

UNDERSTANDING THE IMPACT OF AUTISM ON FAMILIES IN CANADA'S LARGEST  
IMMIGRANT POPULATIONS: A SCOPING REVIEW

By

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### **Committee Page**

The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, a Scholarly Practice Advanced Research Project:

Understanding the Impact of Autism on Families in Canada's Largest Immigrant Populations: A Scoping Review

Submitted by Ashifa Dhanji in partial fulfillment of the requirements for the degree of Master of Science in Nursing.

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## Abstract

**Background:** Autism has been identified as one of the fastest growing developmental disabilities affecting all ethnicities. Children who have a diagnosis of autism spectrum disorder (ASD) have difficulties with verbal and nonverbal communication as well as developing and maintaining relationships. As adults, affected individuals may have difficulties living independently. With Canada's growing ethnocultural diversity, it is important that health and community service providers understand how ASD is understood and experienced by immigrant families.

**Objective:** To identify and describe the current state of research literature that has explored the experiences of families who have a child diagnosed with ASD among families that represent the largest recent immigrant populations in Canada.

**Methods:** A scoping review was conducted in February 2018. Three databases were searched for literature published between January 2008 and February 2018. Inclusion criteria were: (1) research studies of any design; (2) published in English; (3) published between January 2008 and February 2018; (4) a study sample that consisted of, or addressed the needs of immigrant families from Philippines, India, China, Iran and Pakistan who were living in Canada or the United States, and have children diagnosed with ASD.

**Results:** Thirteen articles met the inclusion criteria. Nine articles addressed Chinese immigrant families; one article discussed Indian immigrants; two articles focused on families from Pakistan and one study focused on Iranian-American mothers. Four major themes were identified in the literature: culture and community, bilingualism, parental responses to ASD and culturally safe service provision.

**Conclusion:** There is limited literature addressing the experiences of immigrant families with children who have a diagnosis of ASD. Culture specific stressors, strengths, and challenges influence how families understand and cope with a diagnosis of autism in the child. Bilingual language practices of immigrant families may not disadvantage children with ASD. Policies supporting cultural competency training for service providers should be put in place for educators and therapists supporting families with children who have a diagnosis of ASD.

**Keywords:** Autism spectrum disorder, immigrants, culture, bilingualism, parental stress, Philippines, India, China, Iran, Pakistan

## **Lay Summary**

Increasing numbers of children of all ethnicities are being diagnosed with autism spectrum disorder. This scoping review explored published studies that address experiences of immigrant families from India, China, Iran and Pakistan who have children with autism. This review found that there is limited literature on the experiences of immigrant families who have children with a diagnosis of autism. Within the 13 articles included in this review, the most common topics were culture and community, bilingual language practices, parental responses to autism, and culturally safe service provision. Culture influences the way families experience and make treatment decisions about autism. Professionals who provide culturally sensitive care were found to have positive interactions with immigrant families. Cultural awareness should guide policy makers, researchers, and service providers in decision making that affects immigrant families.

## **Preface**

This Scholarly Practice Advanced Research (SPAR) project is original unpublished work by Ashifa Dhanji. All work presented in this project was supervised by Dr. Susan Dahinten and Dr. Maura MacPhee during the planning, research and analysis phases. The culminating product, a scoping review, has been reviewed and approved by the above committee members.

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A big thank you to my husband, our two children and my parents. Knowing that I could count on your unwavering support got me through this graduate program. I am truly blessed to have you in my life.

## **Dedication**

To all the families that I have had the honor to care for. I have learned so much from you.

Thank you.

## **Chapter 1: Introduction**

Approximately 1% of children in the United States (US) and other countries are diagnosed with autism spectrum disorder (ASD) according to the American Psychiatric Association (2013). Autism has been identified as one of the fastest growing developmental disorders (Autism Speaks, 2017), although the global increase in the rates of autism may be attributed to changes in diagnostic criteria, improved diagnostic methods, and increased awareness among professionals and public (Elsabbagh et al. 2012). The Centres for Disease Control and Prevention (2016) reported an increase in the prevalence of ASD in 8-year-old children from one in 150, to one in 68 between the years 2002 and 2012. This increase was also found by Christensen et al. (2016) in a study that examined prevalence and characteristics of autism reported by parents and guardians of children residing in 11 states in the United States (US).

Ouellette-Kuntz et al. (2014) presented information from the National Epidemiologic Database for the Study of Autism in Canada. Data from three regions of Canada including the province of Newfoundland and Labrador, the province of Prince Edward Island and six counties in the province of Ontario were examined. This study found a significant increase in prevalence of autism among children ages 2-14 years between 2003 and 2010 with an average yearly increase ranging from 9.7% to 14.6%. In a more current report focusing on Canadian children and youth ages 5-17 years residing in six provinces and one territory including Newfoundland and Labrador, Nova Scotia, Prince Edward Island, New Brunswick, Quebec, British Columbia and the Yukon, Ofner et al. (2018) concluded that the prevalence for ASD in 2015 was 1 in 66. Clearly, many families are affected by ASD, making it a priority for research in developmental pediatrics.

Signs of ASD typically manifest in the early developmental years. Children diagnosed with autism have persistent deficits in social interactions including verbal and nonverbal communication. There are also challenges with social reciprocity which impacts development and maintenance of relationships. Other symptoms may include restricted repetitive behaviours or interests, inflexible adherence to routines, as well as preoccupation with unusual objects. The presence of these and other symptoms vary depending on the severity, therefore, autism may also

be referred to as ASD. As adults, individuals with a diagnosis of ASD tend to have difficulties with living and working independently and are prone to anxiety and depression (American Psychiatric Association, 2013). ASD is a lifelong disorder with significant implications for the diagnosed children, youth, and adults as well as their families and care givers.

Christensen et al. (2016) found that autism affected children of all ethnicities and races across the US. However, there is mixed evidence on the comparative prevalence of autism among children of immigrant families. Several studies have suggested that children of immigrant families, or children born after their mother migrated may have higher rates of autism (Gillberg, Schaumann, & Gillberg, 1995; Crafa & Warfa, 2015). For example, in a study by Becerra et al. (2014), children of foreign-born black mothers were at 76% higher risk and those born to foreign born Filipino mothers were at 25% higher risk of receiving a diagnosis of autism. In contrast, a study in the United Kingdom did not find any significant difference between non-immigrant and immigrant families (Powell et al., 2000). However, in addition to possible differences in rates of autism, there may be other differences among immigrant families that are important to consider with respect to their understanding of autism and the treatment decisions they make, such as cultural backgrounds (Mandell & Novak, 2005).

Recent literature has addressed the needs of families caring for their children who are diagnosed with autism, and there has been some effort to address needs of immigrant families. For example, a study by Khanlou et al. (2017) found that immigrant mothers report several barriers to accessing supports and services for their children including language barriers, socioeconomic constraints, lack of social network, and lack of quality of existing social services. And although not focused on immigrant families, Dyches, Wilder, Sudweeks, Obiakor and Algozzine (2004) reported significant variability in rates of children identified with autism between racial groups. The percentage of Black and Asian children identified with autism during the years 1999 and 2000 was disproportionately high while the percentage of Hispanic children was disproportionately low in relation to the 0.1% of children diagnosed with ASD in US. The authors raised the questions whether certain cultures are more accepting of a diagnosis of ASD or whether certain behaviours associated with a diagnosis of ASD are not perceived as a disability by some cultures, and therefore not reported.

## **Demographics and Immigration in Canada**

The Canadian population is increasingly foreign-born and ethnically diverse. Immigrants are admitted to Canada to primarily meet the nation's three objectives: enhance economic growth, unite families, and maintain the country's humanitarian traditions (Statistics Canada, 2017a). While in 2011 about 21% of Canadian population was foreign born, it is estimated that by 2036 this proportion may increase to about 24.5% to 30% (Statistics Canada, 2017b). The first census collected by Statistics Canada in 1871 reported 20 ethnic origins. In contrast, the 2016 census reported over 250 ethnic origins (Statistics Canada, 2017c). Current immigration trends from 2016 suggest that most immigrants originated from Asia, and the five top countries of birth of recent immigrants to Canada were the Philippines, India, China, Iran and Pakistan (Statistics Canada, 2017d).

### **Problem Statement**

Given the growing numbers of children receiving a diagnosis of ASD globally and increasing numbers of ethnically diverse immigrant families in Canada, it is important for service providers to understand the experiences of immigrant families who have a child with ASD and how cultural and ethnic backgrounds may influence families' perceptions of ASD and their treatment decisions. However, it is not clear whether the research literature adequately reflects the diversity of children with ASD living in Canada and the needs of these families.

### **Purpose and Research Questions**

The purpose of this scoping review was to identify and describe the current state of literature that has explored the experiences of immigrant families in Canada who are raising children with a diagnosis of ASD. This scoping review focused on immigrant families from the Philippines, India, China, Iran and Pakistan, representing the largest groups of recent immigrants in Canada (Statistics Canada, 2017d). However, due to limited research from Canada, a larger body of research conducted in the US was included in this review. The following research questions were explored:

1. What research studies have been published that address the experiences of immigrant families with children who are diagnosed with ASD and reside in Canada or the US?

2. What themes are emerging in current research literature that lends to better understanding of the needs of immigrant families with children who are diagnosed with ASD?
3. What are the policy, practice and research implications of these findings?

This scoping review is intended to inform the care provided by health and community professionals to immigrant families who have children diagnosed with ASD and provide guidance for future research to better serve Canada's population with its changing ethnocultural composition.

## **Chapter 2: Methods**

A scoping review was conducted to answer the research questions guiding this study. The methodology of scoping reviews has clear advantages including systematic research strategy, replicability, and transparency. However, its limitations lie in the absence of quality assessment and potential bias as literature is selected based on relevance to the research topic (Grant & Booth, 2009). Scoping reviews are best suited when exploring new evidence or broad areas to lay the foundation for future systemic reviews that may pose more specific research questions. Often, scoping reviews are utilized to examine the extent and type of research conducted, as well as gaps in the identified topic. While scoping reviews may include data from a variety of study designs and sources, the reviewers may decide to exclude literature that is considered beyond the scope of their research (The Joanna Briggs Institute, 2015).

### **Search Strategy**

A comprehensive search of three online databases, CINAHL, PsychINFO and MEDLINE (Ovid), was undertaken in February 2018 to identify literature relevant to the research questions. The general search terms included: autism, immigrants, minority groups, Philippines, India, China, Iran and Pakistan. The search strategies used for each database, and the numbers of direct hits are outlined in Table 1. A professional librarian from the University of British Columbia was consulted to assist in the search strategy for this review.



**Table 1. Search Strategy and Number of Hits**

Source	Search Strategy	Number of Hits
CINAHL	(Philippin* OR India* OR Chin* OR Iran* OR Pakistan*) OR (MH "Asia, Southeastern+") OR (MH "Asia, Western+") OR (MH "Middle East+") OR (MH "Ethnic Groups+") AND (MH "Autistic Disorder") OR (MH "Asperger Syndrome") OR (MH "Pervasive Developmental Disorder-Not otherwise specified") OR autism or asd or autism spectrum disorder or aspergers or "pervasive developmental disorder" AND (MH "immigrants") OR (MH "Minority Groups") OR immigrant* OR Emigrant*	25
PsychINFO	(Philippin* OR India* OR Chin* OR Iran* OR Pakistan*) OR DE "Chinese Cultural Groups" OR DE "South Asian Cultural Groups" OR DE "Southeast Asian Cultural Groups" AND Autism or asd or autism spectrum disorder or aspergers or "Pervasive developmental disorder" OR DE "Autistic Thinking" OR DE "Autism Spectrum Disorders"	1952
Medline (Ovid)	(Philippin* OR India* OR Chin* OR Iran* OR Pakistan*) OR asian continental ancestry group/ or asian americans/ AND Autism or asd or autism spectrum disorder or aspergers or "pervasive developmental disorder" OR child development disorders, pervasive/ or asperger syndrome/ or autism spectrum disorder/ or autistic disorder/ AND "Emigrants and Immigrants" OR Minority Groups/	6
<b>Total</b>		<b>1983</b>

## **Inclusion and Exclusion Criteria**

The inclusion criteria were: (1) research studies of any design; (2) published in English; (3) published between January 2008 and February 2018; (4) a study sample that consisted of or addressed the needs of immigrant families from the Philippines, India, China, Iran and Pakistan who were living in Canada or the US, and have children diagnosed with ASD. Studies were also included if the sample consisted of immigrant families from a variety of countries of origin, if at least half of the participants were from countries relevant to this review. Studies not available for full text review were excluded.

## **Study Selection**

Study selection for this scoping review was done in a three-step fashion. Firstly, all articles were screened for duplicates; secondly, titles and abstracts were reviewed for relevance to the study. If there was any ambiguity or uncertainty in the second screening of titles and abstracts, these articles were added to those that met criteria for full text review. A third and final screening involved full-text review for inclusion and exclusion criteria to ensure each article would contribute in answering the research questions guiding this scoping review. In addition, the reference lists of articles meeting all the inclusion criteria were searched for relevant literature. All search results from the three databases, CINAHL, PsychINFO, Medline (Ovid), and the article retrieved from reference lists, were charted in Excel work sheets for tracking during the three-step literature selection and review process.

## **Data Extraction and Analysis**

Data were extracted from literature that met the inclusion criteria for this review. This data included: names of authors, year of publication, population focus, sample size, study design and findings. In addition, each article was read several times to capture the nuances of the emerging concepts, which were tabulated and clustered together to identify major themes. Articles with similar overarching major themes were grouped together for further comparison and analysis to determine the main focus and to identify emerging subthemes. Finally, all literature was categorized according to major overarching themes and subthemes. The resulting data was tabulated and reviewed to synthesize the extent, focus and findings of available research addressing immigrant families from countries representing Canada's largest current immigration groups who have children diagnosed with ASD.

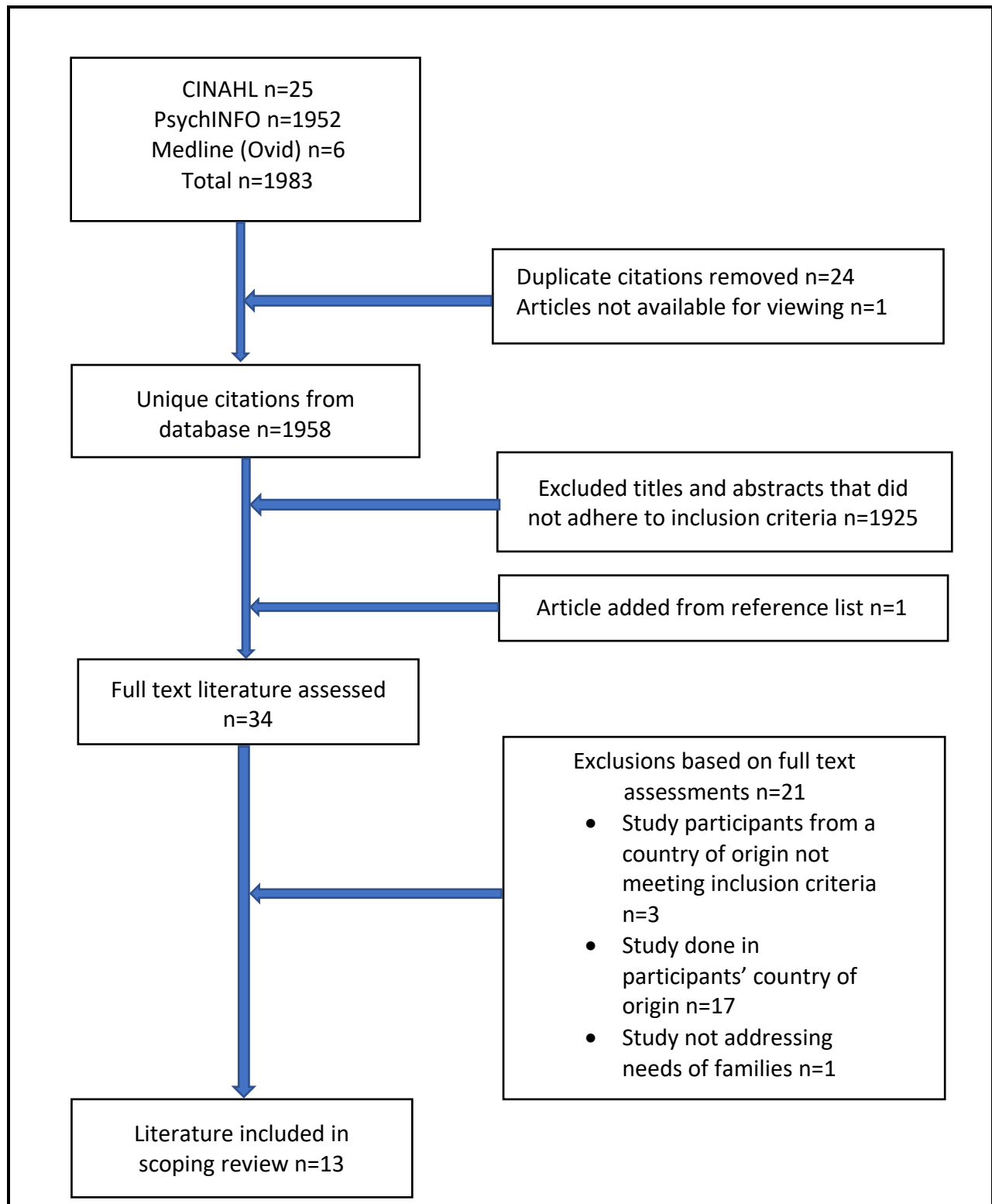
## **Chapter 3: Results**

### **Search Results**

A systematic search of three data bases resulted in 1983 hits. After removing 24 duplicate citations and one article that was unavailable for full text review, 1958 unique citations remained for further consideration. A total of 1925 articles were excluded after reviewing titles and abstracts for relevance to the research questions guiding this study. Any articles with titles or abstracts that seemed ambiguous were retained for full-text review. A total of 33 research articles were considered for full-text review. The reference lists of these articles were searched for additional literature relevant to the research questions, and one article was added that met inclusion criteria. In total, 34 articles were read in full for consideration of inclusion to this scoping review.

During the full text review, 21 articles were identified that did not meet the inclusion criteria and these were excluded from the scoping review. Three articles addressed families from countries that were not the focus of this study. Another 17 research studies were excluded because participants were residing in either India, China, Iran or Pakistan and were therefore not immigrants of Canada or the US. One study addressed the target population identified for this study but was focused on language development in children with autism and did not address the needs of the families. A total of 13 articles remained in the final selection for this scoping review. The selection process is outlined in Figure 1.

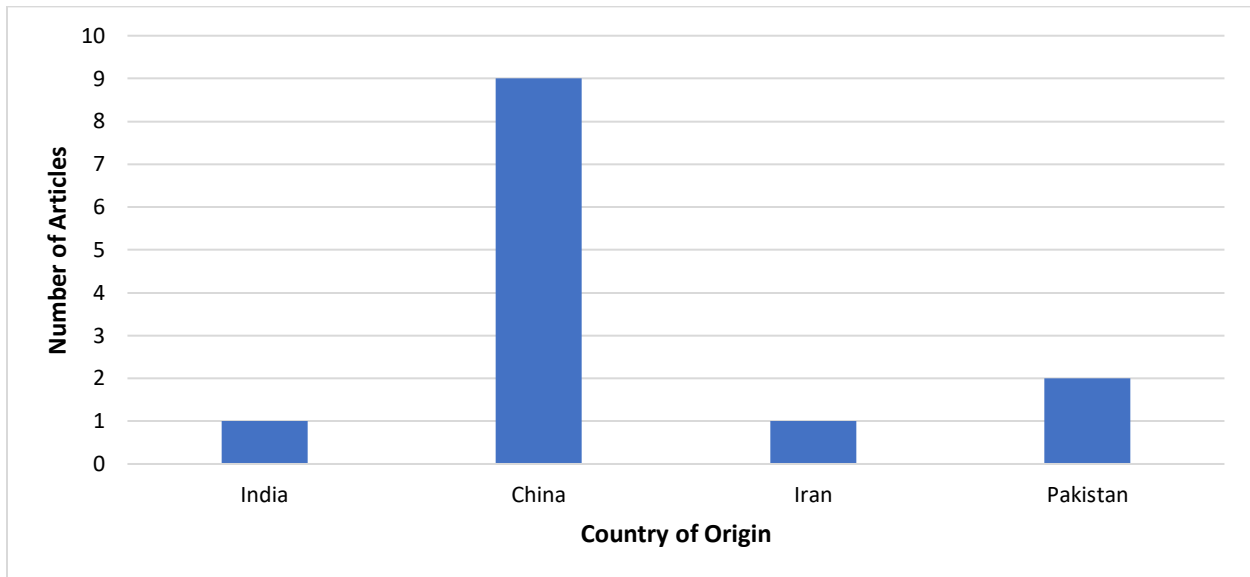
**Figure 1. Flowchart of Article Selection**



## Summary of Selected Literature

Research Question 1 was addressed first. Table 2 lists the 13 articles selected for inclusion in this scoping review in alphabetical order by author name, and Table 3 summarizes the characteristics and findings of each study. The study samples and their foci varied. Nine articles addressed the Chinese speaking immigrant families, one article addressed the Indian immigrant families, two articles discussed the needs of immigrants from Pakistan, and one article discussed families from Iran (see Figure 2). No articles were found that focused on the immigrant population from the Philippines residing in Canada or the US. Eight studies used a sample consisting of mothers, fathers, couples and grandparents; two articles focused only on experiences of mothers, and one case study involved a family of parents, grandparent, sibling and cousin living in the home. One study consisted of children diagnosed with ASD and focused on their language development, and one article addressed service providers' perspectives. Study designs also varied. Ten articles reported on qualitative research studies (including one case study), and three articles reported on quantitative studies.

**Figure 2. Articles per Country of Origin**



**Table 2. Studies Included in Scoping Review**

#	Authors (Year)	Journal	Title of Article
1	Chiang (2014)	Focus on Autism and Other Developmental Disabilities	A parent education program for parents of Chinese American children with autism spectrum disorders (ASDs): A pilot study
2	Gray & Chiang (2017)	Journal of Autism and Developmental Disorders	Brief report: Mealtime behaviours of Chinese American Children with autism spectrum disorder
3	Huang & Zhou (2016)	International Journal of School and Educational Psychology	Perceived self-efficacy, cultural values, and coping styles among Chinese families of children with autism
4	Jegatheesan, Fowler & Miller (2010)	Disability and Society	From symptom recognition to services: How South Asian Muslim immigrant families navigate autism
5	Jegatheesan, Miller & Fowler (2010)	Focus on Autism and Other Developmental Disabilities	Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families
6	Petersen, Marinova-Todd & Mirenda (2012)	Journal of Autism and Developmental Disorders	Brief report: An exploratory study of lexical skills in bilingual children with autism spectrum disorder
7	Ravindran & Myers (2013)	Focus on Autism and Other Developmental Disabilities	Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey
8	Tarian (2015)	ProQuest Dissertations and Theses database	Experiences of Iranian American mothers with children with autism
9	Tsoi (2016)	ProQuest Dissertations and Theses database	Disparities between U.S.-born and China-born Chinese American families caring for a child with autism spectrum disorder
10	Wang & Casillas (2012)	Journal of Asian and African Studies	Asian American parents' experiences of raising children with autism: Multicultural family perspective
11	Yu (2016)	Journal of Autism and Developmental Disorders	Bilingualism as conceptualized and bilingualism as lived: A critical examination of the monolingual socialization of a child with autism in a bilingual family
12	Yu (2013)	American Journal of Speech-Language Pathology	Issues in bilingualism and heritage language maintenance: Perspectives of minority-language mothers of children with autism spectrum disorders
13	Yu (2010)	ProQuest Dissertations and Theses database	Talking with bilingual Chinese-American immigrant parents of children with autism spectrum disorders about intergenerational language practices.

**Table 3. Characteristics of Included Studies**

#	Author/Year	Sample/Purpose/Study Design	Summary of Findings
1	Chiang (2014)	<p><i>Sample:</i> 9 Chinese-American families of ASD children.</p> <p><i>Purpose:</i> To examine the impact of a group format parent education program on stress and parenting confidence.</p> <p><i>Study Design:</i> Quantitative – One group pre-test post-test pilot study.</p>	<ul style="list-style-type: none"> <li>- Culturally sensitive parent education reduced parenting stress, increased parental confidence in caring for the child with ASD, and increased quality of life.</li> <li>- Majority of mothers in the sample maintained higher than normal levels of parenting stress even after receiving parent education sessions.</li> </ul>
2	Gray & Chiang (2017)	<p><i>Sample:</i> 31 Chinese-American parents of children aged 3-12 years of age.</p> <p><i>Purpose:</i> To examine meal time behaviours of children with ASD, to inform interventions for feeding problems.</p> <p><i>Study Design:</i> Quantitative – Descriptive. Survey results were compared with reference data from the BAMBI scale authors.</p>	<ul style="list-style-type: none"> <li>- Culture may influence children’s meal time behaviour and food preferences.</li> <li>- Compared to non-Asian children, this sample had lower scores on problematic mealtime behaviours such as aggressive behaviours.</li> <li>- Similar to non-Asian children with ASD, this sample had specific food preferences.</li> </ul>
3	Huang & Zhou (2016)	<p><i>Sample:</i> 7 Cantonese and Mandarin speaking families.</p> <p><i>Purpose:</i> To better understand Chinese families’ struggles in raising a child with ASD; to explore cultural values and coping styles.</p> <p><i>Study Design:</i> Qualitative – Descriptive; semi-structured interviews.</p>	<ul style="list-style-type: none"> <li>- Study participants believed that ASD was a temporary condition similar to language impairment.</li> <li>- Parental stressors included child characteristics, isolation, stigma, and loss of income to care for child.</li> <li>- Religion was a spiritual and emotional support.</li> <li>- Parents reported lack of caregiving confidence and viewed community care providers and educators as experts.</li> <li>- Despite struggles, learning about ASD and caring for the child led to personal growth, resilience and hope.</li> </ul>

**Table 3. Characteristics of Included Studies (cont.)**

#	Author/Year	Sample/Purpose/Study Design	Summary of Findings
4	Jegatheesan, Fowler & Miller (2010)	<p><i>Sample:</i> 3 South Asian families from Pakistan and Bangladesh.</p> <p><i>Purpose:</i> To explore Muslim immigrant families' experiences with complex disability, culture, family dynamics and utilization of services.</p> <p><i>Study Design:</i> Qualitative – Longitudinal, part of a larger ethnographic study grounded in 17 months of fieldwork that included over 700 hours of observation.</p>	<ul style="list-style-type: none"> <li>- Parents felt most supported by professionals with same ethnic background.</li> <li>- Clashes with European-American professionals resulted in discontinued treatment.</li> <li>- Bilingual practices were discouraged by most therapists.</li> <li>- Mothers' diet and health during pregnancy was believed to cause ASD.</li> <li>- Religion and folk treatments played a significant role in understanding ASD.</li> </ul>
5	Jegatheesan, Miller & Fowler (2010)	<p><i>Sample:</i> 3 South Asian multilingual families from Pakistan and Bangladesh living in the US.</p> <p><i>Purpose:</i> To explore how South Asian Muslim families make sense of ASD and to describe their experiences and beliefs.</p> <p><i>Study Design:</i> Qualitative – Longitudinal ethnographic study with 17 months of fieldwork and over 700 hours of participant observation.</p>	<ul style="list-style-type: none"> <li>- Religion played a significant role in acceptance of child's ASD diagnosis.</li> <li>- Study participants felt that they had been chosen by a higher power to raise a special child.</li> <li>- The diagnosis of ASD contributed to family's resilience and strength.</li> <li>- Multilingualism was perceived as critical in everyday life for full inclusion in religious activities and English institutions such as the school.</li> </ul>



**Table 3. Characteristics of Included Studies (cont.)**

#	Author/Year	Sample/Purpose/Study Design	Summary of Findings
6	Petersen, Marinova-Todd & Miranda (2012)	<p><i>Sample:</i> 14 bilingual children who spoke Chinese (Cantonese or Mandarin) and English, and 14 monolingual children who spoke only English. All children had ASD and ranged in age from 43-73 months.</p> <p><i>Purpose:</i> To compare bilingual and monolingual children's conceptual production vocabularies and language scores; to describe language development in children with autism.</p> <p><i>Study Design:</i> Quantitative – Exploratory study; brief report.</p>	<ul style="list-style-type: none"> <li>- Bilingual children with ASD had same vocabulary skills in both English and Chinese.</li> <li>- Bilingual children scored higher in some vocabulary tests compared to monolingual children.</li> <li>- Switching languages between home and school or therapy did not affect language development.</li> </ul>
7	Ravindran & Myers (2013)	<p><i>Sample:</i> 24 Indian parents living outside of India (US, Canada, Kuwait).</p> <p><i>Purpose:</i> To explore parental beliefs about ASD causes, treatments, services and practices.</p> <p><i>Study Design:</i> Qualitative – Descriptive; internet survey; content analysis.</p>	<ul style="list-style-type: none"> <li>- The majority of parents believed that immunizations and environmental toxins cause ASD.</li> <li>- Karma, destiny and fate were considered to cause ASD by 79% of the parents.</li> <li>- Disclosure about beliefs in karma, destiny and fate was not volunteered and required probing by researchers.</li> <li>- About 50% of the parents preferred a combination of Indian and Western treatments for the child.</li> <li>- 54% were dissatisfied with services provided for ASD.</li> </ul>

**Table 3. Characteristics of Included Studies (cont.)**

#	Author/Year	Sample/Purpose/Study Design	Summary of Findings
8	Tarian (2015)	<p><i>Sample:</i> 6 Iranian-American mothers.</p> <p><i>Purpose:</i> To understand the experiences and coping strategies of Iranian-American mothers of children with ASD. To explore how cultural factors, affect the experience of raising a child with ASD.</p> <p><i>Study Design:</i> Qualitative – Exploratory study.</p>	<ul style="list-style-type: none"> <li>- Self-blame for ASD diagnosis was common.</li> <li>- Many mothers reported feelings of shame and social and marital stress.</li> <li>- Faith and family were most important in coping with stress</li> <li>- Cultural and linguistically appropriate services resulted in more satisfaction.</li> <li>- Learning about ASD resulted in personal growth and resilience.</li> </ul>
9	Tsoi (2016)	<p><i>Population:</i> 7 professionals/field consultants with experience in working with US born and China born Chinese-American families.</p> <p><i>Purpose:</i> To explore service providers’ perceptions of cultural differences between US born and China born Chinese-Americans families; to inform how to provide culturally responsive services.</p> <p><i>Study Design:</i> Qualitative – Face to face structured interviews.</p>	<ul style="list-style-type: none"> <li>- China born Chinese American families had more difficulties in accepting their child’s diagnosis due to culture and language barriers.</li> <li>- US born Chinese American families were better able to navigate services but had higher expectations of service providers.</li> <li>- Understanding and coping with ASD may change over times with exposures to Western society and English language.</li> </ul>

**Table 3. Characteristics of Included Studies (cont.)**

#	Author/Year	Sample/Purpose/Study Design	Summary of Findings
<b>10</b>	Wang & Casillas (2012)	<p><i>Population:</i> 6 Mandarin speaking immigrant Asian-American families.</p> <p><i>Purpose:</i> To better understand Mandarin-speaking immigrant families' experiences in raising a child with ASD.</p> <p><i>Study Design:</i> Qualitative study – Semi-structured interviews.</p>	<ul style="list-style-type: none"> <li>- All participants experienced difficulties in accessing services.</li> <li>- Three overarching themes: cultural differences between Eastern and Western parenting styles including role of religion and superstition; family strength through difficulties; and expectations for the future.</li> </ul>
<b>11</b>	Yu (2010)	<p><i>Population:</i> 15 English and Mandarin speaking Chinese-American parents of children with a diagnosis of ASD.</p> <p><i>Purpose:</i> To explore language practices of parents with ASD children.</p> <p><i>Study Design:</i> Qualitative – Phenomenology; exploratory interview study.</p>	<ul style="list-style-type: none"> <li>- Bilingualism was an added stressor for families due to service provider recommendations to use English only with ASD children.</li> <li>- Parents felt judged and inadequate when failing to follow through with professional advice.</li> <li>- Families complied with monolingual recommendations because of beliefs that their child would have better success with therapies.</li> <li>- Families experienced feelings of loss when giving up their heritage language.</li> </ul>

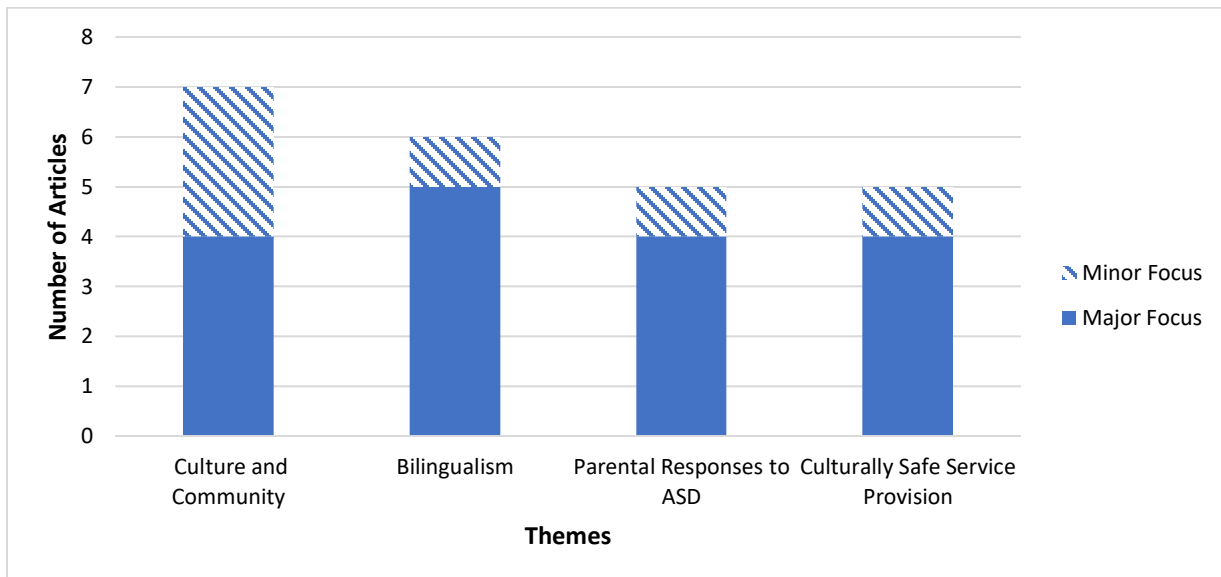
**Table 3. Characteristics of Included Studies (cont.)**

#	Author/Year	Sample/Purpose/Study Design	
12	Yu (2013)	<p><i>Population:</i> 10 bilingual Chinese English-speaking mothers.</p> <p><i>Purpose:</i> To explore factors that influences parents' choice of language use with their child who has a diagnosis of ASD and examine the impact of this choice on the child and family.</p> <p><i>Study Design:</i> Qualitative study – Phenomenology; interview study</p>	<ul style="list-style-type: none"> <li>- Proficiency in English language was regarded more advantageous than proficiency in the Chinese language.</li> <li>- Proficiency in English language facilitated access to services and was believed to result in better outcomes in school and society.</li> <li>- Bilingualism was believed to have negative effects on child's learning.</li> <li>- Bilingualism resulted in restrictions on language use in everyday life.</li> <li>- Limited resources in Chinese language put the Chinese speaking child at disadvantage for accessing services.</li> </ul>
13	Yu (2016)	<p><i>Population:</i> Bilingual Mandarin-Chinese speaking Chinese American family with a six-year-old who has a diagnosis of ASD.</p> <p><i>Purpose:</i> To examine beliefs and practices of a bilingual Mandarin speaking family that was advised by professionals to speak only English to their child with ASD.</p> <p><i>Study Design:</i> Qualitative – Ethnography; discourse analytic case study. Data collected over four months and 22 visits.</p>	<ul style="list-style-type: none"> <li>- Professionals cautioned against bilingual practices with ASD children.</li> <li>- The family complied with professional advice despite their wish to pursue bilingualism.</li> <li>- Power differential between the mother of the ASD child and professionals may have influenced the decision to comply with monolingual practices.</li> <li>- Family communication in English resulted in complex language practices within a bilingual context and defied professional advice of rigid monolingual practice.</li> </ul>

## Identification of Themes

To answer Research Question 2, the 13 articles were analyzed in an iterative fashion to identify the main reoccurring themes and their subthemes. Four main themes were identified: culture and community, bilingualism, parental responses to ASD, and culturally safe service provision. Figure 3 shows the frequency with which each theme occurred across the set of articles, and whether the theme was a major or minor focus of the article. Seven of the articles discussed more than one theme, while the six remaining studies focused on only one theme. Culture and community had a major focus in four studies and minor focus in three other studies; therefore, the most frequently occurring theme in literature. Bilingualism was the theme that occurred most frequently as a major focus in five articles and was also a minor focus in one article. Parental responses to ASD and culturally safe service provision each had major focus in four articles and minor focus in one. Further examination identified common concepts within each theme. These concepts were grouped together as subthemes and are presented in Table 4 along with the main theme of each article.

**Figure 3. Frequency of Themes in Articles (change)**



**Table 4. Themes in ASD Research**

#	Authors	<b>Theme 1: Culture and Community</b>  Subthemes: 1. Stigma 2. Cultural beliefs 3. Cultural influences on child behaviour	<b>Theme 2: Bilingualism</b>  Subthemes: 1. Parental versus professional perspectives 2. Language development	<b>Theme 3: Parental Responses to ASD</b>  Subthemes: 1. Stressors 2. Coping 3. Personal growth	<b>Theme 4: Culturally Safe Service Provision:</b>  Subthemes: 1. Family perspectives of service provision 2. Provider perspectives of service provision
<b>1</b>	Chiang			<b>X</b>	
<b>2</b>	Gray & Chiang	<b>X</b>			
<b>3</b>	Huang & Zhou	<b>X</b>		<b>X</b>	<b>x</b>
<b>4</b>	Jegatheesan, Fowler & Miller	<b>x</b>	<b>x</b>		<b>X</b>
<b>5</b>	Jegatheesa, Miller & Fowler	<b>X</b>	<b>X</b>		
<b>6</b>	Petersen, Marinova- Todd & Mirenda		<b>X</b>		
<b>7</b>	Ravindran & Myers	<b>X</b>			
<b>8</b>	Tarian	<b>x</b>		<b>X</b>	<b>X</b>
<b>9</b>	Tsoi			<b>x</b>	<b>X</b>
<b>10</b>	Wang & Casillas	<b>x</b>		<b>X</b>	
<b>11</b>	Yu (2010)		<b>X</b>		<b>X</b>
<b>12</b>	Yu (2013)		<b>X</b>		
<b>13</b>	Yu (2016)		<b>X</b>		
<b>Total</b>		<b>7</b>	<b>6</b>	<b>5</b>	<b>5</b>

Notes: **X** = Major focus, **x** = Minor focus

## **Thematic Analysis**

The literature in this scoping review was further examined to identify how each of the themes, culture and community, bilingualism, parental responses to ASD, and culturally safe service provision, impacted the experiences of families with children who had a diagnosis of ASD.

### **Theme 1: Culture and community.**

Culture and community was the most frequently occurring theme in literature. Seven of the 13 articles discussed the impact of culture and community as experienced by families who have children with ASD. There were three subthemes in the seven articles: stigma, cultural beliefs, and cultural influences on child behaviour.

#### ***Stigma.***

Tarian's (2015) qualitative study of Iranian-American mothers found that fear of stigma, fear of scrutiny by community members, and concerns that autism in their child may be attributed to poor parenting, made it difficult for families to share the child's diagnosis with family and community, and enhanced feelings of isolation. The author noted that professionals working with this population need to be aware of parents' potential reluctance to be open about a diagnosis of disability and should allow time for parents to come to terms with the child's disability without additional pressures to share the child's diagnosis with family and community. Tarian also suggested that Iranian-American parents may benefit from education in their native language to better understand ASD and that support groups be established to alleviate feelings of social isolation.

Stigma was also discussed by Huang and Zhou (2016) in their study of Cantonese and Mandarin speaking families who reported "loss of face" (p. 65), and fear of their child being seen as unusual as the primary reason for their isolation and not seeking community support. The authors highlighted that stigma and isolation were not necessarily experienced; rather, these were perceptions. Therefore, the authors advocated for better understanding of parents' fears and coping mechanisms and use of workshops and support groups to facilitate adaptive thought processes and coping.

### *Cultural beliefs.*

In a study by Wang and Casillas (2012), all six Mandarin speaking families reported a belief that Western practices such as speech and behavioural therapies would cure ASD. The authors noted that a diagnosis of ASD does not always involve a physical or cognitive disability. Therefore, families may have same hopes for children with ASD as for typically developing children, and expect that certain symptoms associated with ASD such as communication and socialization difficulties, may be cured by therapies. The understanding that ASD is a transient phase in the child's life was also supported by Huang and Zhou's (2016) study looking at coping styles among Cantonese and Mandarin speaking families.

Jegatheesan, Fowler, and Miller (2010), found that immigrant families from Pakistan and Bangladesh listened to relatives' when trying to determine the cause of ASD in the child and consulted the elders in the family for use of folk treatments. Common causes of ASD were believed to be the mother's health, lack of adherence to religious practices, and eating certain foods during pregnancy. However, in another study looking at the same three Muslim families from Pakistan and Bangladesh, Jegatheesan, Miller and Fowler (2010) reported that study participants believed in karmic connections to the child and that they were predestined to have the child with ASD born in their home.

Cultural beliefs were also examined by Ravindran and Myers (2013). The authors stated that although 58% of Indian immigrant families reported a combination of Indian practices such as yoga, meditation, and food choices, as well as Western therapies to support their children's development; families were reticent to share their preferred and actual treatment choices with the researchers, suggesting a lack of full disclosure to service providers. The authors suggested that open communication and transparency about parents' choice of treatments should not be assumed. Rather, respectful enquiry that invites information sharing will allow for monitoring of non-Western and Western treatment outcomes. Furthermore, a treatment approach that is built on partnership between service providers and families, acceptance of individual beliefs, and a plan toward best outcomes for the child is ideal. Education sessions and seminars about ASD that include extended family members and elders is necessary in supportive and accepting provider-family relationships (Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010).



### ***Cultural influences on child's behaviour.***

Only one study was found specific to the influence of culture on behaviour of immigrant children with ASD, but this study raises important questions about how we view and respond to behavioural problems among children with ASD. According to Gray and Chiang (2017), current literature suggests that children with ASD are more likely to display difficult mealtime behaviours and food selectivity compared to typically developing children. The authors investigated mealtime behaviours of Chinese-American children diagnosed with ASD. Parents of 31 Chinese-American children completed The Brief Autism Mealtime Behaviour Inventory (BAMBI), which consists of 18 Likert scale questions on mealtime behaviours. The authors found that in comparison to literature findings on non-Asian children with ASD, Chinese-American children with ASD in this study showed fewer problematic behaviours and rarely displayed aggressive or disruptive behaviours during meal times. However, the children in this study had specific food preferences and disliked certain foods, similar to literature findings on non-Asian Children with ASD.

Gray and Chiang (2017) concluded that culture may influence meal time behaviours of children diagnosed with ASD. Therefore, generalizations about child behaviours across cultures are not useful in facilitating better nutrition in children. Yet, there are very few studies focusing on problematic meal time behaviours of ethnic children with ASD. A better understanding of the role culture plays in child behaviour would facilitate family specific meal time planning and reduce parental meal time stress.

### **Theme 2: Bilingualism.**

Bilingualism was the most common major theme in the literature, appearing in six articles. Two subthemes were identified: parental versus professional perspectives, and language development.

#### ***Parental versus professional perspectives.***

Parental perspectives on monolingualism versus bilingualism were investigated in a phenomenological study by Yu (2010) through in-depth interviews with 15 Mandarin speaking immigrant families. Family communications in the heritage language were perceived to enhance intimacy, facilitate conversations with elders, and be part of cultural identity. These findings were consistent with the follow up study by Yu (2013) which focused only on the interview data

from mothers from the 2010 study, and the two ethnographic studies by Jegatheesan and colleagues (Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010) of immigrant families from Pakistan and Bangladesh. Families in the latter two studies continually switched between using English in American society, speaking their native language Bangla, Hindi, Arabic, Urdu, Kachhi, or Gujrati with family and community, and reciting daily prayers in Arabic. The three Muslim families in Jegatheesan, Miller et al.'s (2010) study felt that full immersion in their communities and in American society required communication in multiple languages.

Despite the high value families placed on maintenance of heritage language, professionals, therapists and educators consistently recommended that only English should be spoken to the child diagnosed with ASD (Jegatheesan, Fowler & Miller, 2010; Yu, 2010; Yu, 2013; Yu, 2016). This recommendation had implications for the Chinese immigrant families who often started out speaking only their native language to the child. For example, in Yu's (2010) study, a large majority of Chinese speaking parents were encouraged by service providers to speak only English to their child in order to prevent difficulties with English language acquisition and facilitate better learning outcomes. Three of the parents in this study who complied with provider recommendations reported feelings of guilt and inadequacy when they switched back from speaking only English to speaking their heritage language. The most common reasons reported by study participants who complied with service providers' recommendations were lack of services in languages other than English, and perceptions that English usage would enhance access to much needed services and facilitate their child's success in therapy (Yu, 2013; Yu, 2010; Yu, 2016).

Jegatheesan, Miller et al. (2010) highlighted that switching between multiple languages is common practice for Pakistani and Bangladeshi families because the language of prayer, Arabic, is not always the language spoken in the home. While Western professionals focused on the child's deficits, Muslim families from Pakistan and Bangladesh believed that their child with ASD would benefit from a life with complexities, much like children without ASD. Yu (2010) suggested that linguistically appropriate services that provide language support to bilingual immigrant children with ASD would be more beneficial than deeming the children's

communication difficulties as a developmental deficit due only to ASD or recommending monolingual communication as a solution for all families.

### ***Language development.***

Two articles presented research findings on language development in children diagnosed with ASD. Petersen et al. (2012) compared bilingual children who spoke Mandarin or Cantonese and English to children who spoke only English. No statistically significant differences were found in total vocabulary or single word receptive scores, indicating equivalent language proficiency for bilingual and monolingual children with ASD. Yu (2016) conducted a case study of a Chinese family who complied with professional advice to use English only with their child while they continued to use their native language when interacting with other family members. The child in this case study was therefore, exposed to a complex hybrid of English and Chinese language practices rather than the simplicity of monolingualism that was intended by the communication practices advised by professionals.

Petersen et al. (2012), and Yu (2016) concluded that further research is needed for a better understanding of bilingualism and language development in children with ASD. Bilingualism versus monolingualism is a complex issue within the context of multilingual families, and children's language development is not necessarily best fostered through monolingual communication practices. Rather, each case should be assessed individually, and recommendations made based on the child's needs and family context.

### **Theme 3: Parental responses to ASD.**

#### ***Stressors.***

Five articles addressed parental responses to ASD. Chinese immigrant families worried about the future of their child and personal sacrifices involved in raising a high needs child (Wang & Casillas, 2012). In addition, Huang and Zhou (2016) found that Chinese families reported stresses related to having to modify working arrangements due to caretaking responsibilities involved with their child which impacted family income and resulted in uncertainty of when to return to work. Iranian-American mothers with ASD children experienced marital and caretaker stress (Tarian, 2015). In addition, three studies (Wang & Casillas, 2012; Huang & Zhou, 2016; Tarian, 2015) found that immigrant families raising children diagnosed with ASD struggle with isolation due to perceived lack of acceptance from social and community

groups, leading to significant stress. Literature addressing parental responses to ASD had two additional subthemes: coping and personal growth.

### ***Coping.***

One of the most frequently reported coping strategies for parental stress when raising ASD children, was spirituality. In Wang and Casillas' (2012) study, 33% of Chinese parents reported praying for peace. Similarly, Huang and Zhou (2016) stated that Chinese families reported meditation, praying and studying Buddhist texts as critical in coming to terms with their struggles in raising a child with ASD. In a study by Tarian (2015), 83% of Iranian-American mothers felt that their belief in higher powers alleviated parental stress. In addition, 100% of Iranian-American mothers utilized family support as a way to better cope with stress. Family support was also relevant to China born Chinese-American families (Tsoi, 2016). Familiarity and understanding of ethnic minority families' coping styles (Wang & Casillas, 2012; Huang & Zhou, 2016), and the potential impact of faith and religion (Tarian, 2015) are essential in providing culturally competent services, alleviate fears and promote mental well-being in families that are living with high levels of stress.

### ***Personal growth.***

Several study participants reported personal growth and gaining strength as a result of raising a child with ASD. For example, in Wang and Casillas' (2012) study, one mother reported that she was more accepting of people since her child's diagnosis of ASD. All study participants in Tarian's (2015) study reported that raising a child with ASD was an opportunity to learn, and self-education about ASD and related services was a means to cope with stress and a source of personal growth. Tsoi (2016) found that while China born Chinese-American families relied heavily on therapists and professionals to address the children's needs, the desire to self-educate and teach extended family members about autism was one of the positive coping mechanisms of US born Chinese-American families.

The significance of education in reducing parental stress was studied by Chiang (2014) in a study involving nine Chinese-American families. Pre- and post-test scores of parents' self-reports were used to measure changes in parenting stress following a 10-week parent group education session. These sessions were based on parental group's interests, sharing of personal experiences and sharing of information between group members. The results of this study

indicated a significant decrease in parental stress following the series of culturally sensitive group education sessions. According to Tsoi (2016), parents who have an accurate understanding of ASD through professional education are better able to seek out services, advocate for their child, and more inclined to reach out and participate in support groups. The author emphasized that knowledge is empowering and allows families raising a child with ASD to “have a “voice” in the treatment process” (p. 103).

#### **Theme 4: Culturally safe service provision.**

Culturally safe care includes provider awareness of cultural differences, including differences in values and beliefs, and how this influences nursing care relationships and the effectiveness of care delivery (Richardson, Yarwood & Richardson, 2017). There were two subthemes: family perspectives of service provision and provider perspectives of service provision. Existing gaps between the two suggest issues related to cultural safety. Four articles addressed family perspectives and one discussed service providers’ perspectives.

##### ***Family perspectives of service provision.***

Lack of bilingual service providers was one of the factors that impacted the quality of services (Yu, 2010; Tarian, 2015). Families with ASD children felt that service providers’ capacity to use their native language could better support bilingualism in their children and enhance both language and social development (Yu, 2010). Some culture educators were perceived as better able to understand the child, and facilitate mothers’ access to services (Tarian, 2015). Similarly, in a study by Jegatheesan, Fowler et al. (2010), South Asian immigrant families indicated a preference for physicians from their own culture who made enquiries about adjustments, adaptations and support systems for new immigrant families. European-American therapists were reported to not take cultural, lifestyle and social aspects of family life in consideration or allow family input into their child’s therapy goals and decisions. Cultural clashes between the South Asian families and European-American therapists resulted in frequent interruptions to needed services. Also, studies with Chinese-American-parents (Yu, 2010) and Iranian-American mothers (Tarian, 2015), suggested that there was limited communication with school staff and professionals, although families highly valued special education services for their children. Lack of parent-teacher collaboration made it difficult to reinforce at home what was learnt at school.

Yu (2010) and Tarian (2015) suggested that there needs to be more effort put in recruiting educators who share cultural and linguistic backgrounds as the students. However, simply sharing the language, according to Yu (2010), does not equate to culturally sensitive care. Rather, best practice guidelines for education, strength-based approaches, an understanding of sociocultural issues and family dynamics of immigrant families who are raising children with ASD are needed. In addition, improved communication between school staff and parents resulted in better follow through with reinforcing classroom strategies at home according to Huang and Zhou (2016).

***Provider perspectives of service provision.***

Tsoi's (2016) study explored service providers' perspectives of differences between US born and China born Chinese-American families by interviewing clinical experts in the field. According to service providers, China born Chinese-American families relied on other families in their community who had children with ASD, relatives, and community members for information about ASD. These parents were less accepting of a diagnosis of ASD and had difficulties navigating the health care system. Mothers were reported to take on more responsibilities than fathers. In contrast, the US born Chinese parents had a better understanding of ASD and were more active in seeking information on internet and advocating for services such as speech and occupational therapy for the child.

Providers noted other differences between the families based on providers' gender and language barriers. One service provider stated that China born Chinese-American families were more responsive to male clinicians compared to female clinicians. In addition, the service providers noted that language barriers made it difficult to get to know the China born Chinese-American families. The use of a translator did not facilitate provider-family relationships because parents appeared more connected with the translators. According to Tsoi (2016), because of language barriers, the China born Chinese-American parents had more difficulties in understanding the full scope of a diagnosis of ASD in the child. On the other hand, the US born Chinese-American parents were at times misinformed through their information gathering from the internet.

Tsoi (2016) concluded that the two groups of Chinese-American families had different understanding of ASD and different ways of coping. Tsoi recommended that educating Chinese

community leaders, support agencies and health care providers about ASD will ensure that accurate information is provided to Chinese-American families when they reach out for support from these agencies.

## Chapter 4: Discussion

### Key Findings and Gaps

Thirteen research articles were identified for inclusion in this scoping review. Analysis of the articles yielded four main themes: culture and community (the most frequently occurring theme) bilingualism (the most common major theme), parental responses to ASD, and culturally safe service provision. The most significant finding was that service providers commonly recommended monolingual language practices to ASD children of immigrant families. Studies addressing bilingualism in children with ASD emphasized the value of heritage language maintenance to immigrant families, in contrast to the professional view which favoured use of English language with the child. (Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010; Petersen, Marinova-Todd, & Mirenda, 2012; Yu, 2010; Yu, 2013; Yu, 2016). Heritage language maintenance was found to benefit the child with ASD by facilitating communication with the elders in the family (Jegatheesan, Fowler & Miller, 2010; Yu, 2013), allowing full immersion in religious practices (Jegatheesan, Miller & Fowler, 2010), and facilitating intimacy with family members (Yu, 2010).

The cultural practices of immigrant families were found to be diverse, unique to each ethnic group, and in some cases opposing Western views and understanding of ASD, thereby creating tension between service providers and families (Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010). Another common theme in the research findings was the evidence of culture specific parental responses to ASD such as perceived stigma related to having a child with ASD, which resulted in social isolation (Huang & Zhou, 2016; Tarian, 2015). In contrast, other cultures considered parents who were raising children with autism as chosen for a special mission by a higher power (Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010). Despite the struggles with social isolation, accessing services, lack of culturally sensitive services and language barriers experienced by the participants in the research studies included in this review, results from two studies indicated that families achieved personal strength and growth by educating themselves and others about caring for children with ASD (Wang & Casillas, 2012; Tarian, 2015).

Finally, the findings of this scoping review suggest that there is a critical gap in the research literature addressing the impact of ASD among Canada's largest recent immigrant



groups (i.e., families from the Philippines, India, China, Iran and Pakistan). The most frequently studied immigrant population was from China or those speaking Mandarin and Cantonese. There were no published studies addressing the immigrant population from the Philippines.

## **Implications**

Research Question 3 posed in this review was answered by synthesising and analyzing the results from Research Questions 1 and 2. The implications for policy, practice and research are discussed below.

### **Implications for policy.**

The findings of this review may provide direction for policy makers about immigrant families' needs in caring for a child with ASD. Shepherd and Waddell (2015) stated that Canadian policy on autism has a history of conflict between policy makers and families advocating for more comprehensive services for children and their families. The authors highlighted the need for policies that offer “a more comprehensive approach to autism services - across the spectrum of and throughout the lifespan” (p.3562). Immigrant families with ASD children reported having to modify work hours to care for the child, and uncertainty about child care, as having an impact on family income and an added stressor. Therefore, policies that address child care support for families with ASD children should be considered. In addition, policies that ensure language support for immigrant children diagnosed with ASD may facilitate improved language learning outcomes and should be prioritized.

Literature identified in this review highlighted the influence of culture on how families understood, accepted and participated in treatment of ASD, which is consistent with previous research on culture and autism. Policies that support cultural competency and awareness training for service providers would facilitate better communication and collaboration between the diverse immigrant population of Canada and therapists (Ennis-Cole, Durodoye & Harris, 2013).

### **Implications for practice.**

Deficits in social interactions including verbal and nonverbal communication as well as challenges in social reciprocity are common characteristics of children with a diagnosis of autism (American Psychiatric Association, 2013). Therefore, research suggesting that children diagnosed with autism may be capable of bilingual language practices (Petersen, Marinova-Todd

& Mirenda 2012) should be further explored so that best practice guidelines are established for future recommendations to bilingual immigrant families.

The belief systems of immigrant families may differ from the beliefs systems of practitioners in the Western medical system, and this difference has been implicated in the families' experiences with Western clinicians and treatment planning (Welterlin & LaRue, 2007; Daley, 2002). Culture may also impact how difficult behaviours are perceived and reported by parents or caretakers (Chung et al., 2011). Although each family will have unique circumstances for healthcare practitioners to consider, the findings of this scoping review suggested that factors such as culture, language and community are important considerations when interacting with immigrant families who are raising children with ASD. A lack of knowledge and awareness of these contextual factors may contribute to tension between immigrant families and European-American clinicians resulting in suboptimal service provision. Competency in culturally safe practice is required for effective service provision to immigrant families who have a child with ASD.

#### **Implications for research.**

Findings that there is paucity of research on immigrant populations from the Philippines, India, Iran and Pakistan are consistent with Elsabbagh and colleagues' (2012) systematic review that concluded that there is a dearth of studies more generally on the impact of ASD on immigrant families' experiences. Considering that approximately 190,000 immigrants arrived in Canada from the Philippines between the years 2011 and 2016 (Statistics Canada, 2017d), this population needs to be better represented in current research so that practitioners are able to provide appropriate services.

Research addressing autism in the immigrant population is a complex issue including the need to attend to ethnic or cultural differences and other family contextual factors. However, in their recent exploration of research literature on learners with a diagnosis of ASD, West et al. (2016) found that study participants were predominately White youth with a limited representation of other ethnicities. Moreover, in their review of three journals that focus on autism, Pierce et al. (2014) noted that the majority of studies did not report the race of participants or consider ethnicity as a variable in their data analysis of findings. There is clearly a need for research in developmental pediatrics to represent the immigrant population better

through increased efforts in the recruitment of diverse samples and the inclusion of factors such as ethnicity, culture, and immigration in the data analysis of future research findings.

No research studies were found that focused on experiences of fathers, siblings or grandparents of children diagnosed with ASD; while two studies focused on mothers' experiences and one study focused on the experiences of service providers. Eight studies had mixed samples with a combination of mothers, fathers, couples and grandparents. More comprehensive inclusion of other family members or caregivers is needed in future research to better understand the impact of ASD. In the study by Tsoi (2016), US born Chinese-American families fared better than China born Chinese-American families with respect to acceptance of the diagnosis, communication, and coping styles, suggesting that immigrant families' experiences may change over time. Longitudinal studies looking at the effects of acculturation and resulting changes in immigrant families' experiences are needed to appreciate changes over time. At a minimum, years of residence in their new country should be accounted for in data analysis and interpretation of findings.

### **Limitations**

This scoping review provided a systematic search of three databases for relevant literature addressing immigrant families who have children with a diagnosis of ASD. Additional databases and search engines were not searched due to limited time and resources. The literature search for this review focused on only five immigrant populations and was limited to research studies published between January 2008 and February 2018. The study selection process for inclusion in this review did not involve a quality check; rather, selection was based on meeting the inclusion criteria and relevance to the research questions as is common practice for scoping reviews (Grant & Booth, 2009).

### **Conclusion**

This scoping review examined 13 published studies that have addressed the experiences of immigrant families from the Philippines, India, China, Iran and Pakistan who are raising children diagnosed with autism and are residing in Canada or the US. These countries were identified as representing recent immigrant populations with the largest numbers in Canada. Four main themes to guide policy, practice and research were identified in the literature: culture and community, bilingualism, parental responses to ASD, and culturally safe service provision.

Bilingual language practices were found to be highly valued by immigrant families and may not disadvantage children diagnosed with autism. Culturally sensitive practices were found to facilitate communications and service delivery to immigrant families. Canadian policies need to address the needs of immigrant families who are struggling to access services for their children. Canada has a long history of ethnic diversity and immigration; therefore, research needs to be inclusive of ethnic minority groups so that best practice guidelines are developed and applied to all Canadians seeking health care and education.

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