilities including intakes, fundraising, partnerships, and exploring resources for initiatives and special projects. She is dedicated to advocating for the needs of trainees as well as the organization, and she is passionate about innovating new programs and projects that enhance the well-being of individuals with developmental disabilities.

Karen Leung (RSW, BSW, MSc, CCLS), Program Officer



Karen is a registered social worker with a Bachelor of Social Work from Hong Kong. She started her social work career specializing in children's services. Her interest in serving children led to her completion of a Master of Science in Child Life at McMaster University. She worked in hospital settings prior to joining Cherish in 2022; she was also a senior manager before moving to Canada. With 15 years of work experience, she is skilled in family-centred care, child development, and psychosocial care. She is responsible for initiating children's programs and administration work.

Christine Hui (MSW, RSW, NLP Practitioner, HKPCA Member), Program and Administration Officer

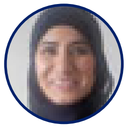
Christine is a registered social worker with a Master of Social Work from Hong Kong. Now she is also a registered social worker in Ontario. She is passionate about social services and is experienced in youth work, school social work services, and rehabilitation services that serve people with developmental challenges and mental health issues. She is also a registered childcare worker in Hong Kong.

Christine is interested in delivering professional counselling services and group counselling to children and youth and their parents. She also has experience administering services to those with different disabilities from preschool to adult, from centre services to home services. Christine believes that each person is unique and has the right to live with dignity and respect, and that we can cultivate strength through encouragement and empowerment. With solid clinical social work experiences, she has been a social work educator in a tertiary institution.

Grace Tameta, Program Facilitator

Grace is a program facilitator at Orchard Park EarlyON Child and Family Centre. During the past 12 years, she has facilitated programs and events for families with children ranging in age from birth to six years. Grace also coordinates workshops to meet the needs of parents or caregivers in the Scarborough East community and raises awareness of inclusion services offered within BGC East Scarborough and partnering agencies, such as SAAAC Autism Centre.

Munira Khilji, Manager

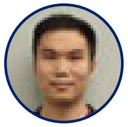


Munira is the manager of the Entry to School and Case Management programs at the SAAAC Autism Centre. Her training as a healthcare professional, experience as a parent of two, and insight as an advocate for health equity in underserved communities deeply inform the initiatives Munira supports. During the past ten years, Munira has championed the need for better support and services for families of children on the autism spectrum. She started off with the community led Thorncliffe Collaborative for Muslim Families, an organization that enabled parents to engage in training opportunities that were accessible and culturally sensitive. She then garnered experience in cross-sectoral partnerships and integrated healthcare pathways through her work coordinating a school-based paediatric clinic for Health Access Thorncliffe Park that focuses on supporting children and youth who experience challenges with learning, growth, behaviour, and development. Currently, Munira supports Ministry-led programming at the SAAAC Autism Centre.

Chapman Cheung, Data Engineer, and Translator

Chapman is currently working as a data engineer. He enjoys meeting new people and actively seeking opportunities to gain new project experience. Through working with the SAAAC Autism Centre, he has supported the team in increasing awareness of autism in the community and providing crucial resources to handle stressful events. He is grateful for the opportunity to learn so much about autism as a part of the SAAAC team and is proud to play a part in bringing positivity to the community.

Bernard Yeung, Classroom Facilitator



Bernard is currently working at SAAAC Autism Centre as a classroom facilitator in the Entry to School program under the Ontario Autism Program. He earned his Bachelor of Science from Trinity College at the University of Toronto, double majoring in psychology and Latin. Following this, he completed his certificate in Autism and Behavioural Sciences and began working at SAAAC as an ABA instructor therapist; he has been happily working at SAAAC ever since.

Dr. Catherine Yu, Family Physician and Medical Director

Catherine is a family physician and the medical director of Health Access Thorncliffe Park, as well as an assistant professor in the Department of Family and Community Medicine (DFCM) at the University of Toronto. An emergency physician for more than 10 years, she now advocates passionately for her family practice patients. She is the engagement lead for the Office of Health System Partnership at the DFCM. She is committed to the implementation of integrated care models of health and social services to achieve health equity for marginalized populations. She received the 2019 Ontario College of Family Physicians Award of Excellence for her work in supporting vulnerable populations. Catherine is Chair of the Board of Directors for the East Toronto Family Practice Network, a network of family physicians with a mission to create equitable access to interprofessional care for all family practices.

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This is an interactive toolkit. Please click on this icon 🗒 *to read further information.*

Introduction

SAAAC Autism Centre is a Scarborough-based charity that provides services and supports individuals with Autism Spectrum Disorder (ASD) and their families. Our organization is a lifeline to marginalized populations in this sector that are living in Toronto and the Greater Toronto Area (GTA). SAAAC's mission is to make 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, as well as providing free and subsidized programs.

Previous Work on Cultural Competence

In collaboration with the Children's Treatment Network (CTN), SAAAC created an accessible digital toolkit titled "Towards Cultural Competence: Communication for Diagnosticians When Working with South Asian and Black Families of Children/Youth on the Autism Spectrum." This toolkit, designed in collaboration with community agencies, provides tips, tools, and strategies for Ontario's healthcare professionals. The toolkit centres the voices of families and makes recommendations to diagnosticians to facilitate a culturally competent approach to autism diagnoses. You can download the toolkit at **https://bridgethegap.saaac.org/**.

Purpose

To provide cultural competence training for diagnosticians, specifically in the context of Mandarin-, Cantonese-, and Tagalog-speaking families and caregivers.

Goals

1. To help diagnosticians better understand the barriers faced by East Asian families
2. To address concerns with the current screening/diagnostic tools
3. To provide strategies to more effectively communicate with families to improve retention of families throughout the diagnostic and treatment pathways

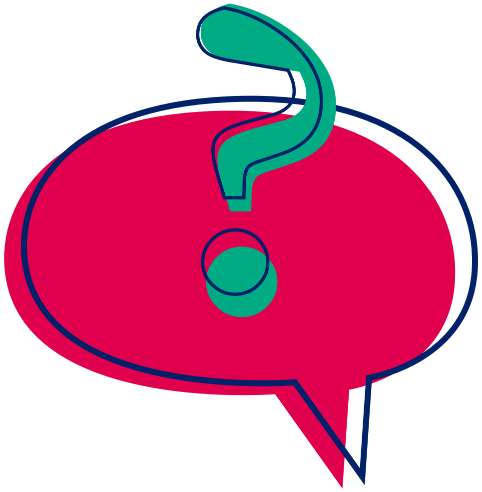
Why?

- Prevalence of guilt, shame, and blame in Chinese and Filipino families and social networks regarding autism
- Belief in genetics as a root cause
- The fear of lost opportunities for children of immigrant families, as well as increased social isolation
- Lack of awareness regarding autism and the resulting delays in diagnoses
- A primary focus on Western therapies
- A lack of caregiver stories and the communication of needs among Filipino and Chinese families in the Canadian (specifically Ontario) context

Methods

For this project, we designed a questionnaire to understand the diagnostic journey and divided it into three parts: pre-diagnostic appointment, assessment appointment, and post-assessment appointment (i.e., after a child's diagnosis), along with a demographics section to capture the culture and socio-economic profile data of the respondents. Community agency **Cherish Integrated Services**, Filipino staff from EarlyON and **SAAAC Autism Centre** were integral in communicating with families. Community liaisons met with caregivers who voluntarily consented on a one-on-one basis and used the questionnaires to guide conversations with families with children on the autism spectrum. The completed questionnaires were analyzed by the SAAAC project team and key themes were extrapolated from the interviews.

The community agencies already have a relationship of trust and familiarity with families, as well as linguistic competence to deliver the questionnaires. Although the majority of our families responded to the questionnaires in a straightforward manner, a few required probing to elicit responses. This additional probing may be due to the private nature of the communities and the stigma surrounding autism, as detailed in this toolkit. This exercise highlights the need for grassroots, culturally responsive approaches to the autism diagnostic journey.



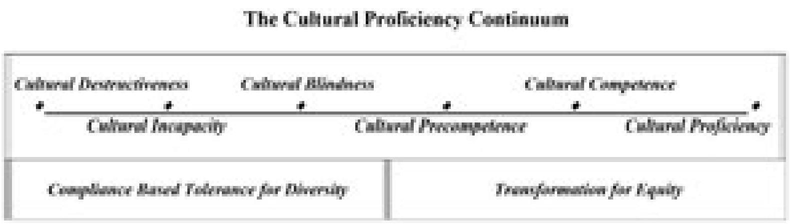
INITIAL REFLECTION EXERCISE:

Situating Myself on the Cultural Competence Continuum

Towards Cultural Competence and Beyond: A Continuum for Practice

The following continuum is a guiding framework to support diagnosticians in creating a sustainable, culturally competent approach to the diagnostic journey. The continuum helps clinicians understand where they are in the journey and where we all want to be for equity. The ultimate goal in transformative equity is to be culturally proficient; cultural competence is the competency that precedes proficiency.

Consider: Cultural Competence



CLICK HERE for an overview of each of the competencies.

Reflect

1. As a diagnostician working towards cultural competence and proficiency, where do you situate yourself on this continuum?
2. What successes have you had on this journey? How did you feel?
3. What aspects of this continuum challenge you? Why do you think this is?

Reference:

The Continuum. Image. (n.d.). Retrieved January 17, 2023, from https://ccpep.org/home/what-is-cultural-proficiency/the-continuum/.

SECTION 1:

Autism and Chinese and Filipino Cultures

> *A big difference between the Chinese and the typical, local culture is the sense of self. Stereotypically, the North American culture sense of self is much more individualized. I would say it is a solid line of self for each person. When a diagnosis is given to a person, the identity change might be perceived as more localized to the person.*
>
> *Whereas in Chinese culture, the sense of self could be considered loosely. For example, the line between myself and my parents is less solid, and therefore the impact of an identity change could be much stronger. In addition, "face," which can be translated as identity, is very important in Chinese culture. Therefore, anything that is altering the recognition of an identity, such as a diagnosis, has a very strong impact to the entire family as a whole.*

—Community Support Worker

Conversation with Carman Chu: Enhancing Autism Support and Understanding for the Chinese Community

Video Chapters

1) Intro (00:00)
2) Autism in Mandarin or Cantonese languages (00:40)
3) Meaning of "play" in Chinese culture (02:38)
4) Significance of "praise" in Chinese culture (04:13)
5) Impact of Autism diagnosis on Chinese families (05:50)
6) Grieving process and copying within the Chinese community (07:16)
7) Feeling of guilt and blame (08:33)
8) Mothers feeling more guilt than fathers (10:40)
9) Lack of clear etiology (12:20)
10) Strategies that diagnosticians can use with Chinese families (12:54)
11) Reassurance by diagnosticians to parents (14:00)
12) Time to process the diagnosis (14:39)
13) Strategies diagnostic hubs can implement immediately after diagnosis (16:22)
14) Explaining Autism to caregivers (17:50)
15) Advice to diagnosticians and diagnostic hubs helping Chinese families (19:56)
16) Providing diagnosis to Chinese families (20:36)

Chinese Culture

Although ASD is well-known globally, it was only recognized by researchers in China in the 1980s. Prior to 1980, the average prevalence of ASD was around 1.9/10,000 *(Sun and Allison, 2009)* while after 1980, the average prevalence has risen to 14.8/10,000. From 2000 to 2009, the median prevalence of ASD among two- to six-year-old children was 10.3/10,000 *(Sun and Allison, 2009)*. There is growing evidence that ASD is more common in Asia than previously thought. However, due to several barriers deterring families from accessing diagnostic assessments, gaps in diagnostic testing, cultural stigma, and the understanding of autism in China, ASD is grossly underdiagnosed. The scarcity of resources to help support individuals on the autism spectrum in China also acts as a significant barrier.

It is important to understand that cultural factors play a role in not only the diagnostic process but also in how a family adapts to having an autistic child. But these factors are commonly overlooked and receive less attention due to the more significant behavioural, social, and communication challenges that the child is facing. Although symptoms of neurodevelopmental disorders may be similar across cultures, there are significant variations in symptom description, interpretation, and acceptance.

When analyzing the different factors that play a role, one must consider both the macro-level and micro-level influences. Macro-level factors, such as societal acceptance of the disorder or the availability of services, are ones that affect people in that society. Micro-level factors are ones that relate to an individual family's response to or acceptance of the diagnosis of autism. It is these micro-level factors, which vary considerably, that influence a family's response to diagnosis and treatment *(Bernier et al., 2010)*. We discuss some of these factors in more detail on the next page.

Read more: **Appendix 1a: Autism and Chinese and Filipino Cultures**

Barriers to Access

1) **Societal Pressure and Cultural Factors**
2) **Religious Beliefs**
3) **Limited Understanding of Autism**
4) **Misconceptions of the Etiology of ASD in Chinese Culture**
5) **Perceived Stigma**

1) Societal Pressure and Cultural Factors

Chinese culture is generally believed to be more collectivistic with the needs and goals of the "family" taking priority over the needs and goals of the "individual." Societal pressure for conformity in Chinese culture adds another level of pressure on families. This pressure for conformity means individual differences, such as disabilities, are rarely accepted by Chinese society and usually perceived negatively. This leads to increased levels of stress for parents, thus deterring them from seeking diagnostic assessments or treatment *(Lin 2014; Mak et al., 2010)*.

Chinese culture traditionally has a high social identity value or what is known as "face" (*mianzi* or *lian* in Mandarin Chinese) *(Wong et al, 2016; Ji et al., 2014; Mak et al., 2010)*. Loosely, this refers to the amount of dignity or prestige that is associated with an individual and is tied to a cultural understanding of respect, honour, and social standing. "Losing face" are actions and or words that are disrespectful, while "giving face" are respect-giving actions. As a result, this value emphasizes the importance of positive evaluation by others *(Zhou et al., 2018)*. It is this value, however, that also leads to the shunning of individuals with disabilities or autistic individuals, as they are often regarded as a disgrace to the family and harmful to the family lineage *(Lin, 2014; Lin, 2015; Wang et al, 2013)*. Thus, to preserve the "face" of the family, Chinese culture places an emphasis on keeping matters "in-house" and discourages the discussion of issues outside of the family. This leads to families holding off on seeking a diagnostic assessment or treatment for their child *(Wang et al., 2011)*. They are more likely to seek help from family rather than from external resources *(Wang et al., 2013; Lin et al., 2011)*. In China, grandparents are often a resource for the family, and they are usually central to caring for autistic grandchildren *(Ji et al., 2014; Ding et al., 2010)*.

2) Religious Beliefs

Religious beliefs can also act as a barrier to access for Chinese families. For example, in Confucianism, one of its precepts is that men are superior to women *(Ding et al, 2010)*. This belief can put additional stress on mothers, as they may not communicate their concerns with their child; this can further delay assessments. This belief can also lead to families seeking diagnoses and treatment for their male children more actively than for their female children *(Wang et. al., 2011)*. Filial piety is another Confucianist concept, which advocates for practices of respect and caring for one's parents. As a result, parents invest their efforts into raising their child with the hope that, in the future, their child will be able to care for them. Filial piety is one of the foundations of Chinese parent–child relations and socialization. This belief can add stress to caregivers if their child has a disability and will not be able to support them in the future.

In a more positive sense, one of Confucianism's key principles is the positive role of adversity on personal growth. Adversity is considered to be motivation, which can help families overcome the grief experienced after diagnosis and encourage them to move forward and start treatment *(Lin, 2015)*.

Taoism is another Chinese philosophy, and it is based on the writings of Lao-tzu that advocate for humility and religious piety. This philosophy teaches that all living creatures ought to live in a state of harmony with the universe and the energy found in it. Many Chinese families follow Taoism and its "non-doing or do nothing" approach *(Lin et al., 2011)*. This approach enforces the idea of spontaneity, rather than interference, and letting things take their natural course. "Do nothing and everything is done" is another way to frame it. This approach also leads to families accepting their fate and to focus on self-cultivation; at times, this can help families to manage their own stress, but it can also delay families in seeking diagnostic assessments and therapeutic interventions. Although certain beliefs held in Confucianism and Taoism may act as barriers, some of the philosophies taught in both religions can be valuable in the post-diagnostic period to help build resilience and coping strategies for caregivers.

3) Limited Understanding of Autism

In East Asia, autism is commonly viewed as an intellectual disability, rather than a neurocognitive disability. One study showed that 25 percent of parents in the United States considered their child to differ from neurotypical children in intellect. By contrast, 70 percent of parents in Japan felt the same way *(DeWeerdt, 2017)*. The study

highlights how parents perceived a difference in intelligence. In East Asian cultures, an autistic child is commonly misdiagnosed as "mental retardation." Another misconception is that autism is a curable medical condition that fades with time. With this in mind, parents feel that by waiting, their child will get better on their own, which often delays diagnostic assessment. Parents are more likely to state that their child has a "developmental delay," "speech delay" or "communication problem."

In a study by Huang et al., only 57.8 percent of respondents were able to recognize signs and symptoms of autism. This finding suggests that parents are less likely to identify autistic traits. They may have a low awareness of these traits, or they may have a different perception of the term. Lack of societal awareness of autism can result in the shunning of autistic children, resulting in further delay of assessment and treatment *(Mak et al., 2010; Chan et al., 2018; Mitter et al., 2019)*. This same lack of awareness is also linked to deficits in social support, adding another barrier to access for these families *(Ding et al., 2010; Lu et al. 2018)*.

4) Misconceptions of the Etiology of ASD in Chinese Culture

As the etiology of autism appears to be multifactorial, families may feel confused about the cause of ASD for their child. Although several genetic and non-genetic factors have been identified, no diagnostic markers are currently available. As the cause of ASD is still unclear, families may hold various beliefs about what may have caused their child's autism. One of the beliefs is that their child's autism is punishment for the bad actions of previous generations *(Wang et al, 2011)*. This is a similar belief held by many South Asian cultures and religions (e.g., the concept of past karma). Another belief is that autism has a supernatural cause *(Lin, 2015)*. This leads to many families approaching fortune tellers for explanation and treatment of their child's autism, rather than seeking help from medical professionals *(Lin, 2015)*.

The lack of certainty about the cause of autism—compounded with existing cultural stigmas around autism—can act as a strong barrier that can prevent families from accessing diagnostic assessments. As a result, families are forced to rely on their own beliefs, whether it be cultural or religious, to explain the cause of their child's autism. This reasoning can lead to several misconceptions. It is important to also understand that parental perspectives of ASD can influence parental responses to a diagnosis, which has a direct impact on education and treatment choices.

5) Perceived Stigma

Stigma continues to exist in China, and there is still a sense of shame felt by parents when their child is diagnosed with a disability. The perception is that the mental illness and/or disability of their child is punishment for their own behaviour—more specifically, the mother's behaviour *(Tsang et al., 2003)*.

In a study with 43 caregivers of autistic children, caregivers reported fear that their child's autism would result in discrimination. This worry is based on the traditional Chinese belief that a child's behaviour and success is a direct reflection of the parents and their parenting style *(McCabe et al., 2007)*.

Chinese culture also prioritizes academic excellence, and a diagnosis of autism can be viewed as a direct contrast to that definition of success. Autistic children with behavioural challenges in schools are also usually regarded as ““naughty” or “having bad parenting experiences,” rather than being referred to as having autism *(Huang et al., 2012)*. This type of negative labelling can discourage parents from getting their child assessed.

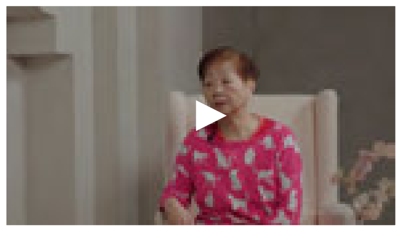
Although it is commonly known that parenting can influence a child's development, there is a common misconception within Asian culture that parenting behaviour and style can be the cause of a child's autism. In China, there is a belief that autistic children are the “bad seeds” of a family and a failure of the parents due to poor biological roots *(Wong et al., 2016; Zhou et al., 2018)*. Although this perception is not true, it acts as a strong deterrent in stopping families from seeking diagnoses *(Bernier et al., 2010)*.

Also, keep in mind that research has shown that Asian parents of autistic children report significantly higher levels of stress. This is even more true with Chinese parents who focus more on their social status and identity. One of the worries for parents is that their autistic child will be less suitable for marriage and socially shunned after the diagnosis. This means that parents consider it shameful to get a diagnosis of autism *(Ng et al., 2021)*. Interestingly, in South Korea, to preserve parental investment with their child, healthcare providers purposefully misdiagnose autism as reactive attachment disorder *(Kim et al., 2022)*. This diagnosis was better received by parents than an autism diagnosis, which means they are more willing to engage in therapeutic interventions.

Reflection

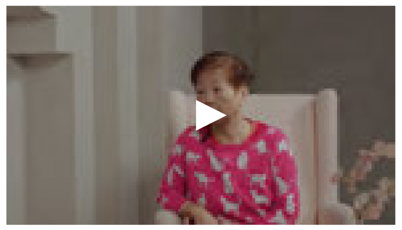
To understand this from a parent's perspective, please review the following video clips:

Joanna's Journey

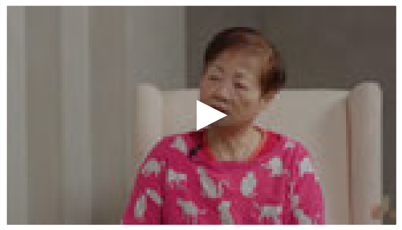


Unveiling Emotions During the Diagnostic Process

Resistance to Seeking Community Support



Navigating Differing Perceptions of Autism



Advice for Recently Diagnosed Families - Ask for Help

1. What resonates with you after watching these clips in terms of professional practice?
2. What questions do you have?

Filipino Culture

By understanding the cultural identity, needs, and beliefs about autism in the Filipino community, we can improve the service access of Filipino immigrant families with autistic children. However, there is limited information regarding the prevalence of autism in the Philippines. A 2007 congressional report from the Republic of the Philippines estimates that one out of 500 Filipino people are autistic, which roughly equates to approximately 140,000 Filipinos out of the population of 70,000,000. Of those affected, only 10 percent have been formally diagnosed. Another report using Commission of Human Rights (CHR) data identified that around 1.2 million or one in 100 Filipinos are on the autism spectrum.

It has been reported that autism impacts 17.9 per 1,000 Asian American and Pacific Islander children in the United States. However, similar to the Chinese community, shame and stigma related to autism negatively affect how Filipinos perceive the developmental disability, which can lead to delays in assessments, and contribute to under-reporting and delayed interventions (Filipino American Parental Beliefs and Perceptions about Managing Care for Children and Adults with Autism Spectrum Disorder).

There are several studies that have shown that immigrant families are less likely to access healthcare in Canada, but recent research has shown that Filipino immigrants are even less likely to access healthcare in Canada compared to other immigrant demographics *(Brown et al., 2017; Kalich et al., 2016)*. Individuals from the Philippines are one of the largest immigrant groups in Canada *(Salmani et al., 2019; Statistics Canada 2017)*, and most start their journey as temporary foreign workers *(Pratt et al., 2017)*. It is quite common for one member of the family to begin the process and establish a stable setting before bringing their immediate family members to Canada *(Kelly et al., 2011; Madianou and Miller, 2011)*. This process can take anywhere from two to five years before families can be reunited *(Kelly et al., 2011)*.

It is important to understand the overall journey and the situation regarding autism in the Philippines so that we are able to better support Filipino families here in Canada. In the Philippines, similar to China, a diagnosis of autism can lead to shame and stigma *(Lally et al., 2018)*. Due to limited government-funded programs, families must rely on private therapy, which can be another barrier to access *(Lally et al., 2018; Quinledero et al., 2015)*.

The culture in the Philippines is a blend of traditional Filipino and Spanish Catholic traditions. There are also influences from other parts of Asia and America. At its core, the Filipino culture is collectivistic, and priority is placed on conforming to social norms. Similar to Chinese culture, traditional Filipino cultural values and generational differences strongly influence current beliefs and perceptions about autism within the community. A study by Quilendrino et al., in an analysis of 41 Filipino families, found that the average age of diagnosis of autism in the Philippines is 3.9 years old. Families reported a common trend of negative perceptions, feelings of denial, and a lack of hope that their child will overcome their developmental delays. The lack of understanding of the diagnoses also affected parental views of their children, their parenting practices, confidence regarding the management of situations, and their relationships with their children. Societal pressure and general stigma about developmental disabilities in the Philippines also impacted the parental views of their children *(Paiki et al., 2016)*. This reality directly impacts immigrant Filipinos here in Canada, as some of their cultural beliefs about autism are carried over when they come to Canada *(Anzaldo, 2020; Elorza, 2019; Lairmore, 2019)*. These beliefs can add to the already existing list of barriers that they face to accessing diagnostic testing and support.

Misconceptions on the Etiology of Autism in Filipino Culture

In 2020, a study conducted by Anzaldo (*2020*) identified that Filipino immigrant families have a broad ranging set of perceptions surrounding the cause of autism. Due to the lack of clarity on the exact etiology of autism, the Filipino community holds several beliefs about autism's causality, including but not limited to the following:

1) **Environmental factors**
2) **Pharmaceutical products**
3) **Prenatal events**
4) **Genetic history**
5) **Supernatural causes**

The misconceptions can range from biological causes like genetics, to supernatural explanations like witchcraft/black magic (*kulam* in Tagalog) *(Anzaldo, 2020)*. The study also showed that the lack of understanding and the prominence of misconceptions led families to engage in a broad range of alternative treatment options, rather than standard, evidence-based treatments such as ABA. There was higher use of non-evidence-based therapies, such faith-based therapies, which use cultural practices to help with healing. Due to strong religious ties with Filipino culture, families commonly choose to see faith-healers (*manghihilot* and *albularyo* in Tagalog) to help with symptom management for their child. Lairmore (*2019*) also suggested that members of the Filipino community are more likely to access faith healers over healthcare due to mistrust of mental health practitioners.

It is also important to understand the role of parenting in Filipino culture, as there is importance placed on collectivistic virtues including the following:

1) ***Pakikisama***
2) ***Kapwa***
3) ***Hiya***

In Tagalog, *pakikisama* in the simplest term, means getting along with others, and typically refers to behaviours that maintain harmony. *Kapwa* loosely translates to a "shared identity" and the unity of "self" with "others." *Pakikisama* and *kapwa* appear to have a positive influence on families with children on the autism spectrum based on Anzaldo's study (*2020*). *Pakikisama* suggests the importance of all family members (extended family included) in assisting the child on the autism spectrum with some of their challenges, while *kapwa* promotes the inclusion of the child in social gatherings *(Leskela et al., 2022; Nadal, 2011; Paiki et al., 2016)*.

However, the term *hiya* in Filipino culture, which in the simplest terms means "shame," is considered to be the highest form of disgrace. This belief values respecting a person in authority or elders, and involves avoiding the disruption of group harmony *(Leskela et al., 2022; Nadal, 2011; Paiki et al., 2016)*. Similar to Chinese culture, the "loss of face," which refers to the sense of loss of an individual's social integrity, exacerbates feelings of shame. In the study by Anzaldo, half of the participants indicated that the feeling of shame often resulted in delayed assessments, receiving a diagnosis, and starting treatment for their children. This sense of shame was a predominant feeling when

Filipino immigrants interacted with authority figures from other cultural backgrounds, such as medical doctors *(Paiki et al, 2016)*.

When discussing their child's development and future, the participants referred to the Filipino culture of *ahala ha* meaning "to let go and let God," or, more succinctly put, to place matters in God's hands *(Anzaldo, 2020)*. This belief implies a sense of losing control to their external environment, similar to having an external locus of control, where the belief is that things that happen are out of one's control or due to external factors. Families who exhibit this kind of thinking often do not want to engage in the diagnostic process or treatment, as they consider their child's autism to be their family's fate.

The priority placed on the reunification process with family members may be another cause for families delaying intervention. Multiple studies have suggested that families focus more on rebuilding their relationships than on accessing services *(De Leon, 2009; Pratt, 2006; Pratt et al., 2017; Well et al., 2013)*.

The following cultural factors can all act as barriers to access for Filipino families:

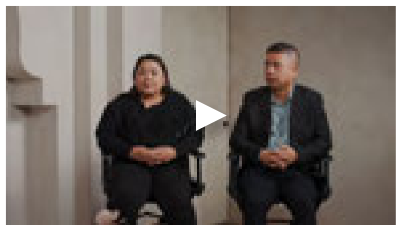
1) **Unfamiliarity with autism**
2) **Stigma around autism and mental health**
3) **Stress of the settlement process**
4) **Intergenerational trauma**

By understanding these factors, we can positively influence access to services for Filipino immigrant families with children on the autism spectrum.

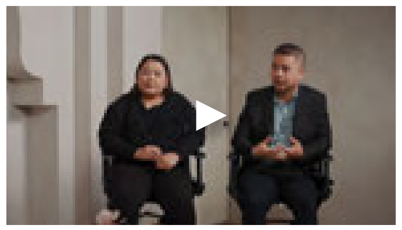
Reflection

To understand this from a parent's perspective, please review the following video clips:

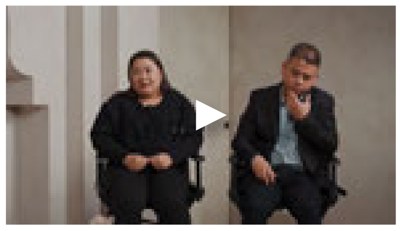
Meet the Esquierdo family



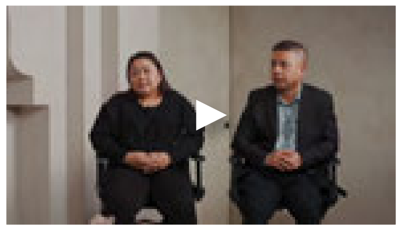
Autism Unfamiliarity



Navigating Cultural Transitions for their Autistic Son



Understanding Autism in the Philippines (PART 1)



Understanding Autism in the Philippines (PART 2)

1. What resonates with you after watching these clips in terms of professional practice?
2. What questions do you have?

SECTION 2:

What Are Caregivers Saying?

Key Themes

The community agencies recorded the families' responses to the questionnaire and returned completed questionnaires to the SAAAC project team. The project team reviewed the data and collated the themes based on keywords and phrases. Direct quotes from respondents are interwoven with the themes to highlight them in the families' own words.

Our goal was to speak with families from three main linguistic groups: Cantonese, Mandarin, and Tagalog, as they are three groups who are increasingly accessing services. Interview responses were direct, and very few families elaborated on their responses. We wonder if the lack of details in responses is due to the internal struggle these families might face when trying to balance cultural beliefs around keeping the diagnosis "in house" versus letting other families know that they are not alone.

The interviews were coded by similar themes across all three linguistic groups. For more information please refer to **Appendix 1b- Themes from Literature**

Click themes to view videos and read quotes from parents

Negative Perceptions

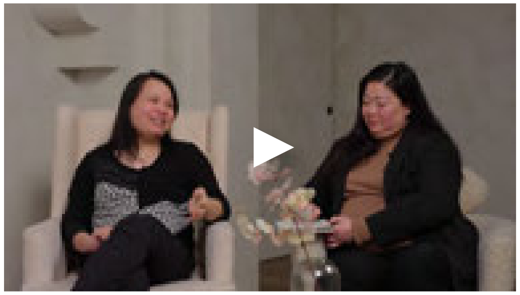
There are negative perceptions within the Chinese and Filipino communities regarding autism. These include not wanting to upset family members (especially grandparents) by sharing a diagnosis, as well as negative cultural perceptions of autism in the communities. This can lead to feelings of isolation and self-blame.

> "When I had spoken to my family back home and also [to] my Filipino cousin, they were in denial and said X is only delayed. That X will talk eventually. It was sad that autism was treated unfairly back in the Philippines. There is also a misconception about the difference [between] autism and intellectual disability in our Filipino community."
>
> – *Tagalog-speaking caregiver*

> "I told my friends and family. A lot of them were surprised that my son has autism because they thought he seemed normal. I think they didn't understand much about autism and that there are various levels of autism. My husband would not tell anyone about my son's autism, he felt shameful sharing about it."
>
> – *Cantonese-speaking caregiver*

> "No, I am afraid of others' attitudes toward these special children. I also do not make the elders in the family worry about the child so [I] did not tell others. I only shared and got the information from the parent's WeChat group."
>
> – *Cantonese-speaking caregiver*

General perceptions of autism, its impact on socialization and support groups



Na Li's Story: Autism Perception and Support in the Chinese Community

The Esquierdo Family:
Family Response to Autism Diagnosis

Family and Community

For the families in this study, family means everything, both as a source of comfort and/or discomfort. Immediate family is identified as a source of confidence among caregivers after diagnosis, and some community resources helped with next steps.

> “My daughter and my husband were very supportive to me when I was upset about the situation. They encouraged me. Family is so important in this situation.”
>
> *–Cantonese-speaking caregiver*

> “I cried and was grateful I had the support of my husband during this process.”
>
> *–Tagalog-speaking caregiver*

> “My husband was there. I was feeling anxious, fearful, [and] in shock about the screening.”
>
> *–Mandarin-speaking caregiver*

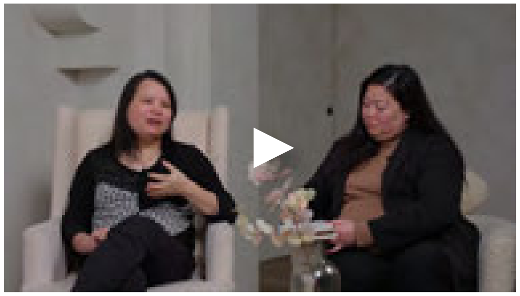
> “I told most of my family members, but not many of my friends. The social worker helped me a lot with applications to funding. I joined an online parents’ course that ran several sessions about how to take care of kids with autism; it was very helpful.”
>
> *–Cantonese-speaking caregiver*

> “Yes, I talked to his grandma as she helps take care of him. I don’t have many relatives. I don’t talk to my friends about it. Only close friends. I [have] some friends I go to if I need help, many of whom are the parents of my son’s classmates.”
>
> *–Mandarin-speaking caregiver*

> “Later on, the church had a support ministry with other parents with children with autism, and they could share their own experiences and give advice. [They] shared a lot of resources (workshops, information).”
>
> *–Mandarin-speaking caregiver*

> “I shared his diagnosis with our family back in the Philippines for support, and also because my husband and I wanted to understand our family history. We sought advice from our neighbour as well, whose child has autism. We also shared his diagnosis with the daycare staff in 2021 and school staff in 2022.”
>
> *–Tagalog-speaking caregiver*

Positive experience: Cultural background and its impact on diagnosis



Na Li’s Story: The Role of Cultural Background in Autism Diagnosis and Support

Concerns with the Assessment

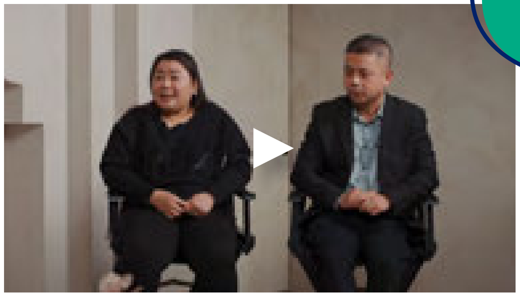
Caregivers expressed their feelings about the actual structure of and process for the assessment. A better understanding of what to expect could help to alleviate tensions for families.

> "The assessment was quite short, conducted two times and around 15 [to] 20 minutes each time. I think a longer observation of the child's behaviour would be helpful for the assessment. Besides, if the assessors have direct interaction with the child instead of observing in another room, they would have more details of the behaviours and [get] an accurate understanding of the child."
>
> —*Cantonese-speaking caregiver*

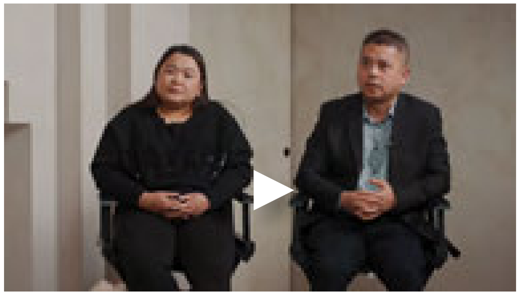
> "I would want to have seen my son during the assessment. I also want to see what the assessment criteria were. There were some situations where I feel like how my son responds to a criteria is up to interpretation. My son may respond in a different way than usual, and the assessor has a lot of power to determine what action is right and wrong. I want[ed] to see what the assessment criteria was when the assessor played with my son, to know if they assessed him fairly. I should have been able to see my son during the assessment; this part was unacceptable for me."
>
> —*Cantonese-speaking caregiver*

> "It felt uncomfortable that my son was in another room during the assessment. Especially as an immigrant, I didn't know if this was normal. It was also uncomfortable that the assessor who went with my son was quite young."
>
> —*Cantonese-speaking caregiver*

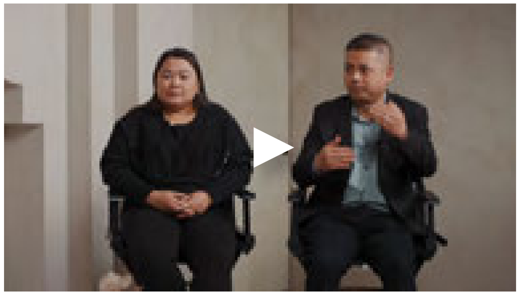
READ MORE **Appendix 3: Cultural Context for Screening and Diagnostic Tools**



Khristine and Patrick: Diagnostic Assessment Experience (PART 1)



Khristine and Patrick: Diagnostic Assessment Experience (PART 2)



The Esquierdo Family: Diagnostic Assessment and Wait Times

Suggestions from Caregivers

We asked caregivers what, in their opinion, would have made this process a better experience. The following are sentiments captured across all three cultural/linguistic groups.

Support in Understanding the Diagnosis

> "I read the report by myself and tried to understand with assistance from translation software. The report provided different related services for us. I tried to seek help from some of them but learned they only provide English-speaking services; I prefer someone who can speak Cantonese so I can understand more about my son's progress."

—Cantonese-speaking caregiver

> "No explanation of the assessment result was provided. I [could] only understand the result by searching the dictionary. It would be much better if a face-to-face discussion of the assessment result [could] be provided, also with translation for us."

—Cantonese-speaking caregiver

> "Yes, it was clearly discussed [with] us. Afterwards, we were given a package, which included a letter, information on what to do next, and a list of services they can access. However, all that information was overwhelming and it seems like the actions required moving forward was like a full time job."

—Tagalog-speaking caregiver

Translation Services

> "A translator would help a lot in facilitating my understanding of the assessment. They are encouraging and caring [and] that make me feel supported and comfortable. If some practical skills [for] handling the child's behaviour can be shared, [that] would help me a lot."

— Cantonese speaking caregiver

> "They provided the services list. If service agencies [could] communicate with parents in Chinese, it would be helpful for parents to understand their child's progress."

—Cantonese-speaking caregiver

> "[I talked] to the family doctor that I was referred to by the online parents group, [and] it was a lot more comfortable. He also spoke Cantonese and it was easier to talk to him, and I was comfortable asking any questions. I was also able to see him more regularly versus in the diagnosis, I only saw the doctor once or twice."

—Cantonese-speaking caregiver

> "I requested to have an interpreter with me for this appointment. I didn't ask any questions because I didn't know what to ask."

—Cantonese-speaking caregiver

> "I did not ask for a translator, but I knew it was available if I needed it. My husband and I were comfortable enough with English. There were some terms that I wasn't sure about, such as ASD [and] DSM5, and I had to ask to clarify and they gave me a clear answer."

—Cantonese-speaking caregiver

More Information and Resources

> "They called me. They were nice and friendly. They told me the time and place and which doctor I [would] see. They didn't tell me any further details about what [would] be done for the assessment."
>
> *—Cantonese-speaking caregiver*

> "I expected to have more community resources to help me learn more about what I [would] do for the next step. It would be helpful if there was information provided in Chinese."
>
> *—Cantonese-speaking caregiver*

> "They can provide more information on services, especially organizations closer to my home. It was challenging to go to an organization that was far away from my home."
>
> *—Cantonese-speaking caregiver*

> "Autism has a wide spectrum and different levels. I expected to receive more information after the assessment to allow me to have more readiness in taking care of my child. It would be helpful if there was information given regarding the specific level of autism that my son was diagnosed with. Because he was considered [to have] mild autism, I found it hard to receive resources including government funding and services because my son was deemed ineligible for them. I also didn't know how to find funding [so] [I] paid out of pocket for services."
>
> *—Cantonese-speaking caregiver*

> "I prefer a diagnostician to offer me more information to help me understand about autism, as well as [to] offer me more community resources that help me to know how to support my child."
>
> *—Mandarin-speaking caregiver*

Follow Up

Families indicated they were not invited for follow ups, and that this would have been welcome. Families also expressed that it would be nice to be seen after their children started receiving support, in order to measure progress and to receive validation.

> "Follow-up actions from different professionals [could] be provided, so I can seek their advice after the assessment."
>
> *—Mandarin-speaking caregiver*

> "More flexibility and easily accessible staff at the doctor's clinic for simple clarification/questions [would help]. "
>
> *—Tagalog-speaking caregiver*

> "[It would have been nice to be] offer[ed] space for me to digest information. Then I could ask questions and express my concerns."
>
> *—Mandarin-speaking caregiver*

Summary of Reflections

- Most families accepted the diagnosis as is and did not feel the need to get a second opinion.
- There were concerns about the cultural validity of the assessments. For example, a parent expressed concerns with the birthday party scenario on the assessment as their child did not have schema for this. Additionally, concern was expressed about conducting the assessment in English—what if the child did not know English? What if they were not verbal yet?

- Empathy, kindness, and not rushing were identified as essential qualities for a diagnostic assessment.
- The information felt overwhelming to many. Providing space and time to digest and process has been recommended in addition to offering resources and booking a follow-up to check in on families. Also providing culturally specific resources would be beneficial.

> “Every time I met the doctor, he usually comment[ed] that my child did not improve much after his observation and he heard my sharing. He used to recommend I increase [the intensity of my child’s] training and offered social support. I hoped the doctor could value my effort and see that my child would improve gradually.”
>
> —*Mandarin-speaking caregiver*

- Families felt comfortable in spaces where they felt represented and when they felt affinity to the diagnostician.

> “It would be better if there were some [efforts made] to reduce the language barrier.“
>
> —Mandarin-speaking caregiver

> “I felt more comfortable meeting with physicians who [spoke] with me in my first language. I consulted another Chinese pediatrician afterward. I felt Chinese pediatrician understood my child’s needs and concerns.”
>
> —Mandarin-speaking caregiver.

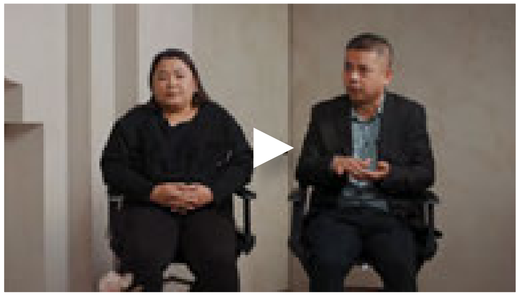
> “There was a Mandarin family where the doctor spoke Cantonese and English but not Mandarin. They felt having a Mandarin-speaking [healthcare worker] would have made it easier.”
>
> —Interviewer’s reflection

- Families expressed a greater sense of comfort when the office was designed as a play place rather than a clinical setting.

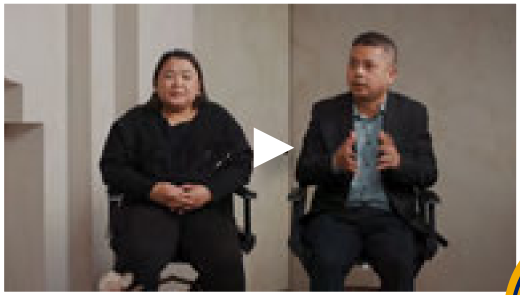
> “I was with a doctor in a room. It was a children-oriented place, so it made me relaxed.”
>
> —Mandarin-speaking caregiver.

- Caregivers would appreciate a better understanding of next steps—what happens after the assessment? What does it mean for their child in a broader context to be autistic? What are the implications of the diagnosis, how it [would] impact school, life, and their future.

Understanding the Filipino Experience Further: A Parent Perspective



The Esquierdo Family: Perception of Autism in the Filipino Community



The Impact of Limited Resources on Child Diagnosis in the Philippines

Next Steps for Diagnosticians

READ MORE: **Appendix 2: Recommendations**.

Click each recommendation below to read more in the appendix.

Cantonese- and Mandarin-Speaking Caregivers

1. Using a caregiver's own religious beliefs, help reframe some of those beliefs to nurture a sense of resilience, tolerance, and self-acceptance in caregivers. »
2. Ask more open-ended and probing questions to gain more information during the visit. »
3. Be aware of different cultural meanings to words. »
4. Suggest support groups and connection with other families. »
5. Offer parent education and parent training. »
6. Communicate with extended family, such as grandparents. »
7. Help with coping strategies. »

Tagalog-Speaking Caregivers

1. Engage in intrapersonal reflection. »
2. Learn more about the Filipino community's cultural identity. »
3. Cultural definitions of words may vary. »
4. Tailor your approach. »
5. Provide genuine collaboration and reframing. »
6. Acknowledge that there are social issues. »
7. Using the concept of kapwa to promote connectedness. »
8. Facilitate further awareness within the community. »
9. Consider the importance of cultural liaisons. »
10. Promote community connectedness. »

Dr. Catherine Yu: Championing Autism Support in Diverse and Under-Resourced Communities

Video Chapters

1) Intro (00:00)
2) Role within the Autism Community (00:32)
3) Thoughts on current diagnostic pathways (01:29)
4) Gaps in current diagnostic pathways (03:15)
5) What does an ideal diagnostic pathway look like? (05:41)
6) Family physicians enhancing diagnostic pathway accessibility (08:09)
7) Personal experience as a caregiver (10:27)
8) Common challenges faced by caregivers in getting a diagnosis (11:51)
9) Demographic of the community served by Dr. Catherine Yu (14:35)
10) How does culture affect the pathway to diagnosis? (15:34)
11) Autism diagnosis and East Asian families (16:04)
12) Families lost to follow-up (17:37)
13) What can be done by diagnostic hubs to retain families? (19:41)
14) Strategies to support Mandarin, Cantonese, Tagalog speaking families (20:47)
15) Tools available to family physicians for developmental screening (23:31)
16) What should diagnostic hubs learn from experiences of diverse and under-resourced communities (25:29)
17) Advice to family physicians to better support families who have children on the autism spectrum (27:00)
18) How can diagnostic hubs and primary care teams work together? (28:18)
19) How can diagnostic hubs engage better with families? (30:08)
20) How can diagnostic hubs better support diverse and under-resourced communities (32:21)
21) Importance of community liaisons in the diagnostic process (34:41)

SECTION 3:

Reflections

Reflection Exercise: Case Studies

READ MORE: **Appendix 4: Strategies for Case Studies**

Case Study 1: Tagalog-Speaking Family

Anne-Marie has been referred to you by her family physician for concerns around her daughter Abigail's speech. In the referral note, the physician mentions that the initial concerns were brought up by daycare staff who had noted that Abigail was not very talkative.

Anne-Marie mentions that Abigail has been going to the same daycare for years, and that her older daughter also went there. However, for the past two years, Abigail only had access to virtual programming due to the pandemic. Abigail is two years old, and Anne-Marie is worried about the daycare's concerns.

You notice that she is very nervous and seems hesitant. Your secretary mentioned that Anne-Marie had rescheduled this appointment three separate times over the past two months. She asks if the daycare staff will be joining as well, and you confirm that they will not be joining but that her family doctor mentioned their concerns in the referral letter.

After a brief introduction, you begin asking her questions about the family's personal history and Abigail's developmental history. Anne-Marie mentions that she really has no concerns about Abigail and believes she is just shy. You decide to probe further and ask her about what Abigail's father feels. Anne-Marie mentions that her husband is still in the Philippines and has not seen Abigail for two years now.

As you further assess Abigail, you notice gross motor and fine motor delays. You also note that she hand-flaps when she is excited. She is also mouthing many of her toys. There are clear signs of ASD in Abigail. You ask Anne-Marie if she has had any concerns about Abigail and she tells you that she finds Abigail "naughty" and is "stubborn." But she also mentions that she is not worried as her older daughter was naughty and did not listen at Abigail's age. Anne-Marie mentions that she is not concerned as "it's in God's hands," and she is confident that Abigail will get better.

You complete the history-taking and your assessment. You review some of your findings with Anne-Marie, but you mention to her that there will need to be a follow-up to discuss this further after you have had a chance to review everything in more detail. She understands and asks you, "Is everything okay with her doctor?" You decide to briefly touch on Abigail's strengths and deficits, but you emphasize the importance of early intervention and its impact. You ask Anne-Marie if she has any questions and if she understands. She politely responds yes, and you move to book her in for a follow-up visit. You also remind her of the office's no-show fee and ask her, "I notice you had to reschedule quite a few times. Is everything okay?" She responds, "Sorry, doctor. Yes, everything is okay. Sorry for the trouble."

Anne-Marie and Abigail fail to show up for her follow-up appointment. Your secretary reaches out to the family and receives no response.

Reflection Questions

1. Was there anything you would have done differently in the way Anne-Marie was approached?
2. How would you reframe the discussion around your concerns about Abigail?
3. Were there any potential barriers at play in Anne-Marie's situation?
4. What are the possible reasons for why Anne-Marie did not attend the follow-up appointment?
5. What would you have done differently?
6. Are there any other approaches a diagnostician could use to possibly make the assessment and environment more inclusive and welcoming?
7. Do you think there was anything more to Anne-Marie rescheduling? Was that a sign of hesitancy or do you think there are other priorities in her life right now?

Case Study 2: Mandarin-Speaking Family

Mei Lin and her son Yuze were referred to you by Yuze's pediatrician, who suspects that the child may be on the autism spectrum, referencing poor eye contact and limited communication. In the referral letter, the pediatrician was kind enough to indicate that Mei Lin will need a translator.

On the day of the visit, you arrange for a phone translation service. Mei Lin arrives with her husband Jin, as well as Yuze's grandparents. You greet the family in the waiting room and take Mei Lin, Jin, and Yuze into the examination room. You advise the grandparents that they can wait there or grab a coffee, as the visit will take a bit over an hour.

During the examination, you note that both Jin and Mei Lin's information about their son's behaviour at home is limited. You notice that their son does not follow simple instructions, and you are having difficulty getting him to sit down on the floor to play with some of the toys. You also notice that he is avoiding your gaze. Yuze appears to be very attached to his parents and it is difficult to get him to interact with you. After the first 30 minutes of the assessment, which has yielded very little interaction, you decide to talk to the parents a bit more to see if they can provide any additional information. As you are speaking to Jin, you notice Mei Lin saying something in Mandarin to Yuze. Yuze quickly starts picking up the toys and putting them away. He even looks at his mother, says something in Mandarin and awaits her response. You are surprised, as this does not match with what you have observed so far. You decide that you will bring Yuze in again in a couple of weeks to reassess him.

Jin seems flustered after you tell him about your decision. He wants to know why but as you try to explain your concerns about his son's development, he appears more confused. Jin lets you know that he will call and book the follow-up as he has to check with his employer about taking time off to come for the appointment. Jin and family do not call back to book an appointment.

Reflection Questions

1. What could be the reasons for Yuze's family not booking a follow-up?
2. Could you have done anything differently?
3. Do you think having a translator would have made the visit better?
4. What specific concerns come to mind about the child's development?
5. What concerns do you hear from the caregivers about the child's development?
6. Are the parents the only ones involved in the child's care? What about the grandparents and extended family?
7. Is the child's lack of eye contact or avoiding mutual eye gaze due to a developmental delay or could it be a cultural norm?
8. Is there another way to assess eye contact?
9. Do the parents also avoid eye contact?
10. Could there be a reason for why the child does not want to play on the floor? Are the parents hesitant to let the child play on the floor?
11. What are some potential reasons that the child was unable to follow directions from you but appeared to follow directions from the mother?
12. How could you paraphrase your language while explaining concerns?
13. Is there any information a doctor could gather from the community health worker to better assess the child?

Case Study 3: Cantonese-Speaking Family

Liu arrives with his son Yichen. Yichen is five years old. Yichen was referred by his family doctor due to concerns around speech, behaviour, and poor social interaction. You begin the assessment by welcoming Liu and Yichen, and asking how the day has gone so far. You tell him what will be happening today, as well as how the next few visits will go. You offer to have a translator present, but Liu says they do not need one.

The family doctor's referral indicates that Yichen's school teacher also had concerns around his social skills. He does not engage with other children. The teacher also mentioned that when Yichen gets frustrated, he sometimes bangs his head. You discuss this with Liu, and he admits that Yichen does bang his head at school, but he does not do it at home. He believes that Yichen is copying other children at school. Liu seems more anxious as you mention details of what the teachers have observed. He states that he does not observe the same behaviour at home. Liu mentions that it has only been a few months since Yichen started at his new school and he is still adjusting. He believes that the teachers should give Yichen more time and be patient. You mention to Liu that the teachers are probably looking out for the best interest of Yichen and that, by identifying any struggles he has now, they can put the right supports in place.

Liu responds that Yichen is a "smart boy," and he just needs some discipline to help focus. You decide to continue with the assessment and bring out the "birthday/tea party" scenario. Yichen seems very confused at the activity and does not interact or follow along well. Liu notices this and mentions that this particular example was not a fair assessment of Yichen. You discuss with Liu that that is not completely accurate. You explain what the assessment was looking for, and that Yichen has signs and symptoms suggestive of autism. Liu appears shocked and confused when you mention the word autism. You ask him if he has heard of autism. He shakes his head but asks if it will affect his son's ability to attend school. You mention that there is likely a high chance that his son will always require support and he may not be able to attend post-secondary studies. You give him some information about resources and book a follow-up appointment in two weeks to discuss the results in more detail. Liu and Yichen do not show up for their follow-up appointment.

Reflection Questions

1. What factors could be influencing Liu's feelings towards the educational system?
2. Do cultural influences play a role on how he may be viewing academics in his child's life?
3. Do you believe the "birthday/tea party" scenario was a good assessment tool in Yichen's case?
   i) If not, would there be other options or scenarios that could be used?
   ii) If you are unaware of those scenarios, how can you find out about other ones?
4. Was there another way to discuss Liu's concern about the birthday party scenario rather than just telling him his view was incorrect?
5. Are there any resources that you could provide Liu?
6. Was it useful to mention autism at this visit? Why or why not?Could it have been held off until the next visit?
7. What are the repercussions of delaying the discussion of autism specifically until the next visit?
8. What may Liu be feeling at the end of the appointment?
9. Why do you think Liu and Yichen did not show up for the follow-up appointment?
10. Were Liu's feelings and concerns validated in this visit?If yes, how so and if no, why not?

Reflection Exercise: What Might You Say?

PLEASE READ: **Why Can't We Talk About Autism in the Asian-American Community?**

Reflect on the following quote from the article:

> "I strongly believe we can make inroads in the autism community if we are able to let go of that closed-off mentality that plagues our culture. Instead, we push everybody away; we put up walls because we are afraid that we would be a disappointment."
>
> – *Sunny Jang, parent*

As a diagnostician, you may encounter families who have deeply held beliefs (at times, misconceptions) about autism that are shaped by culture. The more we understand who our caregivers are, the better we are able to reframe these beliefs and provide accurate information and hope. Here are some common beliefs/statements you may encounter. Consider the cultural competency framework. What might you say in response to the following scenarios?

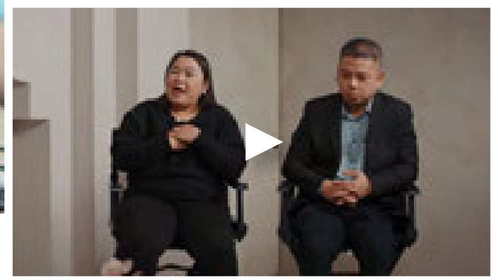
STATEMENTS **Here are some common statements heard from family and caregivers on the autism diagnostic path.**	**REFRAMING** **How could you approach these statements as a diagnostician?**
“He doesn’t look autistic, so he can’t be.”	Try to better understand what the caregiver means by this, and what they believe are physical traits or signs of autism. Their response will provide context for their preconceptions of autism, including where they originated. Explain what autism is and that it is not based on appearances. Explain the concept of it being a “spectrum.” Ask about what they already know about autism and provide additional information to better explain what autism is. This will help families to reframe their perspective of autism.
“I thought his speech delay was because we spoke both Tagalog and English at home.”	Clarify the misconceptions and explain what autism is. Clarify that it is not rooted in speaking two languages at home. Help families find resources that they can rely on to better understand the diagnosis and be more informed.
“Why are you talking about it? We should be embarrassed!” *—one spouse to another during an assessment*	Normalize the process, and validate that it is okay to feel different emotions. Probe further to understand why one of the spouses may be feeling a certain way. Explain to the caregivers what confidentiality is and how it applies in this setting. Also explain to them that seeking answers is the first step to helping their child.
“Is it my fault? It is because I was not strict enough with my child, right? Was it because I did…”	Probe further to see why they may feel like it is their fault. There may be cultural factors at play. Clearly explain that it is not their fault and that they did nothing to cause their child’s autism. Help reframe their “guilt” to motivate them to learn more about autism and its etiology—specifically that it is multifactorial.
“Thank you, but I will leave it in God’s hands. As we say in the Philippines, ‘Let go and let God.’”	Acknowledge how and why they might believe this statement to be true. Recognize that they may not want intervention at this point, and explain how the treatment can help. It may be useful to use their religious beliefs to build on the sense of hope and trust they have in God. That hope may help motivate them to get their child into treatment earlier.
“When I went to a CARES session, I noticed that I was the only Asian parent. I thought it was odd, and I felt alone.”	Acknowledge their feelings. Share information there are support programs available that are comprised of parents from other cultures with whom they might connect or have more shared experiences.

Reference: Jang, S. (2021, June 21). “Why Can’t We Talk About Autism in the Asian-American Community?” *Autism Parenting Magazine*. Retrieved February 4, 2023, from https://www.Autismparentingmagazine.com/Autism-asian-american-community/

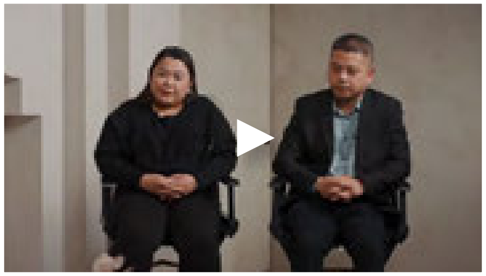
Closing Thoughts

READ MORE: **The Emotional Journey Post-Diagnosis**

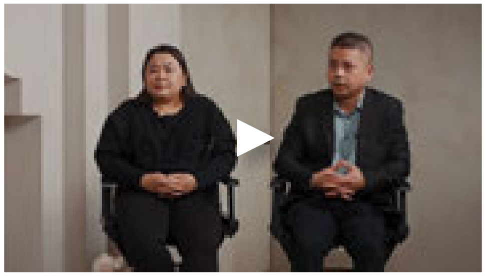
Navigating Autism:
Empowering Chinese Families with Cherish Integrated Services



Diverse Reactions: Parents Navigate an Autism Diagnosis

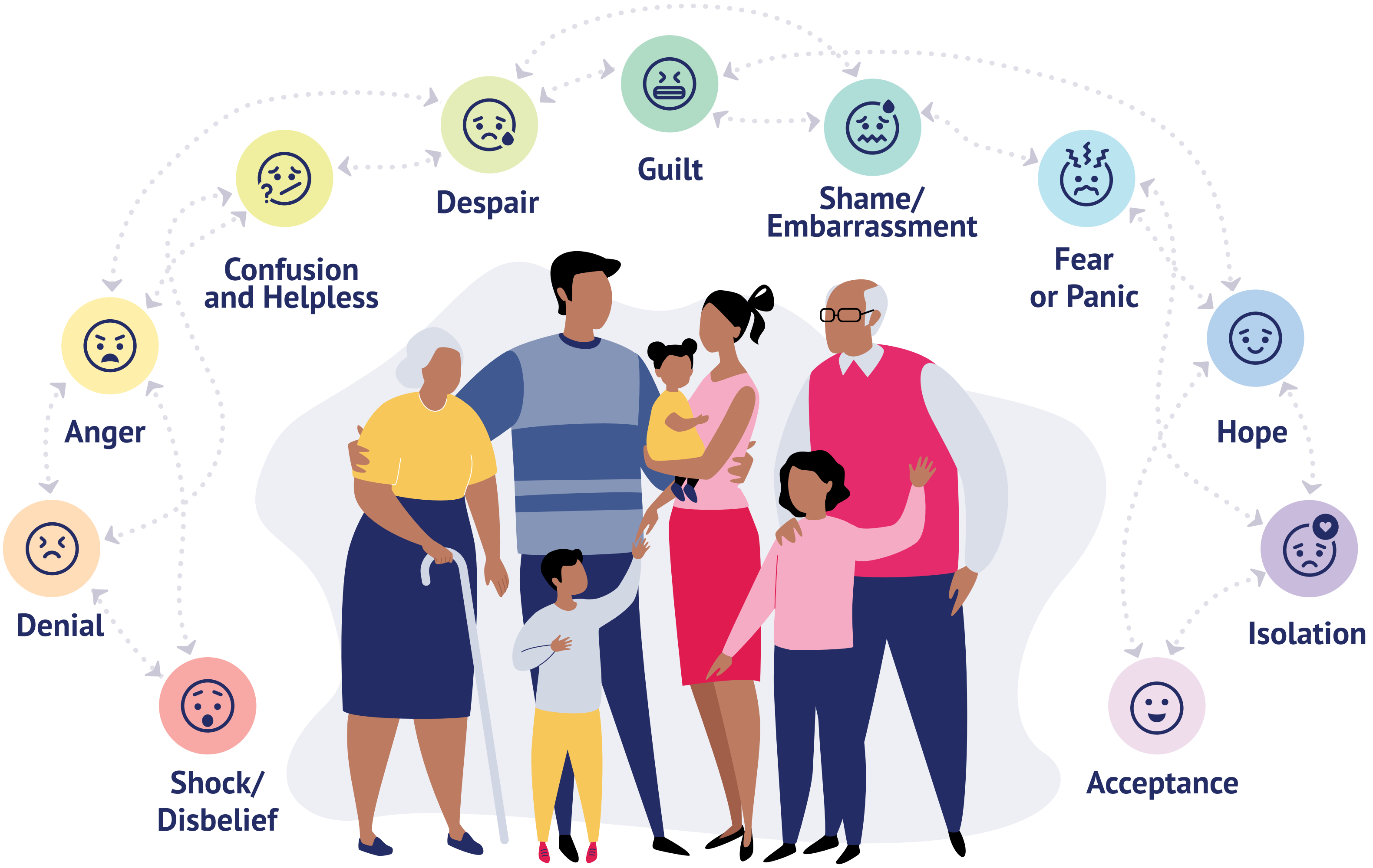


The Esquierdo Family: A Caregiver Reaction to an Autism Diagnosis (PART 1)



The Esquierdo Family: A Caregiver Reaction to an Autism Diagnosis (PART 2)

The Emotional Journey Post-Diagnosis



Shock/ Disbelief

Denial

Anger

Confusion and Helpless

Despair

Guilt

Shame/ Embarrassment

Fear or Panic

Hope

Isolation

Acceptance

Appendices

Appendix 1a:
Autism and Chinese and Filipino Cultures

Adjustment of Expectations

When parents receive a diagnosis that their child has autism, a part of their journey, in terms of coping with and learning about the diagnosis, is thinking about the future *(Wang & Casillas, 2013)*. Parents often have to adjust their expectations. Mandarin-speaking immigrant parents specifically often have hopes and dreams of their child achieving success, such as attaining higher education in their new country. After receiving a diagnosis of autism, these parents often have to adjust their expectations. For example, they have to start thinking about whether their child can grow up to become independent, to make friends, and to have social relationships *(Wang & Casillas, 2013)*.

Filial Piety

In East Asian cultures, there is often an expectation of filial piety where parents care for their child in the hopes that their child would then care for them during old age in return. When parents learn that their child has autism, they have to accept that this traditional reciprocity will not be an option for their autistic child. Instead, parents learn to be optimistic that their child will develop life skills and demonstrate progress in programs and treatments *(Su, Khanlou, & Mustafa, 2021)*.

Immigration Status

Immigrant families may experience language and communication barriers as they learn how to navigate various healthcare services and programs.
It is also important for healthcare professionals to consider how to communicate with immigrant families, as there may be differences with direct and non-direct interactions, as well as non-verbal mannerisms, which could affect the clarity and accuracy of messages shared during the interactions *(Welterlin & LaRue, 2007)*. Healthcare professionals should also take into consideration the immigration status, which could affect the eligibility criteria of families looking to access services *(Welterlin & LaRue, 2007)*.
A safe and open conversation between healthcare professionals and families can help families to be more comfortable with learning about the services that are available to them.

Appendix 1b:

Themes from Literature for Mandarin- and Cantonese-Speaking Families

1) Filial Piety

a. Parents came to this country looking for the Canadian dream:
   i. That dream includes being financially successful and providing better opportunities for their children.
   ii. The belief is that, when a child receives an autism diagnosis, those dreams are shattered, and that the child will not be able to get married or carry on the lineage.

b. Parents have to adjust their expectations that a child on the autism spectrum will be able to care for them as they get older.

2) Model Minority and Maintaining Privacy

a. There is a prevailing belief in working hard, keeping your head down, and not challenging the status quo.

b. Many people in this community avoid placing burdens on others.

c. Problems are dealt with “in-house,” without sharing outside the family.

d. There is an idea that you should focus on your own problems.

e. Many families rely on each other rather than external services.

3) Shame

a. It is believed that one must suffer in silence, for it is disgraceful to be open about challenges in public.

b. You must keep the diagnosis private, as it will bring shame to the family if disclosed.

c. There is a belief that parenting is to blame for the child’s challenges, and that the child’s behaviour is a direct reflection of the parents.

d. There is a belief that an autism diagnosis is the result of past sins in previous generations.

4) Emphasis on Success

a. Success is measured both in terms of family lineage and academic success.

b. The success of a child is often defined by academics.

c. There is a belief that a child must go to college.

d. There is a belief that a child must get married.

5) Religious Beliefs

a. In Taoism, the message is to “leave it be” in order to let problems work themselves out.

b. In Confucianism, men are prioritized over women, which means girls are less likely to be assessed or taken for treatment.

6) Limited Understanding of ASD

a. Misconceptions on the cause of ASD lead to the belief in other causes, such as poor parenting, supernatural causes, and sins from the past.

b. Many feel that autism could resolve on its own with time. This leads to parents being more likely to wait before getting assessed.

c. Faith-based healing is believed to be able to help with supernatural causes of ASD.

Themes from Filipino Families

1) Shame (or *hiya*)

a. There is a cultural expectation that we must suffer in silence; it is disgraceful to be open about challenges in public.

b. One must keep family struggles and challenges confined to the four walls of the house.

c. *Nahihiya* (or shame) prevents families from support, instead choosing to rely on each other.

2) Limited Understanding of ASD

a. There is a limited awareness within the community.

b. An increase in community agencies that focus on Filipino families with children on the autism spectrum would be beneficial.

c. There is a lack of representation with the general Filipino community and Filipino immigrant families with children on the autism spectrum *(Anzaldo, 2020; Lairmore, 2019; Dhanji 2018; Elorza, 2019)*.

d. Autism is not often found in Philippines-based literature *(Lally et al., 2018; Quinledero et al., 2015; Lucerno, 2017)*.

e. There are many misconceptions about the cause of ASD, including the belief that ASD is not lifelong and may resolve on its own with time.

3) Religious Beliefs

a. *Bahala na* is a prevailing idea, translating to leaving it in God's hands.

b. There is a belief that faith-based healing can help.

4) Mistrust in Healthcare System

a. Members of this community are more likely to go to faith-based healers than healthcare professionals.

5) Lack of Community Upon Arriving in Canada

a. Going from a collectivistic to individualistic environment can be traumatizing for families that have recently arrived.

b. Families having this experience are less likely to access diagnostic assessments and treatment.

6) Shared Identity (*kapwa*)

a. Community is prioritized over individual needs.

7) Privacy

a. Problems are dealt with at home.

b. It is not acceptable to burden others.

c. There is a belief that you should focus on your own problems.

d. Families believe that their issues should not distract others.

e. Many families prefer to rely on each other, rather than to reach out to external services.

The Esquierdo Family: Impact of Autism Diagnosis on Relationships

Appendix 2: Recommendations

Recommendations for Cantonese- and Mandarin-Speaking Families

As discussed in our previous toolkit (available here), cultural competency is a fundamental requirement for working with individuals of diverse backgrounds. Its foundation lies in developing respectful responses when supporting people of all cultures, languages, classes, genders, and race. It aims to protect and preserve their dignity *(Sue, 2017; Sue et al., 1992)*.

Here are some important approaches to consider:

1) Using a caregiver's own religious values, help reframe some of those beliefs to nurture a sense of resilience, tolerance, and self-acceptance in caregivers.

2) Ask more open-ended and probing questions to gain more information during the visit.

a. Examples:
   i. When asking about extended family, instead of, "Do you live with anyone else?" you can ask, "Who else lives with you?"
   ii. When asking about diet, instead of, "Is your child a picky eater?" focus on, "What foods does your child like/not like to eat?"

3) Be aware of different cultural meanings for words.

a. E.g., "Playing or play" in Chinese culture can have more of a negative connotation and mean "naughty or misbehaving."

4) Be prepared with suggestions for support groups and connecting with other families.

a. Have support groups available for patient familiespost-diagnosis.
b. Connection to community is essential.
   i. Help with networking and making friends.

5) Parent education can be an important tool.

a. Review what autism is and the causes of it.
b. Remind families that autism is lifelong and not curable.
c. Remind parents that they are not the cause of their child's autism, and that it is not related to their past sins.
d. Discuss the etiology of ASD.

Autism Support in the Chinese Community: A Panel Discussion

6) Have options for parent training at the ready.

a. Parents often want to be provided support at home.
b. Home-based therapy is likely more useful.
c. Engage with grandparents, who may be contributing to care.

7) Communicate with extended family/grandparents.

a. Have these family members present during assessments if the parents agree to it.
b. Extended families can often provide more insight and collateral information.

8) Provide coping strategies.

a. Planning as a coping strategy may be more effective than other strategies.
b. Acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and the aforementioned planning were the most frequently employed coping strategies.

Recommendations for Filipino/Tagalog-Speaking Families

There are a number of factors that impact a Filipino family's ability to access a diagnostic assessment and treatment for their child on the autism spectrum. Understanding the dynamic intersectionality between environmental, experiential, and cultural factors is key in improving retention in the diagnostic pathway. This will also improve service engagement and utilization for Filipino families in Ontario. Not only do culturally responsive practices and cultural humility create a welcoming environment, but they also nurture trust and improve the therapeutic alliance. These positive effects further improve overall satisfaction for these families. By not understanding the cultural beliefs that may be surrounding a Filipino's understanding of developmental delays and autism, it will likely lead to poor adherence to the recommended treatment options as well as potential negative health outcomes for the child.

1) Engage in intrapersonal reflection.

a. A good self-exercise is to ask yourself the following:
    i. "What systems affect my life?"
    ii. "How do these systems influence how I process and filter incoming information?"
    iii. "How do these systems affect my interaction with myself?"

By doing so, one can gain a better understanding of one's own inner biases.

2) Learn more about the Filipino community's cultural identity.

a. This will help you to better understand how the Filipino community's own identity is formed by experiences and acquired beliefs.
b. You will better understand how community impacts how Filipino families receive, filter, and interpret information *(Dennison et al., 2019; Fisher-Borne et al., 2015)*.

3) Cultural definitions of words may vary.

a. Understand that there may be a difference between cultural definitions of words.
    i. For example, Filipino families may describe behaviours associated with autism symptoms as "abnormal" and "normal" *(Alzaldo, 2020; Elorza, 2019)*.
    ii. In Canada, these terms may be considered inappropriate language in the context of describing a child, but these words may reveal cultural differences in language *(Dennison et al., 2019; El-Lahib, 2015; Espinosa et al., 2018; Fong et al., 2016)*.
    iii. Without cultural context, diagnosticians and therapists may interpret the use of certain words as a sign that the family is experiencing significant cultural stigma around autism. Knowing that "normal" and "abnormal" are common descriptions used in Tagalog is important. The Filipino community commonly uses "normal" for verbal and socializing children, and "abnormal" for non-verbal children.

By taking another approach and understanding that there may be cultural differences in these words, diagnosticians and therapists can further explore and hopefully gain a more descriptive assessment of the child.

4) Approach is key.

a. Diagnosticians and therapists must be cautious in the way concepts are clarified with families. Simply correcting families and telling them that their beliefs are "incorrect or wrong" promotes a hierarchy in the therapeutic alliance. Mimicking, mirroring, and clarification of terms is a better method, giving families the impression that intentions of the diagnostician or therapist are to understand the family's perspective.

5) Foster genuine collaboration through reframing.

a. The foundation of this strategy is understanding and accepting that parents are the experts in their own lives. By approaching families with this perspective in mind, it may reveal unseen protective factors, including extended family members. This approach also helps healthcare providers to better understand all the factors that influence a family's decision-making system (e.g., religious factors). By understanding all of these factors, the doctor or therapist can possibly reframe them so they can help families come to terms with the diagnoses and start therapy.

   i. *Bahala na* (leaving it up to God) was discussed above. With limited understanding, a diagnostician or therapist may view this as a belief that may negatively impact the family accessing support. However, by reframing this concept of "leaving it up to God" and understanding that this same belief can also be related to hope (or *pag-asa*), a diagnostician or therapist can help families come to terms with the diagnosis. This will give families hope for their children's development and future, which is an essential coping strategy to ensure that there is a continued investment in their child's development. By acknowledging and integrating internal protective factors. It helps to build trust with families.

   ii. Another example is around remittance culture. For many Filipino families who have recently arrived in Canada, they continue to support their family members back home. However, when first hearing this, many diagnosticians or therapists may automatically feel that this type of support places an unnecessary financial burden on the family. However, with a deeper understanding of Filipino culture, one would see the importance of kapwa, or a sense of belonging to these families. By understanding the deeper meaning and value of remittance culture in a family's life, the diagnostician or therapist may now be able to identify the family's support network.

6) Acknowledge the social issues.

a. Several social issues impact the Filipino community, and they cannot be excluded when assessing a child for ASD.

b. Understanding how families cope with stress, any lingering emotions from the reunification process, how both impact family dynamics, and the negative impact of experiences of prejudice and discrimination all play roles.

c. These factors can negatively impact the individual's perspective on themselves, their children, and their family, resulting in delays in accessing diagnostic assessments and treatment options.

d. By acknowledging these social issues and identifying protective factors, a diagnostician or therapist can help empower families. This improves service utilization and engagement within the Filipino community.

7) Encouraging connectedness and using the concept of kapwa:

a. By incorporating the concept of *kapwa* when providing a diagnosis, healthcare providers decrease the stress that families feel. Connecting Filipino families with others (e.g., support systems) helps them to re-recognize the healing power of connection with others—a trait inherent to *kapwa*. This also helps the family to feel empowered and to build a stronger support network.

8) Improve awareness within the community.

a. Awareness campaigns are essential to discussing the etiology of ASD and the benefits of early identification.

b. Awareness campaigns need to address the various cultural beliefs held by the Filipino families and discuss them through the lens of cultural humility.

c. Discussion also needs to involve recognizing signs and symptoms of ASD, how to seek help, how ASD is diagnosed, what treatment looks like, and what ASD looks like throughout a lifespan.

9) Seek earlier access to cultural liaisons.

a. Cultural liaisons are essential, as they support families and work to make treatments and other services accessible. However, in many cases, cultural liaisons only get involved with families when community members report a risk to a family's well-being. Introduction to cultural brokers right after assessment is crucial.

10) Help families to build or connect with the community.

a. Moving from a collectivistic environment to a more individualistic one can be traumatizing for first-generation Filipino Canadians. This can lead to isolation and a sense of alienation. Connecting them to other families and helping Filipinos to build a network of support can significantly improve acceptance of the diagnosis and adherence to treatment plans.

Cultural humility strategies discussed above incorporate self-reflection, continuous learning through collaboration with cultural liaisons, and the integration of advocacy to develop a culturally competent practice. This not only improves overall satisfaction of families through the diagnostic pathway, but it also builds a sense of trust and creates a welcoming and accepting environment that respects a family's cultural identity and life experiences.

Appendix 3: Cultural Context For Screening And Diagnostic Tools

The birth of a child is a life-changing event. From the minute they are born, expectations are placed on the child's temperament and development based on the family's wishes and their own past experiences. However, when a child faces challenges and is noted to have delays in speech development, abnormal repetitive behaviours, or difficulties with social interaction, this can be life-changing for the family.

Screening Tools

Currently in China, several screening tools are used, including the following:

1) Autism Behaviour Checklist (ABC)
2) Autism Spectrum Screening Questionnaire (ASSQ)
3) Social Communication Questionnaire (SCQ)
4) Chinese/Clancy Autism Behavior Scale (CABS)
5) Modified Chinese Autism Spectrum Rating Scales (MC-ASRS) in screening for ASD in Chinese children aged six to 12 years.
6) Mandarin version of Childhood Autism Spectrum Test
    a. The Mandarin CAST demonstrated a better validity in distinguishing children with ASD from children without ASD *(Sun et al., 2014)*.

Diagnostic Tools

For diagnostic assessment, the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview–Revised (ADI-R) are commonly used in mainland China *(Sun et al., 2014)* and the Philippines. However, both the screening tools and diagnostic tools are not as culturally responsive as was once believed. This means diagnostic assessments may vary across cultures. This is even more complex as different diagnostic instruments and standards may differ in different cultures. The concern is that when screening tools or assessment tools are not culturally appropriate, they can produce misleading results *(Musquash and Bova, 2007)*. These negative results can sometimes have unforeseen consequences, such as families being lost in follow-up, or children being misdiagnosed or falsely diagnosed.

Prior to screening or assessments, it is important for diagnosticians and therapists to let families know that assessment of their child is a collaborative effort and that, although they may feel that the diagnostician is the expert, the family is the expert on their child. In Chinese and Filipino cultures, a commonly held belief is that doctors and therapists know more about child development, and it is their responsibility to "evaluate" their child.

In the Filipino culture, there is a sense of mistrust with the medical system, so families may be suspicious of screening and assessment; that is why going out of your way to reassure families prior to the screening can be very useful. They may believe that if their child is labelled, they will be excluded from school- or other community-based programs. It is also important to remember that in Filipino and Chinese cultures, independence is encouraged later than in Western cultures. Also, there is a great importance placed on children being quiet and modest.

Early Signs of ASD

Consider the early signs of ASD and how cultural differences might impact a family's perception of their child. During the completion of developmental checklists and history taking, diagnosticians and therapists commonly ask questions about speech or communication delays. On the other hand, due to cultural differences, some of the early signs of ASD, such as delayed speech and lining up toys or other objects, can be interpreted as "being quiet" or "being tidy," which are characteristics highly valued by Chinese and Filipino parents. Does the current standard of milestone checklists suit Chinese and Filipino children? How do we help these parents spot early signs of autism? How do we raise awareness of autism in the Chinese and Filipino Community, break down the stigmas, and make sure that families get enough support?

Use of Utensils and Scissors

Most screeners and diagnostic assessments will ask if a child uses utensils, like forks or spoons. This can be confusing for families who teach their children to use their hands or to use chopsticks. In Chinese culture, where chopsticks are introduced at an early age, the initial question may elicit a "no" response, which may be interpreted by the diagnostician as a flag around motor skills. Also, it is important to note that mastering the use of chopsticks requires more advanced fine motor and cognitive skills, which can take longer to master in comparison to the use of a spoon or fork. In addition, it is quite common for Filipino and Chinese families to feed their child and may not encourage children to feed themselves until they are older.

Another cultural difference is the use of scissors. In both Filipino and Chinese culture, the introduction of scissors is done at an older age, primarily for safety reasons. So, families may be uncomfortable when the diagnostician/therapist asks their child to use scissors to complete a task.

Reflections

In many Western cultures, children commonly play with their own reflection. However, there is a belief in certain cultures that mirrors can steal a person's soul or spirit. In Filipino culture, if there is a death in the family, there is a belief that the dead may try to show themselves in mirrors. During that time, it is recommended that mirrors are covered, and that people should avoid looking at their reflections. This is good to keep in mind if the diagnostician observes hesitancy when parents are asked to allow their child to look in a mirror. In Chinese culture, there are important guidelines for where mirrors are placed. This relates to principles of feng shui and the flow of qi.

Floor Play

In Chinese culture, children and toddlers are typically not placed on the floor to play. Using tables or floor mats for assessments can help to alleviate some of the parents' concerns.

Eye contact is a commonly listed red flag for ASD and is found in numerous developmental screening tools. It is considered a form of impaired non-verbal behaviour as criteria for the diagnosis of ASD. However, in both Filipino and Chinese cultures, direct eye contact with authorities or doctors is considered to be a sign of disrespect *(Lian, 1996; Sue, 2008)*. Research has shown that this "gaze avoidance" is a sociocultural norm in many East Asian cultures.

Reciprocal Social Interaction

How a child interacts socially is another example of how culture can impact behaviour. One of the core problems of ASD is in reciprocal social interaction, but there are differences in cultural beliefs about appropriate social behaviour. In Chinese and Filipino cultures, there is more focus on family interactions than interacting with strangers or playing with toys. This may lead to a child seeming "shy" and hesitant to interact with the diagnostician or therapist—not because they have ASD, but because, culturally, it is foreign to them.

Birthday Party Activity in the ADOS

The birthday party activity is a common tool used in the ADOS, but, in Chinese culture, birthdays are only reserved for infants and the elderly. This means that the birthday party concept may be foreign to children, and they may not react appropriately.

Terminology for ASD

In addition, some Asian languages do not have a word for ASD, or they may employ a term that does not accurately reflect what is known about the disorder at present. The current word for autism in Chinese is *zi bi zheng*, meaning self-enclosure disorder. Within a collectivistic culture, this can have significant negative connotations.

Appendix 4: Strategies for Case Studies

	Case Study 1: **Tagalog-Speaking Family**	**Case Study 2:** **Mandarin-Speaking Family**	**Case Study 3:** **Cantonese-Speaking Family**
Strategies	• Bring in cultural liaisons/brokers to help create a more welcoming space. • Offer a translator if needed. • Ask Anne-Marie if there are any specific struggles she is facing with Abigail. • Probe more into why she thinks Abigail may be shy. • Probe more into Anne-Marie's social supports (e.g., extended family or friends here in Canada). • Probe into how Anne-Marie is coping with being away from her husband for a lengthy period. • Ask her if she has discussed her concerns with her husband. • Ask her what she believes may be causing her daughter to be shy or "naughty." • Offer to have her husband in on a call during the next follow up appointment.	• Translation is always useful, even if you feel the families are fluent in English. They may be able to communicate more details and feel more comfortable when communicating their concerns in their own language. • Translation for the child is also useful, especially when providing instructions. Some children may only follow directions given in the language/dialect spoken at home. • Speaking to extended family can provide valuable information about the child's development, as they may be watching the child for most of the day when parents are at work.	• Validate Liu's feelings and concerns. • Allow him to voice his concerns and fears. • Address his concerns about Yichen's academic future. • Find culturally appropriate scenarios that are familiar to both the family and child.

	Case Study 1: Tagalog-Speaking Family	Case Study 2: Mandarin-Speaking Family	Case Study 3: Cantonese-Speaking Family
Keep in Mind	• Building a rapport is key and may take time. • When initially approaching parents/caregivers consider the following: – Ask them how they are doing. – Ask what challenges are they facing at home. – Do they have any concerns about their child? – Focus on the child's behaviours and the impact it is having on them. – Be prepared to have caregivers go back and forth about having their child assessed. – You may need to be patient. • Gradually bring up how having their child assessed may lead to access to services that could help with challenges. • Gradually bring up the benefits of early identification.	• Understand cultural norms and beliefs. • Avoidance of eye contact in some cultures is a social norm. • Playing on the floor is avoided in some cultures, so keep that in mind.	• Certain activities or scenarios used in assessments may not be culturally appropriate. • Academic success is very important in Chinese culture. This can be related to filial piety. • Autism in certain languages can have a negative connotation. Using more descriptive terminology or phrasing can help families understand and accept a diagnosis more easily.

Appendix 5:
East Asian Holidays

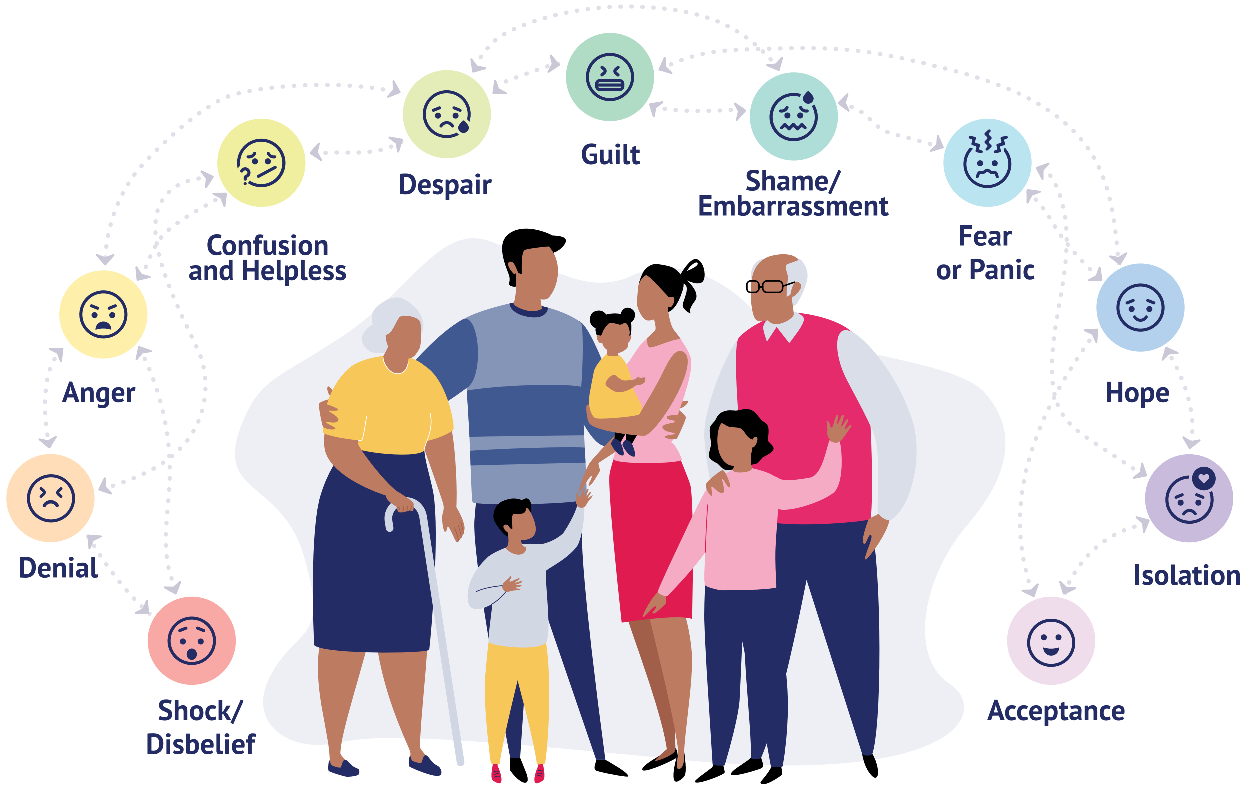
When making appointments with families, please be aware of culturally significant holidays. It can provide a point of rapport-building, with curiosity in mind. For example, "Is X a holiday your family celebrates?" allows the conversation to flow from there.

Families will confirm which holidays they observe, but it is paramount to be familiar with culturally important dates. Here are some sources you can use for research:

- **The China Consulate in Toronto Holidays Observed by the Philippine Consulate General in Toronto**
- **Public Holidays in the Philippines**
- Note: June is Filipino Heritage Month in Canada. It is also Asian Heritage Month.

Appendix 6:
The Emotional Journey Post-Diagnosis

As you have read in this toolkit, it is common for those in Cantonese-, Mandarin-, and Tagalog-speaking communities to suffer the diagnostic burden and go through what they describe as similar to the grieving process. However, there are tips and strategies that diagnosticians and therapists can provide parents to help them reach acceptance. It is important to understand that this is not a linear process and that some caregivers will bounce back and forth thought the various emotional stages, while others may not experience the stages listed below at all. It is important to validate a caregiver's feelings and never assume or convey that what they are feeling is "wrong." Read on to review some of the stages of processing a diagnosis as well as strategies to help with each:



Shock/Disbelief

Shock or disbelief are normally the first reactions for many caregivers. Typically, at this moment, caregivers are so overwhelmed, they may not fully understand what is happening. Some may go into autopilot modeand have little to say during the rest of the conversation. They may be telling themselves, "This has to be some sort of mistake," or, "This is not happening." The concern for diagnosticians is that caregivers are rarely processing or taking in any of the additional information being relayed to them.

Tips:

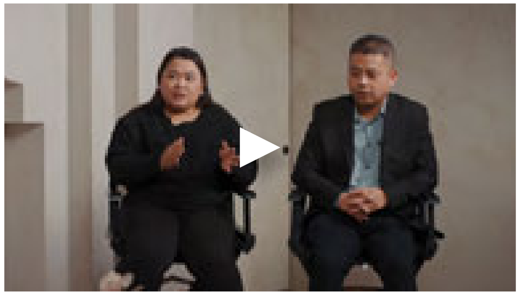
1. **Give time to process the diagnosis.**
    a) For diagnosticians and therapists, it is always ideal to allow time for caregiver to process what you have just told them. Let them go home but book a follow-up in the near future to review next steps.
2. **Caution caregivers against making drastic decisions immediately post-diagnosis.**
    a) Remind caregivers to take time for themselves to process the diagnosis. Advise that they should not make any drastic decisions until they see you again in follow-up.
3. **Ask caregivers to make a list of questions over the next few days to ask at the follow-up appointment.**
    a) This may help them cope with the initial shock and get them focused on a productive activity.

Denial

This is a common stage for families, as they believe that this is some mistake and eventually their child will get better on their own. Some parents may place fault on the diagnostician and ask for a second or third opinion, or, in some cases, seek assessments from non-medical professionals. In these stages, caregivers may believe, "There is nothing wrong with my child and the testing was wrong."

Tips:

1. **Help families to better understand the diagnostic process.**
2. **Help families to acknowledge some of the cultural factors that may be playing a role in their feelings.**
3. **Help families to use denial in a positive manner.**
    a) Let their denial fuel them to learn more about autism and developmental delays. Provide them with vetted resources.



Understanding the Challenges of Early Intervention in the Philippines

Anger

Anger is a common emotion that surfaces in the earlier stages post-diagnosis. Often families will question, "Why is this happening to me?", or, "What did I do to deserve this?" This anger is normally directed at the diagnostician but it can also be directed at their spouse or children. In some cases, if the family is religious, that anger may even be directed at God. If the child is attending school, this anger may lead to fault being placed on teachers, the educational system, or other school representatives.

Tips:

1. **Validate their feelings.**
    a) As a diagnostician, understand that it is okay for the family to feel anger and frustration.
2. **Help redirect their energy.**
    a) Consider how to help families redirect the energy of anger and frustration towards helping them advocate for their child. This is a better use of energy than misdirecting anger at those who are trying to help them. This may involve allowing time for

the caregivers to process the diagnosis or better understand the factors that may be contributing to their anger. The anger may be a manifestation of the caregiver's own feelings of guilt, as they may feel responsible for their child's autism.

Confusion and Helpless

These feelings are even more common in families from underserved or racialized communities. For Cantonese-, Mandarin- and Tagalog-speaking families, the word autism can be a very foreign concept and terms such as ABA therapy, SLP or OT can be just as confusing. They may be wondering, "What does this mean for my child?" and "Will my child be kicked out of school?" and even, "Will they always depend on me?" They may not understand what the diagnostician has relayed but they may also be too confused to ask for clarification. This confusion can make the family feel like they will now have to rely on the advice and expertise of others, such as therapists with whom they have not yet built a trusting relationship. They may question their own judgement and wonder, "How did I miss this with my own child? It is my fault."

Tips:

1. **Help families understand what autism is and its impact.**
2. **Explain the concept of autism being a "spectrum."**
   a) Helping families to understand that ASD is a "spectrum" is extremely valuable and helps to ensure that parental investment in the child's upbringing does not change post-diagnosis.
3. **Empower the family.**
   a) Help empower these families with knowledge so that they can make informed decisions.

Despair

For some caregivers, the challenges they face can lead to feelings of despair. They may never have envisioned their life with a child on the autism spectrum and believe that with this diagnosis, all of their hopes and dreams for their child's future have now vanished. As one parent said, "They are on a train they never wanted to board and there is no getting off," indicating the 24/7 nature of caregiving for a child on the autism spectrum.

Tips:

1. **Explain what burnout is.**
   a) As diagnosticians, it is key to try and prevent burnout of the caregivers.
2. **Help caregivers with self-care.**
   a) Help caregivers to understand that taking time for themselves is important—even if it is just a couple of hours. This may be difficult for certain communities, as culturally, taking time away from parenting may be frowned upon. Reviewing self-care strategies can be extremely valuable, especially if they are framed within their own cultural beliefs.
   b) Remind caregivers and families that it is okay to cry, and at the same time, that it is okay to have fun.
3. **Provide strategies on how to explain the diagnosis to their family and friends.**
   a) If they are struggling to tell their friends and extended family about the diagnosis, offer strategies on how to relay this information.
4. **Recommend community support groups.**
   a) If all the above are not effective, recommend a therapist or support group such as the CARES program.

Guilt

Another common feeling is guilt. As we mentioned in earlier sections of the toolkit, caregivers can sometimes think, "What did I do to cause this to happen?", "Was it because I was stressed when I was pregnant?", or "Am I being punished for something I have done?". The concern with this guilt is that these feelings may recur later in life and not just be isolated to post-diagnosis. Caregivers may feel that they are not doing enough for their child or "I should have had my child checked earlier."

Tips:

1. **Explain to families that it is not their fault.**
   a) Helping families and caregivers understand that it is not their

fault is key in Tagalog-, Mandarin- and Cantonese-speaking families.

2. **Help families focus on the present.**
   a) Help them understand that no one is perfect and that dwelling on past decisions provides no benefit.
   b) Help families focus on the present.
3. **Remind families of all the positive things they have done for their child and how far their child has come because of them.**

Shame/Embarrassment

This has been a very common, complex theme discussed through the toolkit. Caregivers may worry about what other people think. These feelings of shame may be exacerbated in social settings, like taking a trip to the mall or going out to a restaurant if they are not sure how their child will behaver. They may believe that people will think they are terrible parents that cannot manage their child. Parents can feel shame and guilt together in these situations.

Tips:

1. **Help families understand what "unhelpful thoughts" are.**
   a) As diagnosticians, help families understand that what they may be thinking may fall under the category of "unhelpful thoughts." Simply telling them to get over it and stop worrying about what other people think only invalidates their feelings; this may cause them to turn away from support. Some of those beliefs can be deeply embedded in a parent's psyche and it will take time to help them reframe their perception of the situation.
2. **Help them to understand by giving concrete examples.**
   a) For example, in the mall or restaurant situation, remind caregivers that when people see them trying to cope with challenging behaviour, they may actually be respecting the effort and patience it takes.

Fear or Panic

Fear is a very common emotion felt by caregivers—not only close to diagnosis, but at other times as well. They worry about what will happen, how their child will adjust to new interventions, etc. Life transitions typically trigger these feelings. One of the major triggers for caregivers is when they consider what will happen to their child when they pass away.

Tips:

1. **Validate their feelings.**
   a. Remind caregivers that their feelings are completely normal.
2. **Provide relaxation and mindfulness activities they can do at home.**
   a. Provide families with strategies on how to relax, and suggest specific relaxation techniques that they can use at home. The "fear of the unknown" is a very common trigger for panic in most societies.
3. **Encourage them to use their fear to motivate them to learn more.**
   a) Try helping the caregiver to manage their fear by equipping them to gather as much information as they can. Having knowledge about different options can help to quell panic.
4. **Advocate for families but also help them advocate for themselves.**
   a) If solutions are not available, help families to turn their fear into opportunities to advocate for themselves.

Hope

Caregivers can experience this emotion throughout the diagnostic journey. It can be early on after the diagnosis, as they may feel relieved to finally have answers, or it may be later in the journey after they notice that their child is improving with therapy.

Tips:

1. **Help families to celebrate and cherish every moment.**
   a) As diagnosticians, it is important to help families to acknowledge the "wins"—the progress made along the journey. The moments of celebration can be useful for helping families to remain hopeful. These celebratory moments are even helpful on the day of diagnosis.
2. **Focus on what the child is able to do.**
   a) Reminding caregivers of their child's strengths and noting their progress can help families maintain a sense of hope.

Isolation

Isolation can be a very common emotion expressed by the caregivers interviewed. As one parent said, "Our social circle got smaller after the diagnosis…" Families often feel isolated from or shunned by their community; this can be more significantly felt by caregivers from collectivistic cultures. This can be further exacerbated when others point out what their child is unable to do. Families may seek isolation because they do not want to be reminded of their child's challenges.

Tips:

- **Help families to build back their social circle.**
  Help caregivers to connect with support groups and to find other families with children on the autism spectrum. This connection will help families to better understand that they are not alone, as well as to normalize some of the feelings and emotions that they are going through.

Acceptance

Ideally, the goal is to help caregivers reach this stage. This normally means working through some or all the emotions listed above. Caregivers in this stage are not only accepting of their child's diagnosis but they also feel empowered that they have some control over the situation and their emotions in relation to it. Although they may still have some unresolved challenges, they still feel they can cope with and handle whatever challenges may arise. They also understand that they may still have days of anger or despair, but that those days will be followed by days of joy and strength. They will learn to embrace all of their child's accomplishments, regardless of how ordinary others may believe them to be. They will learn to see their child as a person and not as a disability.

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A Note of Appreciation

The SAAAC project team expresses our deepest gratitude to all of the families and agencies who lent their voices, thoughts, feelings, and experiences to this project—both on and off camera. The following are families who consented to participate in the video portion of this project. Our remaining families remain anonymous to protect their privacy. Without them, this toolkit would not be possible.

Cantonese-Speaking Caregiver

Joanna Cheng

Joanna is the mother of a 32-year-old man with autism. She was born in China, educated in Hong Kong, and then came to Canada in 1974. When she came to Canada, she worked at BMO Bank and attended school in the evening to attain education. When she had her son and found out he had autism, she dedicated herself to working hard to find resources for him, including setting up her own ABA programs.

Mandarin-Speaking Caregiver

Na Li Zheng

Na Li is the mother of a 15-year-old boy with autism. She was born in China and came to Canada more than 20 years ago. When she found out her son has autism, she learned to navigate the unfamiliar system to access resources, including culturally relevant and language-suitable services.

Tagalog-speaking Family

Patrick Esquierdo

Born and raised in the Philippines, Patrick, 43, has dedicated his life to supporting his son, who is on the autism spectrum. “My family is the most important thing in my life, and I work hard every day to provide for them and to create a better future for my son.”

He is passionate about education and supporting others from a young age, which is why he chose to pursue a career in developmental service work after moving to Canada in 2016. After completing his Community and Developmental Service Program, he began his journey as an Autism Support Worker.

Khristine Esquierdo

Khristine is the mother to a wonderful 10-year-old boy with autism, as well as a dedicated nurse in one of the hospitals in Markham, Ontario. Her family immigrated to Canada in 2016, hoping to build a better life for themselves. Although it was a difficult decision to leave their home country, she was filled with excitement and determination to make the most of their new life in Canada. In her professional life, she is a valued member of the nursing team at her workplace. As a nurse, she has found her true calling in life. She is passionate about caring for others and helping people in need. Her colleagues and patients appreciate her compassionate care, positive attitude, and dedication to her work.

Partnering Organization

智愛

Cherish

INTEGRATED SERVICES

For Persons with
Developmental Disabilities
– A Registered Charity –

幫助智障人士成長的慈善機構

www.cherishis.org

Charitable Registration #: 81036 2061 RR0001

Cherish Integrated Services is a registered charity serving individuals with developmental disabilities in the Greater Toronto Area since 2010. We offer a range of programs for children, youth, and adults, including day programs, one-on-one training, summer camps, and social group programs. We strongly support immigrant families who have children or dependents with developmental disabilities, with over two-thirds of our service recipients identifying as Chinese immigrants or Chinese Canadians. We help these families integrate into the Canadian community, while providing opportunities to connect with their Chinese culture and heritage through our programs, services, and events.

Our mission is to enrich the quality of life and personal wellness for persons with developmental disabilities, and to enhance their individual and social functioning in daily living. We cherish each person's uniqueness and work hard to integrate each life with the community. We strive to help our trainees realize their full potential, maximize their independence and self-reliance, and to contribute their own strengths to the community.

With a newly renovated 5,200-square-foot facility in Markham, Cherish's trainees will develop and explore a variety of skills including daily living skills, social communication skills, vocational training, cooking, music, dance, crafts, etc. The team of staff are enthusiastic and committed to providing quality services for all trainees. Staff members have expertise in different professional and educational backgrounds, including social work, education, child and youth work, psychology, early childhood education, etc. and are trained in using the structured teaching method to help trainees achieve their goals.

For more information, feel free to contact us.

https://cherishis.org/

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Partnering Organization

Children's
Treatment Network

The SAAAC Autism team wishes to thank the Children's Treatment Network (CTN) for funding and supporting the development of this toolkit. CTN supports more than 23,000 children and youth with disabilities and developmental needs in their homes, communities, and schools. The network provides intake, service navigation, and coordinated service planning, assessment and diagnostic services, specialized clinics, and rehabilitation services. These services include 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.

SAAAC