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Immigrant Parent Perceptions of Disability and Special Education Services

by

Sally Ratemo

A Starred Paper

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Chapter 1: Introduction

People in other countries, especially impoverished countries, have looked for centuries at the United States as the land of opportunity. Families immigrate to the United States for various different reasons: political conflicts, economic opportunities, education, reunification with family, and a combination of these and other concerns (Ueda, 2011). These immigrant families come to the U.S. hoping to provide their children with a better life and advanced educational opportunities. After arrival, they are sometimes unable to understand the educational system (Choi & Ostendorf, 2015). Furthermore, they are often unable to communicate their needs and expectations with regard to their children's education.

Schools in our country are required to meet the needs of diverse students and inform the parents of their rights and responsibilities. Specific to students with disabilities, parent involvement is a legal right mandated originally with the passage of the Education for All Handicapped Children Act in 1975 and maintained in each reauthorization of the law since that time (Hallahan, Kauffman, & Pullen, (2009). Unfortunately, despite the 40 years of such mandates, U.S. special education programs still lack active involvement and participation from parents of diverse cultural and linguistic backgrounds (American Immigration Council, 2012).

Cultural perceptions also play a major role in how or whether immigrant families address the diagnosis of a disability in their families and how and whether they access special education services. Parent perceptions affect the way families interact with school and agency personnel and play an important role in their communication with these professionals (Choi & Ostendorf, 2015). Thus, the purpose of this paper is to examine the research on immigrant parent perceptions of disability and special education services.

Historical Background

Europeans began immigrating to the United States early in the 17th century and brought with them different belief systems, religions, languages, and cultures. Based on the demographic variety that formed a single national identity, the U.S. is often referred to as the “Great Melting Pot” (Ueda, 2011, p. 1). Immigrants have continued to come to the U.S. since the country was founded, and the 1990s brought an influx of immigrants exceeding any previous decade in the history of our country (Nieto, 2009). In 2013, approximately 41.3 million immigrants lived in the United States, and immigrant children comprised 25% of the 69.9 million children under age 18 in the United States (Batalova & Zong, 2015). This diversity can be observed in the malls by the increase in number of ethnic stores, in the supermarkets, which now provide ethnic aisles, in ethnic restaurants offering an array of worldly menus, and also in our school systems where numerous ethnicities are widely represented.

Although large numbers of immigrant families view a move to the U.S. as the open door to endless opportunities, issues arise preventing this transition from taking place with ease. Requirements must be met in order for people to immigrate legally. With legal immigration comes access to social security benefits, healthcare, and education, among other perks (Levinson, 2002). However, it is estimated 3.7% of the nation’s population now consists of undocumented immigrants (Gusmano, 2012). These numbers also include children who are caught up in this illegal transition.

Parents often find ways to enroll their children in schools, hoping their children will have the opportunity to better their lives by accessing the American education system and all the benefits that come from such access. The Supreme Court of the United States issued a landmark

decision in the 1982 *Plyler v. Doe* case, ruling states cannot constitutionally deny students a free public education on account of their immigration status (American Immigration Council, 2012). *Plyler v. Doe* argued against keeping students from their education affecting their social, economic, intellectual, and psychological well-being and posed obstacles to their individual achievement (James & Outman, 2004). Despite this Supreme Court ruling, some states enact rules against equality and deny educational opportunities for immigrant students, especially those from families who reside illegally in the U.S. (Shapiro & Derrington, 2004).

Societal Challenges

Depending upon whether the immigration process was legal or illegal, the transition in to this new society can present multifaceted challenges, especially when a child is diagnosed with a disability. Recent immigrants face numerous challenges when establishing themselves economically and socially. These challenges include language barriers, lack of information, previous negative educational experiences, unfamiliarity with U.S. educational practices, different views regarding parent involvement and help-seeking behavior, and cultural perceptions regarding disability (Bailey, Correa, Gut, Rodriguez, & Skinner 1999). Other challenges include placing their children with disabilities in U.S. schools. Immigrant children's behavior might differ greatly from the school expectations (Haines, Summers, Turnbull, Turnbull, & Palmer, 2015). Al-Hassan and Gardner (2002) referred to numerous developing countries not having mandates and laws for educating children with disabilities. As a result, some immigrants may not be aware of their right to ask for special education services for their children. When parents lack understanding of the educational services and are not involved

with their children's education, students' academic achievement is negatively affected—and this is particularly true for minority groups (Choi & Ostendorf, 2015).

Parents' lack of understanding of the educational services available for students with disabilities may be due in part to their limited English proficiency. The term *Limited English Proficient* (LEP) refers to persons age 5 and older who reported speaking English "not at all," "not well," or "well." Individuals who speak only English or who speak English "very well" are considered proficient in English (Batalova & Zong, 2015, p. 6). According to the Migration Policy Institute, 25.1 million LEP individuals reside in the U.S., which is approximately 8% of individuals over the age of 5. Spanish speakers account for 64% of the total LEP population, Chinese Mandarin or Cantonese account for 7%, and Vietnamese account for 3% (Batalova & Zong, 2015).

It is vital for educators to understand and take into consideration immigrant families' perceptions and understanding of disabilities based upon their cultural context. Educators must also consider immigrant families might have never received support for their disabled child in their country of origin, so they might not realize the services and resources available or the right to inclusive education for students with disabilities. Due to the lack of support for people with disabilities in their home country and the perceived stigma attached to those disabilities, children with disabilities may be kept at home and kept from public view (Hatmaker, Pinzon-Perez, Khang, & Cha, 2010).

Cultural perceptions of disabilities and special education continue to play a major role in immigrant families' perception for the diagnosis of a disability in a family member. This same acceptance also plays a major role in their access to special education services for their child

with a disability. Issues such as language barriers, religious beliefs, and cultural perceptions continue to plague immigrant families in their pursuit of providing stability and access to free and appropriate education for their children with disabilities.

Research Questions

Two questions guided the development of this starred paper:

1. How do immigrant families in the United States perceive disabilities?
2. How do immigrant families in the United States perceive special education services?

Focus of the Paper

I reviewed studies investigating the perspectives, thoughts, and attitudes of immigrant parents and family members regarding special education services or a disability diagnosis. I located only qualitative research studies on this topic, and these were included in Chapter 2 if they were published in the period 2000-2015. Studies and articles published earlier were included in Chapter 1 to provide a historical context.

Using the Academic Search Premier, ERIC (Proquest), ERIC (EBSCO), LibSearch, Google Scholar and PsycINFO databases, I applied various search strategies to locate information on the topic: *immigrant parents, perceptions, special education, disabilities, special education process, culture-based concepts of disability, special education disparity, exceptional children and cultural diversity*. I searched the PQDT Open website to establish dissertations' research on this topic. Finally, I searched the tables of contents of two journals: *Multiple Voices for Ethnically Diverse Exceptional Learners* and *Journal of Special Education*.

Importance/Rationale

My family moved to Minnesota from Kenya in October of 2000. As a young child in Kenya, my younger brother showed little interest in school. Once in the United States, during his continued struggle in school, my parents received numerous calls and attended meetings with school staff to address his issues. The teachers expressed the belief that my brother had the ability to perform, but in comparison to his peers, he needed to be more challenged by the information he was receiving in his classes. They thought he might benefit from a special education evaluation to determine his needs. As soon as the words *special education services* were uttered, my family shut down any further conversations with the school with regard to my brother being evaluated for services. My brother's educational struggles continued through high school and after high school. He refused to further his education, saying school was not for him. When I think back to my educational experience in Kenya, I saw no students with visible disabilities attending my school. My exposure to children with disabilities was either in orphanages, on television, or beggars on the streets. This level of exposure undoubtedly contributed the stigma my parents attached to the special education label. Their reaction also reminded me why immigrant families may struggle with accepting their child's diagnosis of a disability and their subsequent refusal of special education services. From my family's experience, preconceived notions on the character of special education and the labels, which come with receiving those services, hindered my parent's acceptance of assistance. An acceptance that would possibly have changed my brother's view on school and his life.

It is vitally important for immigrant families to know special education services and which special education services are available to them, in order for their children to gain

access. I hope this starred paper will provide information for both parents and educators. For parents, these findings will help understand that there is no shame in disabilities and that special education services provide an opportunity for their children to be successful. For educators, this paper will bring about a greater awareness of the cultural differences of diverse populations they encounter on a daily basis and encourage educators to be more aware and culturally responsive, especially to immigrant families.

Definitions

Culture is a way of life of a group of people, the behaviors, beliefs, values, and symbols they accept, generally without thinking about them, and are passed along communication and imitation from one generation to the next (Texas A & M University, 2015).

Diversity encompasses acceptance and respect. It means understanding how each individual is unique, and recognizing our individual differences. These can be along the dimensions of race, ethnicity, gender, sexual orientation, socioeconomic status, age, physical abilities, religious beliefs, political beliefs, or other ideologies. It is the exploration of these differences in a safe, positive, and nurturing environment. It is about understanding each other and moving beyond simple tolerance to embracing and celebrating the rich dimensions of diversity contained within each individual (Queensborough Community College, 2015).

Ethnicity is a term representing social groups with a shared history, cultural practices, perspectives, sense of identity, geography and cultural roots that may occur despite racial differences. Ethnicity is a shared cultural heritage. The most common characteristics distinguishing various ethnic groups are ancestry, a sense of history, language, religion, and

forms of dress. Ethnic differences are not inherited; they are *learned* (National Center for Educational Statistics, n.d.).

Disability is a physical or mental impairment to substantially limit one or more major life activity. This definition includes people who have a record of such impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability. The ADA also makes it unlawful to discriminate against a person based on that person's association with a person with a disability (Americans with Disabilities Act, 2009).

Education for All Handicapped Children Act (P.L. 94-142) was signed into law by President Gerald Ford in 1975. This law was created in an effort to provide an appropriate education for the millions of children with disabilities who were not receiving a proper education. PL 94-142 required all schools receiving federal funding to provide handicapped children equal access to education and mandated they be placed in the least restrictive educational environment possible. PL 94-142 encouraged states to create policies and practices facilitating the needs of all students with disabilities. The most recent reauthorization of this law is the Individuals with Disabilities Educational Improvement Act of 2004 (Moody, 2012).

Locus of Control is considered to be an important aspect of personality, which refers to an individual's perception about the underlying main causes of events in his/her life. A locus of control orientation is a belief about whether the individual believes that his/her behavior is guided by his/her personal decisions and efforts (internal locus of control) or if the individual believes that his/her behavior is guided by fate, luck, or other external circumstances (external locus of control) (Neil, 2006).

Chapter 2: Review of the Literature

The purpose of this paper was to review the literature investigating the attitudes and perceptions of immigrant parents toward disability and special education services. The nine studies in this chapter examine cultural perceptions of disability, limitations caused by disability, the grieving process for the family of a child with a diagnosis, parental hopes and wishes for their child with a disability, the diagnostic process, the special education process, and communication/language barriers. Studies are presented in ascending chronological order. Perspectives of immigrant parents from various cultures are examined. Studies are organized by the country of origin and include parents from Mexican, Korean- American, Korean, Arab- American, Hmong, West Indian, Haitian, South Asian Muslim, and Somali cultures.

Mexican Immigrant Mothers

Kummerer, Lopez-Reyna, and Hughes (2007) conducted a qualitative study to explore mothers' perceptions of their children's communication disabilities, emergent literacy development, and speech-language therapy programs. They interviewed 14 Mexican immigrant mothers in Chicago and also reviewed their children's therapy files and log notes. The children ranged in age from 17-47 months and were receiving center-based services in an early childhood intervention program for at least a year.

Data were triangulated among interviews with the mothers, therapy files, and log notes. The researchers confirmed the categories emerging from those interviews by also reviewing therapy files and log notes. The mothers' perceptions over time were explored in four categories: receptive and expressive abilities over time, children's speech and/or language

delays, children's emergent literacy abilities, and effective language intervention with Mexican families. Themes emerged within each of these categories.

The first category encompassed all mothers who believed their children's expressive language was "fine," even though six of the 14 children were diagnosed with receptive language delays (Kummerer et al., 2007, p. 275). In contrast, the second theme addressed receptive language and found 11 mothers were concerned about their children's expressive language. The third theme revealed as therapy progressed, 13 of 14 mothers recognized the improvement in their child's communication.

In the second category of perceptions of their children's speech and language delays, three themes emerged. The first theme related to initial identification of the delay. Although 12 of the 14 mothers were aware their children had some type of delay, they seemed upset by the use of the word *disorder*. In the second theme of perceived causes of the delay, mothers varied greatly in their perception of the cause of the delay. For example, one mother attributed the cause to lack of extended family members in the home, one thought oral cavity problems were the cause, and another mentioned cutting her son's hair at 9 months of age. Delays were also attributed to heredity and chronic ear infections, and one mother attributed the speech delay to her child's female gender. The perception of delays across time was the third theme. Eight mothers believed the delay was no longer present after the child participated in therapy for several months, even though six continued to demonstrate significant delays.

The third category addressed perceptions of emergent literacy abilities, and three themes emerged with regard to how children used books and writing. Mothers reported their children scribbled, colored, and formed letters and they were involved in the process. The second theme

revealed how their children interacted with picture books and books with text. Their children turned pages, pretended to read, and vocalized to pictures. The majority of the mothers were highly concerned about the children handled materials, and they often denied their children access to materials because they feared the children would damage them. The third theme showed mothers did not perceive these interactions with books or writing to be meaningful. The final category addressed clinicians' ability to improve speech language therapy for children from Mexican homes. The mothers' first suggested clinicians speak Spanish or provide interpreters. They expressed frustration about doctor visits and appointments with other professionals not understanding their children's difficulties. Second, mothers did not understand pediatrician's orders for speech and language services. They were uncertain of the practices used by clinicians and felt the same techniques should be used for all children regardless of ethnicity.

According to the authors, these mothers' perceptions have implications for speech-language services. Clinicians should explore mothers' perceptions for the cause of communication difficulties, and they should provide examples of "different components of the language system" (Kummerer et al., 2007, p. 278). Mexican immigrant families should be taught to recognize the meaningfulness and importance of emergent literacy behaviors and how to support literacy development. Clinicians need to explain speech-language therapy, the reason to be recommended, and the reason parent involvement is important.

Korean-American Parents

Cho, Singer, and Brenner (2000) conducted a comparative study of the adaptation of Korean and Korean-American parents to their children with developmental disabilities. The

study was conducted in Pusan, Korea, and Los Angeles, California. Groups of 16 mothers were formed in each location, and interviews were conducted with each mother. Three interview protocols were developed to explore parents' experiences and concepts, family stress factors, and clarification of interview responses.

The children in Pusan attended segregated public schools for children with disabilities from kindergarten to grade 12. Children in both groups had disabilities such as autism, Down's syndrome, and multiple disabilities ranged from mild to severe.

Results showed parents in both groups reacted in various ways to the news when their child had disabilities by expressing shock, shame, self-blame, sorrow, denial, and anger. Mothers reported their child cried frequently for the first several months following initial diagnosis: 35% were distressed for the first several months, 46% were distressed for approximately 1 year, and the remaining 19% reported high levels of negative emotions for nearly 2 years. Across both groups, 44% of the mothers reported plans to commit suicide with their disabled child as a response to the problems they encountered. Although mothers were able to resolve their feelings, the majority (63% Korean and 83% Korean American) reported periodic times of negative feelings during times of stress.

Different social and cultural factors influenced how mothers perceived the cause of disability. Eighty percent of Korean mothers attributed the disability to their own actions such as prenatal practices and mistakes in early parenting. Korean-American mothers adopted religious views to deal with self-blame. Seventy-five percent of Korean-American parents believe the church changed their feelings of hopelessness.

Interview results showed that several factors contributed to their stress and demands of raising a child with a disability. These included the child's inappropriate behaviors, public attitudes about disability, transportation, educational expenses, and language barriers. Severe behavior problems made it difficult to find childcare in both groups, especially during emergency situations when relatives were asked to provide child care. Both groups cited public embarrassment as a problem, and Korean mothers reported it twice as often.

With regard to public attitudes, Korean mothers reported experiencing more displeasure from the public, perhaps due to more reliance on public transportation (they had to be in a bus or subway 1.5-3 hours per day to access services). Many of these experiences contributed to more stress and strain within the Korean population. Korean-American mothers used private automobiles and believed that non-Koreans in the U.S. were more accepting and knowledgeable of people with disabilities.

The longer history of disabilities services in the U.S. not only reflects more positive public attitudes, it also allows families to access free and appropriate special education services. In Korea, however, early childhood special education services cost 15-20% of the family's income. Even though services are free in the U.S., language barriers made it difficult for Korean-Americans to obtain the services. They reported dissatisfaction with the translators provided at the meetings. Korean-American mothers reported that the U.S. was a better place to raise a child with a disability, and several reported that they came to the U.S. to obtain these services.

The previous challenges did not seem to affect a parent's long-term reaction to having a child with a disability, and they indicated their lives had changed for the better. In both groups,

parents expressed love and gratitude for their child, and reported that they were less selfish and more compassionate. Ultimately, 63% Korean and 81% Korean American mothers reported initial negative reactions compared to positive ones. The majority of parents adjusted to their lives and their routines changed in response to the challenges of raising a child with a disability.

This study demonstrates that regardless of cultural and social factors, families in each country transformed initial negative emotions into positive emotions. Cho et al. (2000) emphasized the need for practitioners to be aware of suicidal ideation during the first 2 years following diagnosis. Providers should also address concerns of Korean American parents who had difficulty with obtaining services including translators. This study illustrates what impact the provision of services and supports can have and how much families appreciate these supports. When these services are not available, undue expenses and long travel times are required.

Korean Parents

Park and Turnbull (2001) investigated the perceptions, levels of satisfaction, and concerns of Korean parents of children with disabilities regarding the special education services they have been receiving or seeking in the U.S. Park and Turnbull conducted in-depth native-language interviews with eight Korean parents from seven families who had children with disabilities. Among the seven families, four families were U.S. citizens, one family had U.S. resident status, and the other two had foreign student (F-1) status. One child received home-visit services only, one child was in preschool, three were in elementary school, and two were in secondary school. The children ranged in age from 4 to 14 years old. Five families had a child with mental retardation, and the other families had a child with a hearing impairment.

Audiotaped interviews were transcribed and themes generated. Themes from the data analysis included: (a) parents' satisfaction with special education services in America, (b) experiences related to exchange of information with professionals, (c) need for a mediator, and (d) parents' perceptions of inclusion services.

All participants expressed satisfaction with certain aspects of the American special education system and disability-related policies. Three families reported that they came to or decided to stay in the U.S in order to obtain better special education services for their children with disabilities. The other parents expressed relief that they lived in the U.S. because they perceived the best special education services are provided in this country. Parent satisfaction was categorized into three subthemes: (a) adaptation and individualization, (b) parents as partners, and (c) entitlement to benefits.

Adaptation and individualization. Parent satisfaction seemed to depend on the quality of education their children received. Participants praised the curriculum adaptations, the attention their children received, and the level of care and the number of people who cared for their children.

Parents as partners. In the Asian culture the school system and teachers are highly respected. This can sometimes contribute to situations in which parents agree with professionals' recommendations and opinions, even when they have a different opinion. In turn, this may contribute to increased likelihood of treatment noncompliance in the home. However, Korean mothers in this study seemed excited to be regarded as part of their children's team. Two mothers reflected that obedience and silence are not virtues in the U.S when it came to their children's education.

Entitlement to benefits. Traditionally in the Asian culture, a disability was interpreted as a “punishment from God” or genetic problem in pedigree or parental neglect. Consequently some parents may regard their children with disabilities as a burden and an indicator of inferiority. This was not the case for participants of this study. They appreciated their children with disabilities. This appreciation was seen mostly in the families that were eligible for benefits because of their child with a disability; three mothers in the study had husbands or ex-husbands who were in the military and were recipients of additional benefits from the military such as free taxi service, housing priority, and medical check-up and treatment with no or very low cost. Other families not in the military also indicated that received privileges such as no wait times in hospitals (all appointments were pre-scheduled) and handicap/designated parking spots. These privileges seemed to help families accept their children with disabilities more positively and willingly. Four of the families were receiving Medicaid benefits and one single mother was in the process of applying for Social Security Income (SSI). The families also expressed appreciation for free education, free transportation, and the free lending of assistive technology. One family of non-citizens reported that the lack of citizenship excluded the family from common financial benefits such as Medicaid and SSI. The child in this family was not eligible for free hearing aids during this study but in due time would require a pair. The family was given an estimated cost of \$40,000 after surgery and \$400 each time they visited the audiologist. The family reported that as soon as the father finished school, they return to Korea because there were no other financial assistance alternatives for their child in the American system as long as they could not change their citizenship status.

The second theme was exchange of information with professionals. English proficiency of the eight Korean parents varied significantly. Some liked face-to-face communication, whereas others preferred written communication or phone calls. Four subthemes were identified: (a) a desire to know about their child's school life, (b) limited English proficiency, (c) the IEP meeting and (d) the communication style coming from the compliant culture.

Desire to know about their child's school life. Parents reported receiving too many written referrals that they did not have time or language proficiency to read. Many expressed the desire to learn more about their child's day at school, especially parents of nonverbal children who wanted to know more about daily routines such as toileting and feeding. This conflict between wanting more information and receiving too much information was described as something that prevented the parents from describing their exact needs for written information about their child's school life. Parents expressed hesitation about visiting their child's classroom because they were afraid the teacher might feel uncomfortable about their presence.

Limited English proficiency. Interviews revealed that parents began using special education terminology without clearly understanding the exact meaning, especially when the parents are not native speakers of English. Some mothers reported being completely dependent upon their husbands—who had better English skills—to explain information the school provided. Although this may have involved fathers a bit more in their children's education, this reliance also sometimes evoked spousal conflict when the mother felt left out of the communication.

Making the IEP work. All the parents in this study reported they became nervous when sitting in a meeting to hear professionals give progress reports or to outline new objectives and special instructional support. Parents asked to be prepared before the meeting about what they

would talk about so they could have time to summarize concerns and suggestions for the new objectives.

Communication style coming from a compliant culture. Many of the parents admitted that although they see themselves as part of the team, they were still influenced by their traditional values that placed emphasis on respect for authority. Proposing opinions or asking questions went against this value. One mother reported that it was difficult for her to interrupt professionals to seek clarity when she did not understand what was being said. Another mother said that she wished American special education professionals would regularly check throughout the meeting for comprehension instead of assuming that parents' lack of questions meant everything was clearly comprehended.

The third theme that emerged was the need for a mediator. Five of the seven families had experiences with getting help from Korean-American mediators who were mothers of children with disabilities and were proficient in both Korean and English. The participants acknowledged the mediator's help by saying they could not imagine surviving without their help. The need for a mediator was examined in three subtopics: (a) the problem with interpreters, (b) examples of mediator's roles, and (c) assistance with orientation.

The problem with interpreters. All participants reported they knew interpreters were available for important meetings such as the IEP meeting, although only one mother used an interpreter and only because of her dissatisfaction with the process. However, she indicated the interpreter was more focused on delivering the professionals' message instead of caring what she wanted to say. Findings revealed parents did not perceive direct translation to be enough. They

expected more than simple language translation. The illustrations of help from mediators render some insights into what kind of help the families needed and welcomed.

Examples of mediator's help. Five of the seven families were located through mediators, and they expressed appreciation for the mediator's support. The mediators typically had children with disabilities, experienced the special education system in the U.S. for a long time, and were knowledgeable about parental legal rights and procedural safeguards. Mediators assisted with hospital visits, school meetings, transportation, and acquisition of resources such as SSI. The parents in this study seemed comfortable with accepting the mediators because they were Korean like themselves and they had children with disabilities, making them have no feelings of "losing face." The parents were appreciative of the mediators connecting them with other Korean families of children with disabilities, which broadened their support network.

Assistance with orientation. Three of the seven families stressed the need for a mediator to help them navigate the special education system. These families said that they regretted not receiving the orientation immediately after arrival in the U.S. so that they could better access the special education system and handle difficulties when the mediators were not available.

The last theme was parents' perceptions of inclusion services. Five of the seven parents preferred self-contained classrooms because they perceived their children would receive more teacher attention. They believed the more time their child spent with their special education teacher, the greater the chances the child could be "cured" from the disability. Two participants expressed the desire for their child to be cured more than the rest. One enrolled her child in a private early intervention program where the parent received training to implement intensive

intervention plans at home. This focus on a cure did encourage parent to follow through consistently on professionals' recommendations. Sometimes the interventions created barriers to for the children with disabilities, affecting ways they were receiving appropriate education by encouraging parents to stick to intensive therapy and individual instruction, thereby creating obstacles to inclusion where some families believed that children included in the general education setting would not get sufficient therapy and special instruction.

Park and Turnbull (2001) reported some limitations to this study. As with many special education studies, the study included a small number of participants. Another limitation was some of the interviews were conducted via telephone, which may restrict the source to verbal communication with participants because they lived in diverse places; from far west (Washington) to east (Virginia). Richer information could have been collected through direct observation of parents and children in different settings such as school and doctor appointments.

Arab American Parents

Donovan (2013) conducted a phenomenological study to examine the experiences of Arab American parents with their children's special education process. Six Arab American parents were interviewed for this study. Four parents were born and educated in the Arab world and two were American born. Each family had at least one child who had been referred for a special education evaluation, with a total of six boys and three girls. Their identified disabilities ranged from visible disabilities (genetic disorders) to invisible disabilities (specific learning disabilities). Data were collected through interviews and addressed six areas: (a) parental beliefs and understandings of children's disabilities, (b) the impact of children's disabilities on parents,

(c) parent supports, (d) parent advocacy, (e) parent-school communication, and (f) parents' goals and expectations for their children.

Parental beliefs and understanding of their children's disabilities were tied to their cultural-specific perspectives on disabilities. In comparison to the independent American culture where disabilities are considered to be developmental delays in developmental areas, the Arab interdependent culture has a greater range of disability acceptance because the culture has fewer requirements for independence. The difference between independent and interdependent cultures is the prioritization of skills for individuals with disabilities. In independent cultures, the focus for the individual with a disability is on individuality and self-esteem, whereas in the interdependent culture the focus is on interpersonal skills and obedience.

The impact of children's disabilities on parental functioning was tied to feelings of guilt, self-blame, depression, frustration, stress, and helplessness. This finding was specific to parents of children with autism spectrum disorders (ASD), who reported they experienced more conflict, divorce, and demands in comparison to others. Two issues related to parents' coping skills were available supports and advocacy.

Parents indicated many supports including respite care and short-term care were available to assist them in accepting and caring for their children with disabilities. These supports provided direct relief as well as benefits such as improved family life and decreased parental stress. Teacher and parent support groups also helped parents understand their children's disabilities and contributed to less stress and negative affect. These programs were most effective when they were geared at meeting individual family needs.

Appropriate and sensitive cross-cultural communication was key to enhancing acceptance of their children, knowledge of disabilities, and utilization of family supports. Some parents had positive responses to the cultural sensitivity displayed, whereas others were overwhelmed and confused by the complex and technical terminology. Respectful communication was referred to as jargon-free language, open-ended questions to check for parent understanding, and attention to parents' verbal and nonverbal body language.

Parent expectations and goals for their children shifted when their child was diagnosed with a disability. Parents grieved the loss of their ideal child and optimistic expectations and envisioned the caregiving that accompanied this loss. Some parents experienced denial regarding the identification of their children's disabilities. Arab American families' values stemmed from their interdependent orientations. Therefore, parents' expectations and goals for their children were closely related to their perspectives on their child's development and culturally informed belief systems. These values can cause conflict as professionals conceptualize disabilities, set goals, and select appropriate interventions for immigrant children.

Four core themes emerged that related to the referral, evaluation, and identification process. The first core theme related to the stigma associated with special education. Some parents believed having children with disabilities would result in poor future marriage prospects for the entire family. The second theme involved the special education services their children received and the key relationships built or maintained by the parents during the special education process. The third theme focused on parent reflection of the process and included the children's strengths and difficulties, parent understanding of special needs and special education, and the importance of some parents' own advocacy work. They discussed the importance of their

children's right to respect and attitudes of equality and self-confidence. The final core theme examined parents' expectations, plans, and goals for their children after experiencing the special education process. The participating parents' goals for their children were unchanged by the special education process and consideration of their children's disabilities.

According to Donovan (2013), service providers would benefit from knowledge regarding these contrasting cultural orientations and their impact on parental decisions and values. An appreciation for parents' potential reactions to the identification of disabilities in their children is also important. The author attributed the lack of literature regarding the Arab American population to the lack of research and also the reluctance of Arab American families to allow their children with disabilities to be classified for special education eligibility.

Hmong Parents

Vang and Barrera (2004) conducted a study in which they used semi-structured interviews to explore ways in which educators could involve parents of English language learners with disabilities in the educational process. Two of the six female Hmong participants could speak English fluently. The interviews were used not only to gather basic information about the families and the student's strengths and weaknesses, but also to gather parent feedback regarding specific reading strategies the teachers used with their English language learners with disabilities. The interview protocols were available in both English and the family's native language.

The findings suggested that parents had different perceptions regarding the cause of their children's disabilities. One parent responded she did not know the cause of the disability, two reported it was because the children were born premature, one attributed it to their child eating

foods with chemicals in America, one said it was because there was a tumor in the child's brain, and one indicated it was because a cord in her child's brain broke. These parents wished for their children to be able to read and write, become self-sufficient, and complete high school. The findings revealed Hmong parents are highly concerned with and have contributions to make to their children's education. Parents were found to be involved and looked for ways to improve their children's education, especially with regard to academic progress in English. This study also identified three methods to better involve parents:

1. Gain assistance through cultural advisory panels and recruiting cultural/linguistic interpreters for Hmong cultural advisors. This was shown to increase the parent participation and generated higher quality responses.
2. Gather background data about the Hmong families to provide a better understanding of the struggles faced by Hmong parents of children with disabilities when trying to access educational equity for their children. Because teachers in the Hmong culture are viewed as experts and are held in high regard, parents may hesitate to question or speak out about strategies the educators are using.
3. Understand how parents view the cause of their children's disabilities. The 2 parents who were fluent in English were knowledgeable about the "American" culture and could express their perception of the cause of their child's disability. The other parents who were less fluent attributed the cause of the disability to factors that were perhaps related to cultural perspectives of the causes of disabilities.

This study determined that Hmong parents need help to understand the process through which learners typically acquire a second language. These parents seemed to focus more on

whether to use the Hmong or English language to use to instruct the children rather than the use of specific learning strategies. The parents were concerned their children would fail to learn English if the Hmong language was being taught in the classroom. Parents were also concerned with the perceived lack of progress, especially in reading.

This study also found the need to explore ways in which Hmong parents with children with disabilities could be included so they can meaningfully participate in the education of their children. When native learners' language have no strong history of print literacy, more efforts must be made to improve communication between parents and the school. The six parents in the study expressed concern over the unique problems they faced not only with cultural and language barriers, but also as parents of children with disabilities. They reported these difficulties made them feel isolated and without viable options for how to access support for their children with disabilities.

A larger number of participants would have provided a better sense of parent perceptions, and the lack of male parents makes it likely that the responses were only partially reflective of parent concerns. Because participants were all acquired through the parent advocacy group, parents may have already been interested in the educational improvement of their children. These results could be different with other parents who were not involved in parent advocacy groups. Another limitation is that the gender imbalance of the children made the group unrepresentative. In the Hmong culture, boys are treated differently, which could affect parent perceptions of a female child with disabilities.

West Indian Parents

McLeod (2012) conducted semi-structured interviews with three first-generation West Indian families to examine their perception of their children once they were determined to be eligible for special education services. The study took place in a southeastern U.S. state with English-speaking parents of secondary-age students. Three mothers and two fathers were either from Jamaica or Bahamas and had lived in the U.S. approximately 20 years. Their children included two adolescent boys and one girl; one with autism, one with learning disabilities (LD), and one with Attention Deficit Disorder (ADD), who received special education services in the disability category of other health impairment (OHD).

One theme was identified during this study: the family's spectrum of understanding. Embedded within this theme were two conceptual categories: (a) the family's cultural meanings and definitions of disability, and (b) the family's changing views in response to the impact of special education placement and services. McLeod (2012) found that although families could identify the disability label under which their child was receiving services, their understanding of the meaning of the label differed. Labeling failed to convey some of the deeper meanings the families held regarding their child's diagnosis, causing some uncertainty in the families' understanding of the concepts of disability and special education.

Cultural meanings and definitions of disability. In all cases, the families relied upon their cultural views and beliefs to make sense of and interpret the concept of disability. The families defined disabilities as physical anomalies and relatively severe impairments that resulted in social isolation and stigma. These views limited their understanding of the labels used within the educational setting. In their native country, persons with a disability would encounter social

isolation and stigma and were kept from the public eye. Two mothers in this study viewed their children as having relatively mild symptoms that should only be interpreted as the children needing a little extra help. Throughout the referral and placement process, families began to realize that disabilities also include covert disabilities such as ADD and LD, not just physical disabilities.

Changing views in response to special education placement and services. Families had a limited understanding of what it meant to have a label and receive special education services. The participants also experienced nuanced understandings of learning/developmental issues, had conflicting expectations, and intermingled traditional cultural views with new understandings. One participant explained special education was created to help those who have a disability because not everybody “can be smart and have everything going for them” (McLeod, 2012, p. 35). Another participant explained that special education was “like a disorder, you lack something and you can do it but you need a little help” (p. 35). He added that his child “lacked something but he just wasn’t sure what” (p. 35). Families had high levels of expectations for their children regardless of their disability and expected them to work hard, obtain high grades, and go on to college or obtain gainful employment after graduation.

When discussing the meaning of special education, families understood special education to be a place where their children went to receive a little extra help to complete school activities. Families spoke of interaction with educators as doing what they were told and signing forms. Only one family from this study was aware of when they were in an IEP meeting for their child. This shows a distinct disconnect between educators and culturally and linguistically diverse (CLD) families.

Overall, the findings showed that although families knew that their child was receiving special education services and were coming to terms with the label under which their child was receiving educational support, they were dissatisfied with regard to the label and placement. Cultural associations seemed to affect the families' ability to be open to and understand the presentations of the labels, making it harder for them to receive decisions on special education labels and placement.

Haitian Parents

Gregoire (2010) conducted a qualitative study using interview protocol to explore Haitian-Creole parents' perceptions of their child with a disability, the education the child was receiving, their interaction with the school system, and how the disability had affected their relationship with their child and their involvement with the school. This study was conducted in the largest school district in Florida, which included the largest number of Haitian-Creole parents with children in both the general education and the special education program. The children of the 10 parents in this study were of various ages, with six children in the mild disability range and four in the moderate range. Data were collected using tape-recorded interviews and analyzed. Four themes emerged from this study of parent perceptions: (a) home-school collaboration, (b) parental concerns, (c) relationships and perceptions, and (d) fault or cause. Two conceptual themes emerged providing insight into the perceptions: coping mechanisms and locus of control.

Home-school collaboration. The first theme of home-school collaboration explored parental awareness and insight into the eligibility process, how helpful parents found the special education program, what improvements they perceived in their children as a result of placement,

the nature of the interaction and communication between parents and schools, parent perceptions of supports needed from the school, and parent involvement at school.

Some parents understood the eligibility and placement process for special education services. Parent 7 indicated she understood the process completely because she had an older child who had been previously placed in special education. Parent 8 attributed his understanding due to “complete” home-school collaboration and frequent meetings between team members and the parents (Gregoire, 2010). Six of the 10 parents were able to explain the type of specialized services their children received. Others reported confusion about the process that led to the children being identified as children with disabilities. Some parents’ responses indicated that they did not have a clear understanding of what special education entailed even though they attended the meetings where eligibility and placement were discussed.

Nine of the 10 parents interviewed felt the program had been helpful for the family and for their children’s academic functioning. The one parent who expressed dissatisfaction based her grievance upon her child’s behavior issues (her child was placed based on academic delays, not behavioral).

All parents communicated with the school, although the frequency and intensity varied from parent to parent. Parents’ responses were influenced by their perception of their role, children’s difficulties, language barriers and other constraints on their time and resources. Of the nine parents who commented on this topic, seven viewed the partnership between them and the school as a continuum in which the school should provide support services both at school and at home.

Six parents reported they needed help from the school, with four parents specifying needs such as the school to move faster in meeting student needs, providing information on other programming, and providing transition information.

Nine parents spoke about the extent of their involvement with their children with disabilities both in school and with homework activities. Some said that by staying in contact with the school and seeking after-school help, they were able to stay heavily involved. Others reported they were not able to assist with homework because they could not understand it and/or they worked two jobs and were not home to provide assistance.

Parental concerns. The categories addressed under this theme were financial issues, perceptions of “normal” desires for their children, parental reaction to and perception of their children’s problems, and concerns about the future.

Five parents commented that their limited resources aggravated their difficulties. The financial difficulties associated with the medical care of children with disabilities required parents to work several jobs to keep up with expenses. Financial pressures affected their involvement with their children with one parent saying that she could not take time off work to go to their child’s school.

Parents’ perceptions of the term *normal* were extracted from specific comments regarding their children’s behaviors. They used to describe children’s behaviors, perceptions of progress as well as the long-term outcomes they had for their children. One parent perceived her child’s limited attention span and inability to follow directions as an indicator that he was not normal.

Four parents commented on this category and expressed their expectations for their children with disabilities in similar terms using expressions such as, “I would like him to be somebody when he grows up like everybody else. I would like for him to have all his senses like other people” (Gregoire, 2010, p. 88). Another parent stated, “I would like for him to be a somebody in this country. He was born in this country and I would like for him to be a somebody in this country” (p. 88).

Five of the parents addressed how their child’s disability had affected them personally. Some mentioned experiencing stress that was physical in nature. Four parents discussed their children’s behavioral and learning difficulties. Parents also expressed perceptions of how other parents in the Haitian community reacted to having a child with a disability. Parent 8 said, “That is the kind of thing I see in the Haitian community. They are afraid to talk about it. You have got to see the kid is slow, you say it. That’s what’s going to help you. You go out there and you try to find help for them, you know. You just don’t sit down and hide it. I am helping my kid. I am not hurting anybody” (Gregoire, 2010, p. 89).

Concern about the future. Nine of the parents stated they were concerned about their child’s ability to succeed in the future in academic areas such as graduating from high school and going to college and life skills such as safety, acquiring and maintaining jobs.

Parent relationships and perceptions. The third theme that emerged was the parents’ relationships and perceptions. Categories within this theme reflected how parents viewed their relationship with God, their siblings’ relationships, the nature of their interaction with family/friends/community, child differences, home behaviors, and perceptions of attitude versus aptitude.

Seven parents prayed and believed in God. They felt that only God can judge their child's behavior and that God could bring changes in their child. Parents used their relationship with God as a coping mechanism to deal with challenges encountered in raising a child with disabilities.

Four parents discussed their observations of interactions of the child with a disability and their siblings. They described the interactions of the siblings with each other and the role the siblings played in the care of the child with the disability. Parents said siblings played a role in supervision and care of the child with disabilities. They counted on siblings to assist the child with a disability out in the community and to protect them while at school and in the community. One parent discussed sending her children with disabilities out of the home due to behavior difficulties. She had, in fact, sent him back to Haiti for a short period. Another parent said her son's behavioral difficulties left her reticent about allowing him to spend time outside their home. The majority wanted their children with disabilities to be included and felt comfortable allowing them into the larger community.

Four parents gave detailed accounts of behaviors manifested by their child with disabilities. They described the children as being hyper and having bad behavior. Parents discussed their children's inability to follow directions and the struggles this caused in their homes.

Six parents attributed their child's academic difficulties to reasons that made sense to them. They did not acknowledge or understand evaluation results that reflected the child's lower aptitude and instead attributed limited academic progress to the child's attitude. This

demonstrated parents' lack of understanding of their child's specific disability and its impact on the child's academic performance.

Four parents attributed their children's disability to medical issues that included premature birth, an accident that caused a traumatic brain injury, and seizures. Three parents who lacked an understanding as to why their children were identified as being disabled attributed it to "something in the brain" (Gregoire, 2010, p. 96). These opinions seemed to have been formed from previous interactions with medical and educational professionals.

From these four themes, two core concepts emerged: *coping mechanisms* and *locus of control*. Parents who exhibited strong coping skills were active participants in their child's education. Coping skills were also stronger in those parents who identified fewer behavioral problems, fewer financial issues, more intensive and sustained interaction/communication with the school, and more positive concerns about the future. Parents with an internal locus of control relied upon faith in God as a source of strength, sought to establish positive relationships with peers, and actively sought ways to engage their children more with family/friends and the community. Parents with an external locus of control believed it was the children's attitude rather than aptitude that prevented them from being more successful academically. Those with internal locus initiated and maintained contact with school personnel, whereas those with external locus discussed barriers that prevented them from being more involved.

Findings of the study revealed that these Haitian parents seldom disagreed with school personnel and did not seem to grasp the different methods available to address their concerns nor the role they were expected to play in the process as parents of children with disabilities. Most of the parents were not literate in Creole or English and were overwhelmed by the school's

written communications. Findings were also affected by parents' locus of control, which correlated with higher education levels. Parents' involvement was strongly influenced by the values, beliefs, customs, and disability knowledge that closely align with their culture and acculturation. Parents' perceptions greatly influenced their thoughts and behaviors when they realized that the immigrant dreams they had for their children with disabilities might fall short.

South Asian Muslim Families

Jegatheesan, Fowler, and Miller (2010) conducted an ethnographic study to examine the experiences of three South Asian Muslim immigrant families who have young children with autism. Analyses were based on interviews with participants over a 17-month period. The three multilingual families who participated in the study were from South Asia (Pakistan and Bangladesh), practiced Islam, and lived in a large midwestern city. Each family in the study had one son with autism. Jalil, Raqib, and Aziz were between the ages of 5 and 6 and attended self-contained classes for autism in the public school. The interview topics focused on four areas: diagnosis and parental reactions, parent perspectives regarding etiology and treatment, parents' experiences with professionals, and efforts to obtain appropriate services. The results are organized in narrative form according to: (a) recognizing early signs of autism, (b) seeking diagnosis, (c) reacting to the diagnosis, (d) seeking information and formal supports after the diagnosis, (e) accessing appropriate treatment services, and (f) multilingual communication and extended family contact.

Recognizing early signs of autism. Mothers and grandmothers became suspicious when they noticed the children were not communicating or behaving normally during family interactions. Jalil, who was able to communicate in two languages, began forgetting words at the

age of 2, was not learning new words, and was unable to say what he wanted. Raqib was unwilling to interact at the age of 18 months, became frustrated, and cried easily. He did not like being held and turned his gaze away from people. Aziz's mother reported that at the age of 1, he did not interact in his usual way and was unable to communicate simple words. His condition changed progressively as he walked around the house distressed, pressing his palms against his ears, moving in circles, and lining things on the floor. The families said they did not seek professional advice immediately, hesitating for several months.

Seeking a diagnosis. The amount of time the families took to seek a diagnosis varied from 6 to 24 months. Parents described this period as being long and traumatic as they consulted with and were evaluated by a wide range of professionals. The families started by consulting with native language physicians before being referred to specialist who were European-American. The doctor's familiarity with their languages and culture provided a comfort zone for the parents. Parents reported that European-American doctors tended to be straightforward and spent less time getting to know them. Mothers also reported the doctors did not trust the reports they provided, which added to their stress levels.

Parents also discussed relatives who questioned what might have caused "damage" to the child's brain. Most attributed this damage to the mother's health during her pregnancy and lack of adherence to religious practices. Elders who believed that religious and dietary practices could stabilize the child's condition played an important role in the parent's choice of using folk treatments such as drinking holy water and removing evil omens.

Reacting to diagnosis. All three families said they were shocked, in disbelief, stressed, and confused when they were told their child had a disability. Parents reported that medical

personnel used medical terminology from the DSM-IV to describe autism and emphasized the negative prognosis. When parents asked for more information, they were given videos and brochures instead of individualized discussion and support. The families reported a desire for sensitive, respectful, and compassionate communication with health professionals. The parents in this study said they felt their ethnic background contributed to what they viewed as cold and discriminating treatment from health professionals.

Parents stated they did not view their extended family as a coping resource and did not talk openly about their emotions because such talk could negatively impact their extended families. Two of the families shared that it was very stressful to inform elders in their family about their child's condition because they were confused by the diagnosis.

Seeking information and formal supports after the diagnosis. Parents reported feeling alone once they left the diagnostic clinic, even though they were introduced to support groups. These parents reported they did not feel comfortable with support groups because the culture was so alien, they knew no one, felt lost, and felt uncomfortable voicing their concerns and feelings to strangers—particularly men. Fathers reported finding adequate information on autism on the Internet. Relatives and friends also supplied information to the families. Parents reported that they lacked networking within their own community and were not able to find information and support in the broader community.

Accessing appropriate treatment and services. Parents were very active in the education of their children in their home but were unable to advocate for them for services publicly in their community. They seemed to lack insight into their rights as parents of children with disabilities. Professionals held different beliefs than the parents such as what and how to

teach the boys, use of multiple languages in the home, daily lifestyle of the families which included extended family members, friends, and neighbors.

Multilingual communication and extended family contact. Medical and allied health professionals working with the families advised them to use only one language, English (recommended because of its primary status in the country), with their children and their children would be fine. This advice ignored the multilingual nature of these families. It also limited family elders from communicating because they spoke no English. Professionals also recommended limiting visitors to the home and avoiding community events, but these recommendations were contradictory to how they wished to live. Each of the families experienced culturally disrespectful interactions with home therapists such as condescending remarks, remarks about home environment and family interaction styles, authoritative tone of voice, and insistence on using techniques that the family questioned. When parents tried to explain their expectations or requested that the sessions be more controlled and challenging, most therapists resisted.

This study revealed that cultural factors, interpersonal skills, and difficulties accessing services impacted the quality of interaction between parents and professionals during diagnosis and post diagnosis. Parents viewed raising their child with a disability through a cultural lens, which was different from most professionals. Parents desired respectful, friendly, and compassionate interactions with professionals they came in contact with, pointing out differences in European American and South Asian doctors, preferring contact with the latter due to their communication style. Parents asked for meaningful and respectful partnerships from

professionals, instead of the cold and discriminating interactions they had mostly with European American doctors who they felt did not understand their culture.

Somali Parents

Greeson, Veach, and LeRoy (2001) conducted a qualitative study to examine the potential utility of genetic counseling services for Somali immigrants. Five Somali women in the Minneapolis/St. Paul area participated in structured interviews that assessed their perceptions of the nature, causes and impact of disability, and care for persons with disabilities. The five mothers reported an average of two-three children who ranged in age from 0-7. Each participant had personal experience in Somalia with someone who had a disability. Five major themes emerged: (a) the construct of disability, (b) family care for children with disabilities, (c) family stress, (d) role of Allah, and (e) family as the primary life focus.

Construct of disability. Parents understood that *disability* refers to both physical and mental conditions. Their definitions of disability were consistent with western definitions, with participants considering mental disabilities to be more severe than physical disabilities.

Family care for children with disabilities. In the Somali culture, the family cares for the individual with a disability, and the individual is “normalized” within the culture. Extended family assumes responsibility if a parent is unable to care for the individual with a disability. Non-familial agencies/organizations such as nursing homes are regarded as unacceptable and are nonexistent in the Somali culture.

Participants reported that in Somalia, families with a child with a disability received substantial amounts of emotional support and respect along with tangible assistance from other family members, friends and neighbors. Participants described the struggle of raising a child

with a disability as a “test of one’s faith from Allah” and their struggle was held in high esteem (Greeson et al., 2001, p. 372). Most participants expressed disgust with the U.S stating that although material support was available, social support was lacking, with people ostracizing those with disabilities.

Family stress. Even though participants emphasized the role of the family, at the same time they told stories from both the U.S and Somalia about husbands abandoning their families and their children with disabilities because of the stress. They also expressed that burdens were greater when the individuals with disabilities are female because they are typically not regarded as suitable marriage partners.

Role of Allah. Participants reported Allah decides whether a couple will have more children and whether those children will be healthy. Having a child with a disability did not impact a couple’s decision to have more children. Participants said that the absence of reproductive planning is due to religious faith and what comes from Allah, one accepts. Participants wanted to see culturally acceptable services being offered. They wanted parents to be taught about disabilities and helping them to find resources. They expressed that the role of patient advocate could be very important to a Somali family. They also asked healthcare providers to build trust with them. Mistrust and fear of disclosure was cited as a major issue for Somali immigrants. Participants also asked for sensitivity surrounding their culture. They stressed that they are each individuals with varying cultural and religious beliefs.

Chapter 2 Summary

In this chapter, I critically reviewed nine studies that evaluated immigrant parent perceptions of disability and special education services. A summary of these findings is presented in Table 1, and these findings are discussed in Chapter 3.

Table 1

Summary of Chapter 2 Studies

AUTHOR (DATE)	PARTICIPANTS	RESULTS	OTHER FINDINGS
Cho, Singer, & Brenner (2000)	8 Korean and 8 Korean-American families	Both sets of parents experienced a process of transformation with regard to their beliefs and feelings about their exceptional children.	Religion played an important role for Korean and Korean American parents. The study found a strong relationship between social and cultural contexts and parental adaptations to their exceptional differences. Their beliefs and feelings about their exceptional children positively changed. Parents' accounts about available resources between Korea and America were permeated by the dramatic differences based on their individual experiences.
Greeson, Veach & Leroy (2001)	5 Somali Women	Somali families care for their family members with disabilities, seeing the disability as Allah's decision. They treat them with respect and as if they were "normal."	Participants wanted to see culturally acceptable services being offered. They wanted parents to be taught about disabilities and provided with assistance with finding resources. Mistrust and fear of disclosure was cited as a major issue for Somali immigrants. They expressed that the role of patient advocate could be very important to a Somali family. They asked healthcare providers to build trust with them. Participants also asked for sensitivity surrounding their culture. They stressed they are each individuals with varying cultural and religious beliefs.

Table 1 (continued)

AUTHOR (DATE)	PARTICIPANTS	RESULTS	OTHER FINDINGS
Park & Turnbull (2001)	8 Korean parents from 7 families	Korean family perceptions of their children with disabilities with regard to special education services were positive, based upon the supports put in place for their children.	The parents believed their children will not receive enough attention from teachers if they are included in the general curriculum and feared their children will not progress adequately as a result. Most parents still wanted specialized education for their children, rather than interaction with diverse children in natural environments. Parents wanted professionals to look at their desire to improve their child's condition as a strength and help build them set great expectations for their child, celebrate every indication of progress the child makes, appreciate the child as he/she is, and create a transition plan to focus on success.
Vang & Barrera (2004)	6 Hmong Parents	Hmong parents of children with disabilities are concerned about seeking education equity, and they need more knowledge and greater communication.	Hmong parents of disabled children were very concerned about seeking education equity. They said that they needed more communication and knowledge about their children's education. Improving the instruction of Hmong students with disabilities leads to increased parent trust in the programs and instruction being implemented with their children.
Kummerer, Lopez-Reyna, & Hughes (2007)	14 Mexican Immigrant mothers and their children	To promote culturally responsive interventions, professionals should speak Spanish and provide information about the therapy process.	The majority of mothers' recognized their children had a communication delay. They attributed the cause of these delays to medical issues such as ear infections, seizures, or familial factors such as family heredity and lack of extended family. Overall, mothers appeared to be more focused on their children's speech intelligibility and/or expressive language in rather than emergent literacy abilities.
Gregoire (2010)	10 Haitian Parents	Parent involvement was strongly influenced by their values, beliefs, customs and conceptual knowledge about disabilities, which influenced their thoughts and behaviors.	Haitian parents rarely disagreed with school personnel. They lacked an understanding of methods available to address their concerns and the role they played as their children's advocates. Parent perceptions were guided by their coping mechanisms and their locus of control. Parent involvement was strongly influenced by their values, beliefs, customs and conceptual knowledge about disabilities, which influenced their thoughts and behaviors.

Table 1 (continued)

AUTHOR (DATE)	PARTICIPANTS	RESULTS	OTHER FINDINGS
Jegatheesan, Fowler, & Miller (2010)	3 South Asian Muslim immigrant families	Challenges included health and education professionals' misunderstandings of their family organization, linguistic practices, and difficulties in cross-cultural communication with professionals.	South Asian Muslim parents desired respectful, friendly and compassionate communication with healthcare professionals as they were seeking diagnosis and receiving appropriate services and treatment for their children. Parents felt they were discriminated against and treated coldly by European American health professionals because of their ethnicity and language background. Parents disagreed with professionals when they were asked to only speak English to their children and to limit interactions with extended family, which goes against their cultural beliefs.
McCleod (2012)	3 West Indian families	Families' understanding of the concepts of disabilities and special education differed from that of educators.	Most of the families used their traditional cultural assumptions to identify disabilities, most of them being of the physical form. The study found a distinct disconnect between educators and CLD families. Although families knew their child was receiving special education services and were coming to terms with the label under which their child was receiving educational support, they were dissatisfied with regard to the label and placement. Cultural associations seemed to affect the families' ability to be open to and understand the presentations of the labels, making it harder for them to receive decisions on special education labels and placement.
Donovan (2013)	6 Arab American parents	Arab American parents are deeply involved in their children's special education process and lives. They learned about the process and reflected upon how it related to their beliefs.	Parents attached significance to specific steps within the special education process and to cultural stigmas around special education and disabilities. They reported their goals for their children had not changed as a result of the special education process, although the goals were tailored to their children's identified disabilities. Parents were deeply involved in their children's special education process and lives. They learned about the process, which prompted them to analyze their cultural attitudes.

Chapter 3: Conclusions and Recommendations

Cultural perceptions play a major role in how or whether immigrant families address the diagnosis of a disability in their families and how and whether they access special education services. This literature review investigated how immigrant families in the United States perceive disabilities and special education services. In addition, the studies examined the role of families' native culture in shaping these perceptions. As a part of this paper, I reviewed nine studies involving Korean, Mexican, Haitian, South East Asian, West Indian, Hmong, Arab American, and Somali families. Chapter 3 is organized into three major sections: conclusions, recommendations for future research and study limitations, and implications for current practice.

Conclusions

The Chapter 2 research suggested immigrant parents desire respectful, friendly, open, clear, and compassionate communication with education and health professionals as they pursued education equity. Parents wanted to see culturally acceptable services being offered. All parents sought better education and better life outcomes for their children with disabilities. Five themes were common across the nine studies I reviewed: language barriers, lack of trust, lack of collaboration, denial and acceptance and causes of disabilities.

Language barriers. A common theme presented was language as a barrier to accessing services. Mexican mothers recommended professionals speak Spanish to provide information about the therapy process and the use of existing techniques with Mexican immigrant families (Kummerer et al., 2007). Korean American parents indicated translation services were not available, and they were not informed of service options for their children and families, adding

that language was a major barrier in accessing the behavioral services that were available (Cho et al., 2007).

Lack of trust. Lack of trust in professionals was another theme that was widespread across cultures. Arab American struggled forming and maintaining significant relationships with professionals, which hindered how they reviewed their children's strengths, and difficulties, evaluated their understandings of special education and special needs, engaged in advocacy, and considered their goals for their children (Donovan, 2013). Hmong parents asked for improved instruction of Hmong students with disabilities, more involvement in complex issues of school/community relations stating that these improved relationships could lead to increased parent trust in the programs and instruction being implemented with their children. These parents were not only very concerned about seeking education equity, but they also needed far more communication from schools about their children's education (Vang & Barrera, 2004).

Lack of collaboration. The struggle or lack of collaboration with professionals was another major theme. West Indian parents were seeking collaboration with educators in the development of realistic educational and life goals for the children with disabilities (McCleod, 2012). Arab American families reported the need to form and maintain significant relationships with professionals who collaborate with them to review their children's strengths and difficulties, evaluate their understandings of special education and special needs, engage in advocacy, and partner with them as they consider goals for their children (Donovan, 2013)

Denial and acceptance. Parents' denial and/or acceptance of child functioning and their understanding of disability presented across cultures. Mexican mothers asked for more information about the time needed to reconcile their children's disabilities and for clarity on their

perceived role in therapy routines (Kummerer et al., 2007). In order to improve interactions and develop home-school collaborations with families of culturally diverse backgrounds, professionals need to understand families' spectrum of understanding regarding the meaning of disability and special education (McCleod, 2012). Korean American and Korean parents found a strong relationship between social and cultural contexts and parental adaptation to an exceptional child. When Korean parents experienced negative public reactions and costly educational expenses, they experienced significant degrees of high psychological strain. Forced exposure to the public in crowded public trains and buses caused cultural attitudes and restricted resources to interact. Korean American parents in the U.S. however, perceived tolerance and free public early intervention, education for children with disabilities, school bus services, and case management systems served as buffers against negative consequences (Cho et al., 2000).

Cause of disabilities. The cause of disabilities was another theme that was presented with varied reasons across cultures. Mexican mothers varied greatly in their perception of the cause of delay. For example, one mother attributed the cause to lack of extended family members in the home, one thought oral cavity problems were the cause, and another mentioned cutting her son's hair at 9 months of age. Delays were also attributed to heredity and chronic ear infections, and one mother attributed the speech delay to her child's female gender (Kummerer et al., 2007). Korean parents attributed their children's disabilities to their own behaviors such as poorly provided prenatal practices and mistakes in early parenting which parents believed important to the health and intelligence of their babies. Korean American parents were devoted Christians and attributed the causes to a divine plan that would ultimately benefit the child and the family (Cho et al., 2000). Somali participants described the struggle of raising a child with a

disability as a “test of one’s faith from Allah” and their struggle was held in high esteem. Participants reported Allah decides whether a couple will have more children and whether those children will be healthy (Greeson et al., 2001).

Summary. All parents regardless of cultural background wanted the same thing. They desired educational equity for their children of all ability levels. They sought respectful, friendly, open, clear, and compassionate communication with all professionals who came in contact with their children. All the parents wanted to see culturally acceptable services being offered so their children could get a chance at better life outcomes.

Recommendations for Future Research

Future research could focus on parental perceptions and methods of adapting interventions to meet the needs of families from diverse backgrounds. In addition, future studies should include observational measures to confirm and/or more carefully examine home-based language and literacy practices. Research in different contexts is needed to determine how parents from diverse cultures communicate with their children with and without disabilities. Findings indicated a need for greater specificity in research designs to examine child and family characteristics including culturally based interactional styles, type and severity of children’s disabilities, and family demographic data such as level of acculturation, formal education, and socioeconomic status. Future studies should utilize more representative groups of participants to better reflect parent perceptions about instructional strategies. This is particularly the case for first- and second-generation parents.

Limitations. The authors of these nine studies all cited the few number of participants as limitations. In some studies, the interviews were conducted in short durations such as the Somali

and West Indian parent interviews. West Indian parents had a one-time encounter with the interviewer, and the researchers reported that ‘the outcomes could be significantly influenced by the emotional well-being of both the participant and the researcher’ as well as a lack of rapport established between both (McLeod, 2012). Somali parents met for audiotaped interviews that lasted approximately an hour (Greeson et al., 2001). Limited participation from family members other than mothers also limited the studies because for all the families, mothers took major charge of their child’s education and were responsible for everything related to children and household matters.

Implications for Current Practice

As a special education educator and an immigrant, I have had the opportunity to experience disability and special education from the family perspective and also from the educator perspective. From the family perspective, I understand the struggle these families endure, based upon the similar experiences of my family as my brother was assessed for special education services. I vividly remember the raw emotions my family experienced trying to come to terms with the word *disability*. In Kenya, we perceived disability to be mostly physical and debilitating. Reading through these studies, I yearned for someone to connect with the families, to try and understand their cultural perception, and try to help them better understand the American system and all the benefits that were available to them.

On the other hand, from the educator perspective—especially from the special education perspective—I can see how and why we fail to better connect with the families. Many times, by the time the child gets to us, we follow the process and timelines associated with getting them access to appropriate services as quickly as possible so that they do not keep falling behind.

With good intentions, during this process we fail to take a moment to check in with the family as they process the impact of the disability label and the changes the family goes through in that process.

Malcolm X once said, “There is no better than adversity. Every defeat, every heartbreak, every loss, contains its own seed, its own lesson on how to improve your performance the next time.” This quote speaks to the immigrant parents of children with disabilities that I came across in my research. Every day they navigate the world with and for their children, they are overcoming adversities, making peace with the heartbreak of how the disability impacts their child and family and coming to terms with the loss that comes with the diagnosis. As an immigrant and an educator, I feel that we can improve how we address immigrant families, taking their culture into consideration more than we do, embracing them and their differences as they navigate our education and medical system. I know that moving on, I will personally work that much harder to slow the process down for these and all families, so we can face defeats together, so I can better understand their heartbreak, comfort them through their feelings of loss so they have an improved and better experience in the education system.

Summary

This review of literature provided perspective on the challenges faced by immigrant parents of children with disabilities. Immigrant families varied in their perception of causes of disabilities, adaptations to the disabilities, and beliefs regarding the quality of life for their children with disabilities. Cultural perceptions also affected how the families and their child with a disability were received, especially within their cultural community. Regardless of culture, language limitations, and perspectives on disabilities, all the parents loved their children

regardless of their disabilities and the challenges. Like all parents, they want their children to be successful, accepted, included, and able to reach their full potential.

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