

Spring 5-22-2018

# The Support Needs of First Generation Immigrant Families with Sons and Daughters with Disabilities

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**THE SUPPORT NEEDS OF FIRST GENERATION IMMIGRANT FAMILIES  
WITH SONS AND DAUGHTERS WITH DISABILITIES**

**by**

**GEORGE JACOB**

MA, Special Education, University of New Mexico, 2007

DISSERTATION

Submitted in Partial Fulfillment of the  
Requirements for the Degree of

**Doctor of Philosophy of Special Education**

The University of New Mexico  
Albuquerque, New Mexico

**July, 2018**

## ACKNOWLEDGEMENTS

I heartily acknowledge Prof. Ruth Luckasson, my advisor and dissertation chair, for her support and guidance all through these memorable years. I am so thankful for your encouraging words and leading by example. I will forever be grateful for your kindness.

I also thank my committee members, Prof. Jan Armstrong, Prof. Susan Copeland, and Dr. Megan Griffin, for their valuable recommendations. Thank you very much.

I want to thank the Parent Support Group and the families who took part in this study. Your desire to help families with children with disabilities is remarkable. Together we will bring about changes and be leaders. Your voices will be heard. Thank you and God bless you all.

The support from my family has been amazing. Thank you for standing with me. I love you all. And finally, a reminder for myself:

.....but through love serve one another (Galatians 5:13).

And whatever you do in word or in deed, do all things in the name of the Lord Jesus, giving thanks to God the Father through Him (Colossians 3:17).

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**Abstract**

This study examined the support needs of four first generation immigrant families with sons and daughters with disabilities from a city in the South West of the United States and gave them a voice to add to the knowledge base that can inform the development of supports and policies for families. Parents talked about their separation from extended families and being alone in an unfamiliar country without knowledge and information on how to raise a child with a disability. Spouse and children were the closest forms of support, but for a single parent, the needs multiplied. All families shared the importance of having support from other parents and family support centers. The participants interviewed found comfort in connecting with other families speaking the same language and coming from the same country. The information they received about their rights came about in a social context. There was a feeling of camaraderie and willingness to help each other. Mothers noted that first generation immigrant parents often struggled with English and felt much more comfortable when information was available in their native language. There was consensus on the importance to learn the system immediately after coming to the United States. Families were concerned that they did not know their rights and felt they were not part of the team in the school setting. Parents also spoke about the differences in supports in the United States compared to their home countries.

## Table of Contents

<b>Chapter 1: Introduction.....</b>	<b>1</b>
Purpose and Significance.....	3
Research Question.....	5
Research Approach.....	7
Definition of Key Terminology.....	13
<b>Chapter 2: Literature Review.....</b>	<b>22</b>
Theories and Research on Families.....	25
Government Policies to Address the Supports Needs of Families.....	60
Review on Immigration in the United States.....	67
<b>Chapter 3: Research Methodology.....</b>	<b>83</b>
Method.....	88
<b>Chapter 4: Data Analysis.....</b>	<b>96</b>
Presenting the Portraits.....	97
Presenting the Themes.....	105
<b>Chapter 5: Discussion, Findings, and Recommendations .....</b>	<b>118</b>
<b>References.....</b>	<b>135</b>
<b>Appendix A: Letter of Invitation.....</b>	<b>153</b>
<b>Appendix B: Consent Form.....</b>	<b>154</b>
<b>Appendix C: Main Interview Questions.....</b>	<b>157</b>
<b>Appendix D: Demographic Information.....</b>	<b>158</b>
<b>Appendix E: Portraits.....</b>	<b>159</b>

## **Chapter 1**

### **Introduction**

Families with children with disabilities face many disadvantages compared to families with sons and daughters without disabilities (Dowling & Dolan, 2001). The need for supports in order to participate in paid work, engage in leisure activities and enjoy social relationships within and outside the family was expressed by families in a study by Murray (2007). And to participate meaningfully in existing community activities was discussed by parents in a study by Carter, Swedeen, Cooney, Walter, and Moss (2012). The disability of a son or daughter could threaten the family's ability to "belong" in a community (Hall, 2010) and, according to Swenson and Lakin (2014), many times individuals with a disability or their family members have felt unwelcomed at schools, at community events, public places, or even in a church. A large percentage of families indicated that supports were not fully available to participate in congregational activities (Ault, Collins, & Carter, 2013). Carter et al. (2012) conducted community conversations with parents of individuals with disabilities and some concerns voiced by parents were how the community could be more welcoming of people with disabilities and the need for supports in existing activities to make them more inclusive.

Russell (2003) found that many families of children with disabilities had difficulties in getting into, or retaining employment even though they wished to work full or part-time. The author reported that absence of affordable and appropriate child care for children with disability has resulted in them being at a financial disadvantage. In 2011 approximately 3.02 million children requiring significant supports related to disabilities were reported living with family members (Swenson & Lakin, 2014). Russell (2003) reported that families with children with disabilities face on average three times the cost of families of children without disabilities.

In today's society an important characteristic is the multicultural diversity in the United States. According to the U.S. Census Bureau (2006) 33% of the nation's population is culturally and linguistically diverse (CLD) and the number of people who have immigrated to the United States rose 16% over the last 5 years (Lee, Turnbull, & Zan, 2009). The authors wrote that out of the 6.6 million children who received services under the Individuals with Disabilities Education Improvement Act (IDEA, 2004) about 40% were students from culturally and linguistically diverse backgrounds. The U.S. Department of Education reported the number of immigrant students with disabilities continues to increase and forms the third largest group to receive special education services (Antony & Banks, 2010; Lo, 2008).

### **Unique Support Needs of Immigrant Families**

Because each immigrant family has distinct traditions, cultures, customs, religions and languages, as well as unique life circumstances based upon how recently they immigrated (Kim, Lee, & Morningstar, 2007), it often is difficult for the community to understand their expectations, aspirations, and the supports they need. Parents new to the United States have little to no knowledge about the education system, community supports and the special education policies which makes it difficult for them to be equal participants in the decision making processes (Lo, 2012). First generation immigrant parents have reported that their limited English proficiency has hampered their understanding of the disability diagnosis and obtaining information regarding the disability, and also has resulted in receiving lower levels of formal support from professionals (Cho & Gannotti, 2005). Also, the expectation that families should address and advocate for supports comes from mainstream culture of the U. S. and may contradict the values of many immigrant families (Kalyanpur, Harry, & Skrtic, 2000). The rights-based individualistic society found currently in the United States and societal expectations

that families will advocate for supports are often difficult for immigrant families to understand and accept (Kalyanpur & Gowramma, 2007).

King, Esses, and Solomon (2013) wrote that there is a reasonably large body of literature on the support/service utilization experiences of ethnic minority families, some literature on the support/service utilization experiences of immigrant families, and a large body of literature on the support needs of families of children with disabilities. They noted, however, there is little literature on the experiences of immigrant families caring for children with disabilities. And given the growing number of immigrant families in the United States, there needs to be greater information to guide support/service providers and inform policymakers regarding effective ways to meet the needs of the immigrant families with sons and daughters with disabilities (King, Esses, & Solomon, 2013). Some of the challenges immigrant families experience in accessing and utilizing supports are poverty, single parenthood, stressors associated with resettlement, social exclusion, unemployment, and underemployment (King, Esses, & Solomon, 2013). Hence, as pointed out by these authors, these vulnerabilities and challenges compounded with the emotional, physical, and financial demands of caring for a son or daughter with a disability increase the support needs of these families.

### **Purpose and Significance**

The purpose of this interview study is to understand the support needs of first generation immigrant families with sons and daughters with disabilities and thereby add to the knowledge base that can inform the development of supports and policies for families. I propose to understand first generation immigrant families' support needs from their stories on their experiences in the United States of America and the meaning they make of their experiences. I also propose, by analyzing the narratives, to examine, document, and delineate (i.e., portray

precisely) some of the external influences that affect the support needs of immigrant families so as to foster the healthy development of their children with disabilities and the family as a whole. That is, the focus of the analysis for the second part is: How are first generation immigrant families' support needs influenced by extrafamilial conditions?

Through this study, my hope is that immigrant families with sons and daughters also understand they have a voice and can use their voice in expressing their support needs, their experiences in the United States, and the meaning they make of these experiences. Research has indicated that often times first generation immigrant families with children with disabilities hesitate to address their needs due to fear, communication barriers, or cultural ideology (Jung, 2011; Kalyanpur & Gowramma, 2007). Giving the families an opportunity to narrate their stories will be beneficial not just to the families but also will facilitate the development and implementation of family-centered policies that meet the support needs of these families. The study may help to increase the availability of information and outreach services and at the same time encourage the provision of culturally appropriate supports.

According to King et al. (2013) one of the biggest challenges facing immigrant families is lack of knowledge about supports and benefits available to them due to absence of accessible government and service information. Providing culturally appropriate and family-centered supports meeting the unique needs of first generation immigrant families is what this study proposes to address. Through interviews in this study I propose to talk to first generation immigrant families with sons and daughters with disabilities as opposed to talking *about* first generation immigrant families. Through their stories regarding their support needs it can be made clearer what their support needs are and whether they are unique (or do they sound just like "native" families' needs?). The support needs of immigrant families of children with disabilities

are objective; nevertheless, the families' experiences regarding the supports needs are subjective. By hearing families' experiences, a long-range goal will be to transmit the subjective experience into objective supports. Hence through the interviews I will be hearing the subjective experiences of families' objective needs. It is important that we ask first generation immigrant families about their desires and understand their needs. Families, especially first generation immigrant families, may feel isolated from the community and extended family members, and supports may be a huge blessing for them. Their needs may be unique compared to families of U.S. origin.

Once we understand the supports needed by immigrant families it would be feasible to develop policy that provides support for immigrant parents and implement it. Policy development and implementation will come after we recognize the services immigrant family's desire. The purpose of this qualitative inquiry will be to examine and understand the needs of and supports for first generation immigrant families with children with disabilities. Specifically, I seek to understand how aware they are of existing forms of support, which needs have been addressed and which needs have not been met, and how these needs have been addressed.

### **Research Questions**

**Over-arching research question:** What are the support needs reported by first generation immigrant families with sons and daughters with disabilities in relation to:

- Existing forms of supports for their children and family
- Needs of their children and family that have been met
- Needs of their children and family that have not been met
- Their current concerns, worries, and challenges as caretakers

### **Interview Questions**

**Introduction: Sharing your life history (Goal: in order to understand the meaning the families are making of their current experiences in regards to support needs)**

- (a) Please tell me about your early life-you were born in...?"
- (b) Can you share your and your families' experiences at your home country?

**The Details of your present lived experiences (not opinions but rather the details of the participants' experiences)**

- (a) Please tell me about your needs related to having a child with a disability?
- (b) What do you need most help with?
- (c) What kinds of help do you receive currently?
- (d) What kinds of supports are you aware of here in the United States?
- (e) How have you been able to access these supports?
- (f) In the community, who provides you with most supports?
- (g) What areas do you still need help in?
- (h) What are your concerns, worries, and challenges in relation to your son/daughter?

**Reflecting on their experiences and meaning they make of these experiences**

- (a) Looking back on your experiences here, how does life in the US compare to life back home?
- (b) What things you would like to change here?
- (c) Which supports do you wish were easily available?
- (d) What advice would you give to other first generation immigrant families with children with disabilities?

## **Rationale**

The rationale for this study stems from my desire to develop and implement policies supporting families of sons and daughters with disabilities. There is a gap in the literature on different supports needed by first generation immigrant families with sons and daughters with disabilities. Increased understanding on the needs of first generation immigrant families will be very helpful in the creation of policies not just supporting native born families but also families coming from diverse cultures and backgrounds. Some of the needs reported by families include: being able to participate in community activities, being included and the supportiveness of other community members (Ault, Collins, & Carter, 2013), accessible and affordable housing or transportation services, food security and income support, welcoming schools and public places, and families' ability to be part of the community (Swenson & Lakin, 2014), and supports from family, friends, and support groups so as to participate in paid work, engage in leisure activities, and enjoy social relationships (Murray, 2007). This study will examine whether immigrant families identify additional needs beyond those reported for members of the host society.

## **Research Approach**

### **Qualitative Interviewing**

The method of collecting data in this study will be through in-depth interviewing with the focus on hearing the life stories of first generation immigrant families with children with disabilities, mainly their support needs in the United States of America. As the name implies, in-depth interviewing seeks "deep" information and understanding (Johnson and Rowlands, 2012). Through the interviews I will be seeking to achieve the same deep level of knowledge and understanding as the families hold. The goal, as written by Johnson and Rowland (2012) will be

"so that you can physically and ecologically penetrate their circle of response to their social situation, their work situation, or their ethnic situation" (p. 101).

The advantages of in-depth interviewing in this study will be:

(a) Being a first generation immigrant myself, I will be using in-depth interviews to explore or check my understandings (i.e., inspire self-reflections) and to see if what is being narrated are shared by the other participants.

(b) In-depth interviewing will help in uncovering what is usually hidden from ordinary view and to penetrate to a more reflective understanding about the nature of the participants' experience.

(c) As I do have a relationship with member knowledge and lived experience, being part of a first generation immigrant family with support needs, I will be able to "hear" what the participants are saying about the important matters of lived experience and the meanings they make of these experiences. I will not be completely ignorant of the issues to be addressed in the interviews and hence avoid the problem of the in-depth interview process to be uneven in nature (i.e., caused by having the interviewee as the expert and the interviewer as a novice).

In regard to the features in interviewing, I will make attempts to avoid the common pitfalls mentioned by Wang and Yan (2012) such as: (a) an interview is a goal- or task-oriented talk to gather information, in which the interviewer and the interviewee have their respective roles to play (i.e., role of questioning and role of answering); (b) the question-answer sequence is the predominant sequential structure in an interview (i.e., turn-taking); (c) the interviewer is empowered to ask questions, and the interviewee is confined to responding (i.e., exercise of power); (d) interview questions limiting the interviewee's response (e.g., yes/no questions, Wh-questions); and (e) interview questions embodying presuppositions about the matter under discussion.

## **Positionality and Assumptions**

### **Positionality**

One of my very first experiences in the field of special education was hearing the story of a mother of a child with disabilities and her struggles and how she was learning to overcome them. This took place the year I first came to the United States. This experience and other similar experiences with families has had a lasting impression on me. As a special education teacher, I have always found it important to communicate with families and understand their perspectives, family niche, their needs and ways I could help them. I have always felt that I am not just working with students but with families and when I understand a family, I understand the child better. Having that view combined with my Christian faith, compassion and building up families have been dear to me.

Supporting families, often just by hearing them and giving them a voice has been my passion and that was further confirmed by reading Bowen's (1966) family systems theory and Bronfenbrenner's (1986) ecological systems theory. The family systems theory defines family as an "emotional unit" or a "system" in which each member of the family plays a role and has influence on one another. According to the ecological theory, "The heart of our social system is the family. If we are to maintain the health of our society, we must discover the best means of nurturing that heart" (Bronfenbrenner, 2005, p. 260). These theories gave me a piece of mind that what I have always felt was not just my view but was shared by many. Being an immigrant myself I feel a greater need to hear the voices of immigrant families and hear what they have to say regarding their experience here in the United States and how they are learning to overcome difficulties and understanding their support needs. Finding ways to nurture the "heart" (i.e., immigrant family) will lead to harmony among the different micro systems (i.e., the family,

school, service centers). I hold on to the paradigm that strong, well-informed, secure, and well-connected immigrant families will help in creating strong and harmonious communities.

Assimilation will take place naturally. Hearing one another and understanding each other can help in building strong and practical supports which will meet the needs of these families.

### **Assumptions**

Based on my background as a member of a first generation immigrant family and as a special educator with experience with immigrant families with children with disabilities, I do have a few biases and assumptions. First, immigrant families are not aware of the policies on family support existing in the United States. This assumption is based on the idea that it will take time to cross the cultural, language, or societal barriers and understand the policies of this country. Second, educational background of immigrant families may affect the knowledge about policies that provide them with the support. This assumption is based on the premise that parents with college degrees and who are in the academic field will have greater knowledge about disability policies and greater access to the information compared to parents not in the field of academia or having a college degree. Third, families with support from the community (e.g., church, community groups from the same country, co-workers, peers, extended family members) will have more of their needs met. This assumption is guided by conversations with immigrant families and the level of support they are receiving and able to access. Fourth, first generation immigrant families are not comfortable advocating for their rights. This assumption is based on personal experiences and conversations with other immigrant families and after examining the literature on immigrant families.

As a researcher though, I do not desire my assumptions to influence my hearing and understanding of immigrant families' experiences here in the United States. I want to be open

(i.e., not subjective) so as to hear and understand what families are saying and also understand what they are holding back (i.e., discern what is not spoken). A subjective person has made up his or her mind about the issues at hand already. He or she has formed an opinion and is confident about the topic. Such a person has preconceived ideas before listening to others and holds on to the ideas even after hearing from others. Even though it might be impossible not to be completely subjective, my goal is to be sensitive to others' speaking, so that I can learn, and that I can receive impressions.

### **Conceptual Framework: Background of this Study**

The conceptual framework of this proposal is based on the research paradigms explained by Bronfenbrenner (1986) in his ecology of the family as a context for human development theory. As described by him, the family ecological theory is grounded in research paradigms that can be differentiated at three successive levels: (a) social address paradigms; (b) process-context paradigms; and (c) person-process-context paradigms. According to the first paradigms (i.e., social address model) the families' support needs are defined by geography (e.g., rural vs. urban, Japan vs. the United States, or the social background) (Bronfenbrenner, 1986). This model takes into consideration the length of time that a family has been exposed to a particular environmental context (e.g., immigration). But the shortcoming of this paradigm is that it does not take into consideration the characteristics of the family (e.g., family structure, employment, ethnicity, disability of the child, or family beliefs) or the environmental factors (e.g., state policies, neighborhood characteristics).

The social address models have a number of important limitations summarized by Bronfenbrenner (1986):

No explicit consideration is given...to intervening structures or processes through which the environment might affect the course of development. One looks only at the social address-that is, the environmental label-with no attention to what the environment is like, what people are living there, what they are doing, or how the activities taking place could affect the child (p. 724).

The paradigms at the second level (i.e., process-context model) explicitly assess the impact of the external environment on particular family processes (e.g., support needs of families). Bronfenbrenner noted that "although the process-context model represented a significant advance over its predecessors, it was based on an unstated assumption-namely, that the impact of a particular external environment on the family was the same irrespective of the personal characteristics of individual family members, including the developing child" (p. 725). The third research paradigms (i.e., person-process-context model) take into consideration the personal characteristics of the family in determining the impact of the external environment on the support needs of the families.

Understanding ecological factors (i.e., family characteristics, environmental characteristics, and life transitions) influencing support needs of immigrant families is crucial, especially since the great influx of multicultural immigrants to the United States following the liberalization of immigration laws in 1965. The high representation of immigrant families calls out the need to construct a better understanding of effective and supportive ecological systems to facilitate immigrant families' healthy adaptation in mainstream America. Omission of this information is likely to result in an incomplete representation of the families that professionals are serving. I propose that the findings of this study could assist in developing policies that are culturally competent and represent the population of the country.

Influenced by family systems theory, family ecology theory, empowerment-based and strength-based approaches, there is a growing body of research literature promoting family-centered supports that are culturally responsive and meeting the ecocultural niche of the families. Most of the research, though, addresses ethnic minority families of children with disabilities (e.g., Latino families, Asian families). There have been very few studies on first generation immigrant families (i.e., families moving to the US from their country of birth) for whom the policies and support frameworks are quite new and difficult to understand. In the literature review in chapter two, I will examine the theoretical frameworks mentioned above as well as the United States policies supporting families with children with disabilities. I felt it important to examine the support policies so as to compare them to the narratives of the families (i.e., triangulate the findings with what the literature says).

## **Framework and Key Concepts**

### **Definition of Key Terminology Used in this Study**

#### **Generation**

Foner and Kasinitz (2007) wrote in studies of immigration that the term “generation” is used as a measure of distance from the “old country” (p. 270). People who come to the U.S. from another country as adults are referred to as being “first-generation” immigrants, their American-born children as the “second generation” immigrants, and their children in turn as the “third generation” (Foner & Kasinitz, 2007). They wrote that this was different before the 1950s when people born in the U.S. to immigrant parents were referred to as “first-generation Americans” rather than “second-generation” immigrants. According to the authors this usage has fallen out of favor among social scientists. Another common term is the “1.5 generation,” which refers to

individuals born abroad who immigrated as children with their parents and were largely raised in the U.S. (Foner & Kasinitz, 2007; Portes & Zhou, 1993; Zhou, 2001).

\* First generation immigrant families: Foreign-born parents and extended family members (e.g., grandparents) (Portes & Zhou, 1993; Zhou, 2001)

\* Second-generation: Native-born children (born in the US) of first generation families (Portes & Zhou, 1993; Zhou, 2001)

\* Transitional generation (1.5 generation): Those who immigrate as younger children with their foreign-born parents (Portes & Zhou, 1993; Zhou, 2001)

### **Immigrant**

Fong (2004) wrote that “immigrant” usually refers to “foreign-born persons who have left their nation of birth to dwell in another country” (p. 8). She distinguished between foreign-born children and American born children as “immigrant children” and “children of immigrant parents” respectively. Immigrants can be either documented or undocumented (Fong, 2004). She explained that legal or documented immigrants have received the official papers that allow them to enter the country legally and work, though some categories of immigrants (e.g., students) may be restricted in their freedom to accept employment.

Undocumented immigrants are those without legal documents and can include adult persons, children, and any other family members who have no legal documentation (Fong, 2004). She noted the lack of “legal status” will have a definite impact on child and family functioning. According to Fong, children who are undocumented struggle with isolation and loneliness, have problems with identity, play-relationships, and age-appropriate social skills. She noted that findings from studies have reported undocumented youth experience emotional problems (e.g., depression, suppressed anger, or anger manifested through gang involvement).

**Family**

A group of individuals living under one roof (household) and usually under one head (Merriam-Webster).

**Children with disabilities**

The term ‘child with a disability’ means a child-

- with intellectual disability, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and
- who, by reason thereof needs special education and related services

(20 U. S. C. 1401 (3))

**Culture**

Culture refers to different elements that influence “one’s sense of ‘we-ness’” (Turnbull & Turnbull, 2001, p. 61). Turnbull and Turnbull (2001) explained the sense of “we-ness” includes race, ethnicity, religion, geographical location, income status, gender, disability status, and occupation. They also noted that often time culture is used synonymously with race and ethnicity, but they wrote that this interpretation is too limiting and that culture is a much broader than only race and ethnicity.

**Acculturation Framework**

As a result of immigration, societies become culturally plural (i.e., people of many cultural backgrounds live together in a diverse society) (Berry, 1997). Berry (1997) explained that population forms cultural groups, and based on numerical, economic, or political influences are referred to as "mainstream", "minority", "ethnic group", "dominant group", or "non-dominant

group" (p. 8). Acculturation refers to the "cultural and psychological changes that result from contact between cultural groups and their individual members" (Berry, 2013). According to Berry (1997) the classical definition of acculturation was presented by Redfield, Linton, and Herskovits (1936, p. 149): "acculturation comprehends those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact with subsequent changes in the original culture patterns of either or both groups" (p. 7). Banks (2009) described acculturation as "whenever ethnic groups have extended contact, exchange of cultural traits occurs between minority and majority groups, as well as between different ethnic groups" (p. 90).

Using a conceptual framework (i.e., the acculturation framework), Berry (1997) attempted to systematize the process of acculturation and illustrate the main variables that affect an individual's or family's adaptation process. Berry wrote that adaptation refers to "changes that take place in individuals or groups in response to environmental demands" (p. 13) and the adaptation process can be psychological or sociocultural. He explained these psychological and sociocultural adaptations can occur immediately, or they can be extended over longer periods of time. According to Berry, psychological adaptation refers to a set of internal outcomes (e.g., clear sense of personal and cultural identity, good mental health, and the achievement of personal satisfaction in the new cultural context) while sociocultural adaptation refers to a set of external outcomes (e.g., ability to deal with daily problems, particularly in the areas of family life, work, and school).

Psychological adaptations can be a matter of learning a new repertoire that is appropriate for the new cultural context while unlearning one's previous repertoire that is no longer appropriate: "culture shedding" (Berry, 1997, p. 13). He wrote that individuals may experience

"culture shock" or "acculturative stress" when they cannot easily change their repertoire.

According to the author, changes in the "cultural context" may exceed the individual's capacity to cope, due to the magnitude, speed, or some other aspect of the change, resulting in serious psychological disturbances and/or incapacitating anxiety.

Berry (1997) postulated that there are situational variables (i.e., group- or cultural-level factors) and personal variables (i.e., individual factors) that influence the acculturation process. He wrote that situational factors mainly include (a) the society of origin (political, economic, and demographic factors) and (b) the society of settlement (attitudes, social supports available including culturally sensitive health care, multicultural curricula in schools, and multicultural ideology). Personal variables prior to acculturation include age, gender, education, pre-acculturation status, migration motivation, expectations, cultural distance (language, religion), and personality of the individual (locus of control and flexibility) (Berry). He noted personal factors during the process of acculturation that may affect the adaptation include length of time for acculturation, acculturation strategies (i.e., attitudes and behaviors), coping (i.e., strategies and resources available), social support, and societal attitudes (i.e., prejudice and discrimination).

**Acculturation Strategies.** Berry (2013) explained that there are different ways to acculturate and that adopting different acculturation strategies can result in (a) integration/multiculturalism; (b) separation/ segregation; (c) assimilation; or (d) exclusion/ marginalization. Berry postulated that the key variables are diversity and equity: Acceptance of diversity and equity leads to integration (or multiculturalism), acceptance of diversity without acceptance of equity leads to separation or segregation, acceptance of equity without the acceptance of diversity leads to assimilation (melting pot), and finally acceptance of neither equity nor diversity leads to exclusion/marginalization (Berry, 2013).

**Integration/ Multiculturalism**

Integration/multiculturalism occurs when cultural diversity is prized and nurtured and all groups have the right to access all aspects of the larger society (equitable participation), including culturally appropriate education, work, health care, and justice, along with acceptance of the need for change among all members of the society (i.e., mutual accommodations/adaptations) (Berry, 2013). He noted culturally pluralistic societies (i.e., societies in which a number of different cultural groups or ethnic groups reside together within a shared political and societal framework) are developed when these three basic social processes are incorporated: cultural diversity, equitable participation, and acceptance of the need for change.

**Assimilation**

Alba and Nee (2007) wrote that assimilation runs both ways: immigrants change as they become new Americans but the American mainstream also changes as it absorbs them. Banks (2009) explained that as ethnic groups become more assimilated (adapted) and attain higher socioeconomic status, they tend to abandon certain elements of their traditional cultures. However, they sometimes reclaim aspects of their cultural heritage once they are secure in middle- or upper-class status and this assimilation usually occurs in the third generation.

According to Alba and Nee (2007), assimilation is a form of “ethnic change.” They wrote ethnicity can be defined as “a social boundary, a distinction that individuals make in their everyday lives and that shapes their actions and mental orientations toward others” (p. 130). The authors explained that in their “assimilation theory,” the pace and success of assimilation depends principally on three factors: (a) the effect of informal and formal institutions (i.e., customs, norms or informal rules that provide guidelines for action, and conventions); (b) actions, decisions, and choices of individual immigrants and their families (e.g., employment

networks, ethnic networks or mainstream networks, places of residence, languages used at home, amount of interaction with families of other backgrounds); and (c) network ties that families maintain with the same ethnic group for tangible forms of assistance, information on start-up jobs, schooling, and places to live. They noted the greater the interaction with families of other backgrounds, the quicker the assimilation, especially for children.

### **Push-Pull Theory**

The push-pull theory is traced to American demographer Everett Lee, who formulated it as a general theory of migration (Yang, 2010). Yang (2010) wrote that push factors refer to conditions that persuade individuals to leave their families and country of origin behind (e.g., natural disasters, population pressures, economic hardships, political turmoil, or environmental disadvantages). In many low- and middle-income countries, low levels of economic development and high poverty rates result in limited economic opportunities and high unemployment (Loizillon, 2008). Loizillon (2008) added that suppression of human and political rights as well as civil and ethnic conflicts also motivate individuals to immigrate in search of better living conditions.

Pull factors attract immigrants to the host country (Loizillon, 2008). The author wrote that these conditions include greater access to economic opportunities, higher wages, better political or working conditions, connections to family members already in the host country, and flexible immigration policies. Yang (2010) explained that “pull” factors play a more important role than “push” factors for immigrating families. That is, in most cases the desire to improve their lives is much more motivating than an escape from unpleasant conditions (Yang).

### **Stereotype Content Model (SCM) Applied to Immigrant Groups**

Stereotype Content Model (SCM) is a theoretical framework that integrates two dimensions of social perceptions, namely “warmth” and “competence” and is often attributed to people or social groups (Sevillano & Fiske, 2013). The warmth dimension includes “warm, well-intentioned, good-natured, trust-worthy, tolerant, friendly, and sincere” while competence dimension includes “competent, capable, skillful, intelligent, and confident” (p. 101). The authors explained that using the SCM framework, immigrants have been consistently measured as highly competent, unintelligent or as untrustworthy. They noted that this immigrant stereotype reflects the features of their original nation (i.e., perceived structure of nations) and the group characteristics carried by the members of the nation (i.e., national stereotypes).

#### **(a) Social Structure Features of Nations**

Immigrants often undergo categorization by the native U.S. population (i.e., the host country), and this usually reflects the structural, cultural, and geographical features of the nations from which they come (Sevillano & Fiske, 2013). According to the authors the perceived features of a country of origin, namely, level of economic development (e.g., industrialization and economic power), predominant ideology (e.g., nationalism and government services), and nature of the relationships among the host country and country of origin (peaceful or conflicted) are factors that influence the stereotype that the people of the host nation hold regarding the people coming from the other countries. Other features like political power, population, culture and race, geography (i.e., location and size of the nation) also influence the way the host country conceive nations.

**(b) National Stereotypes**

According to Sevillano and Fiske (2013) national stereotypes are often influenced by the stereotypes of preexisting social groups/status held by the immigrants (e.g. Mexican immigrants are perceived close to farm workers, Asian immigrants are stereotypically perceived close to technological professionals). Often in the United States, Mexican and Italian immigrants are perceived as incompetent but warm; Asian immigrants as competent but cold; Canadian immigrants as warm and competent. The authors explained, “their perceived position in society (status, competition) lead to specific stereotypes (competence, warmth), which in turn elicit prejudiced emotions (admiration, envy, contempt, pity) and discriminatory tendencies (active and passive help and harm)” (p. 106). The pace and style of acculturation for each immigrant group are influenced in part by these images that portray the different immigrant groups.

## Chapter 2

### Literature Review

In order to understand the experience of immigrant families with sons and daughters with disabilities in the U.S. and their support needs I reviewed theories, research, and literature on (a) families, (b) categories and types of family supports for families with children with disabilities, (c) government policies and delivery mechanisms used by the US to address the supports needs of families with sons and daughters with disabilities, (d) the United States immigration policies to help understand the context or situation in the US of first generation immigrants who have sons and daughters with disabilities, (e) the frameworks and key concepts used to describe first generation immigrants in the US, and (f) the theories and research on first generation immigrant families, especially those with sons and daughters with disabilities.

#### **Immigrant Families with Sons and Daughters with Disabilities**

By 2050, it is predicted that 50% of the U.S. population will be ethnic minority families (King, Esses, & Solomon, 2013). Also data from studies have indicated an increasing number of children having significant needs due to disabilities (Sloper & Beresford, 2006). With a growing number of immigrant families who have sons and daughters with disabilities in the United States there needs to be new information to guide service and support providers and inform policy makers about the best ways to meet the needs of these families (Cho, Singer, & Brenner, 2003). King, Esses, and Solomon (2013) reported that there is little literature on support and service utilization experiences of immigrant/refugee families with children with disabilities. A review of research on immigrant/refugee families brought forth issues of poverty, single parenthood, social exclusion, resettlement, unemployment, and underemployment. They face social and economic

marginalization and have limited access to health and social services due to their eligibility status (e.g., Supplemental Nutrition Assistance Program) (Skinner, 2012).

King, Esses, and Solomon (2013) wrote that there is a reasonably large body of literature on the support/service utilization experiences of ethnic minority families, some literature on the support/service utilization experiences of immigrant families, and a large body of literature on the support needs of families of children with disabilities. They noted, however, that there is little literature on the experiences of immigrant families caring for children with disabilities. And given the growing number of immigrant families in the United States, there needs to be greater information to guide support/service providers and inform policymakers regarding effective ways to meet the needs of the immigrant families with sons and daughters with disabilities (King, Esses, & Solomon, 2013).

The vulnerabilities of immigrant families are compounded when raising a child with a disability (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999). Immigrant families with sons and daughters with disabilities face high levels of unmet needs, significant barriers to health care for their child, and the uncertainty of their child's health, well-being, and educational success (King et al., 2013). In addition to the emotional, physical, and financial demands of caring for a son or daughter with a disability (Chamba et al., 1999), many immigrant families experience difficulties trying to obtain supports due to lack of information of available supports, lack of access to these supports, and the fragmented service/support delivery policies (Sloper & Beresford, 2006).

### **Literature Review Method**

I searched the literature for post-1990 journal articles, reports, books, and book chapters dealing with immigrant families/first generation immigrant families with sons and daughters

with disabilities and their support needs and their experiences with supports in the US. I also reviewed other literature on all families' experiences with supports and their needs irrespective of their ethnicity, while other literature included different ethnic minorities raising a child with a disability and issues regarding support access, unmet needs, and service experiences. The reason for examining literature on ethnic minorities was that although ethnic minorities and immigrants are not equivalent, as King, Esses, and Solomon (2013) pointed out, it is increasingly the case that immigrants to the United States are ethnic minorities, making the literature on ethnic minorities in general particularly informative.

To review the research on supports for families, my main source of information was professional peer reviewed journals, accessed through *Libraries Worldwide* which includes 27 databases (e.g., WorldCat.org, Article First, ERIC, PsycARTICLES, etc.). Key terms and phrases used for the searches included “support for families of children with disability”, “support for immigrant families of children with disability”, “social support for families with children with disabilities”, “educational support”, “respite care for families of children with disabilities”. All articles chosen were peer reviewed and from English language journals. In order to perform a more comprehensive search of the articles I performed a search by hand and checked the reference lists of the selected publications. Support for families with children without disabilities was excluded.

### **Theoretical frameworks influencing the review**

Several theoretical frameworks and conceptual approaches guided this review, including (a) ecocultural theory, which considers the sociocultural environment of the child and family and how it impacts on family dynamics, and (b) family ecology approach, which points to the importance of considering environmental, family, and child-related factors (Bronfenbrenner &

Ceci, 1994), and (c) family-centered service, considered to be a best-practice approach in early intervention and rehabilitation services for children with disabilities and their families (Rosenbaum, King, Law, King, & Evans, 1998). There is an extensive literature on client- and family-centered services, which outlines how families want to be treated in the support/service delivery process (e.g., Moore & Larkin, 2006; Sumsion & Law, 2006). A social inclusion framework incorporating principles of access and equity also was used to inform recommendations (Omidvar & Richmond, 2003; Skrinda, 2008).

### **Theories and Research on Families and Support for Families**

To understand supports for families of sons and daughters with disabilities I reviewed theories on the “family unit” and their related features: family interaction, family structure, and family functions. The history of family-centered supports for families of children with disabilities can be traced back to Bowen’s Family Systems Theory (1966) and Bronfenbrenner’s Family Ecology Theory (1979) (Seligman & Darling, 1989; Turnbull & Turnbull, 2001). Seligman and Darling (1989) wrote that “family-centered supports” is a conceptual framework that was developed by “marrying family systems constructs with information about families with exceptional children” (p. 4).

The ecology systems theory and family systems theory helps professionals to realize that children with disability do not function in isolation but rather they live within a context (i.e., the family), and when something happens to one member of the family, the whole family is affected (Turnbull & Turnbull, 2001). That is, the family operates as an interactive unit. As Turnbull and colleagues focused on Bronfenbrenner’s social ecology model (i.e., family ecology theory) and Bowen’s family systems theory to understand supports for families of sons and daughters with

disabilities, I hope to examine these theories and family-centered theory (framework) that was developed from the former mentioned theories.

### **I. Family Systems Theory**

According to the family systems theory family is defined as an “emotional unit” or a “system” in which each member of the family plays a role and has influence on one another (Papero, 1990). Bowen (1966) explained that the family is a system because a change in one member produces a compensatory (i.e., offset/correcting or counterbalance) change in other members of the family. He wrote the family can be looked upon as a number of different kinds of systems: a social system, a cultural system, a communication system, a biological system, or as a combination of “emotional and relationship” systems. Bowen noted that the goal of the theory was to understand human family behavior: the forces that motivate the system (i.e., emotional system) and the ways it is expressed (i.e., relationship system). The overall goal, according to Bowen was to “help family members become “system experts” who could know the family system so well that the family could readjust itself without the help of an outside expert, if and when the family system was....stressed” (p. 353).

The theory was guided by another theory called General System Theory which was introduced by mathematician Ludwig von Bertalanffy before the second world war (Papero, 1990). He wrote that the difference between the two was that while General System Theory was derived from mathematics and human thought, Family Systems Theory rested on factual knowledge gained from direct observation of the human family. The theory is comprised of eight concepts: differentiation of self, triangles, nuclear family emotional process, family projection process, multigenerational transmission process, sibling position, emotional cutoff, and emotional process in society (Papero).

According to Bowen (1966), the basic configuration of father, mother, and children is defined as a nuclear family. The nuclear family is alive with emotional activity (emotional process), the functional state and behaviors of each shifting constantly and “what affects any individual, therefore, can affect the whole, and what affects the whole can affect any individual” (Papero, 1990, p. 34). Bowen noted that the basic building block of the emotional system is the triangle. He reported that when anxiety and stress resides among the family members (e.g., between husband and wife) efforts will be made to involve a third member of the triangle (i.e., transmission of the problem to one or more children). This in turn may affect the development of the child/children (Bowen).

Bowen (1966) noted that during these periods of stress the nuclear family may be stabilized through emotional contact with a family of origin (i.e., extended family). But in events of detachment from extended families (e.g., immigrant families), the spouses are usually much more dependent on each other, and the emotional process in the family tends to be more intense. When emotions are high and cannot be contained within the basic triangle, it spreads through a web of interlocking triangles (e.g., therapist, co-worker, neighbor, or friend) until emotional equilibrium is attained (Bowen, 1966; Papero, 1990). Bowen proposed families often do not seek supports until “flexibility of the system” (p. 352) is lost, crossing to the point of panic and dysfunction. Ecocultural factors (i.e., environment, language, values, and beliefs) could also influence the supports sort by the families and their willingness to involve a third person to ease the anxiety.

Bowen (1966) wrote that the relationship between the father and mother significantly impacts the functioning of the next generation and he used the term family projection process to describe the concept. A child with the least emotional separation from his/her parents may

respond anxiously to stress in relationship between the parents, which in turn may be mistaken for a problem in the child (Brown, 1999). Brown (1999) wrote that a “detouring triangle” is thus set in motion, as “attention and protectiveness are shifted to the child” (p. 96). Another example of detouring triangle is when the disability of a child distracts one parent from the pursuit of closeness in the marriage (Brown).

Examining Family Systems theory through a multigenerational lens, Papero (1990) reflected:

Each nuclear family, therefore, is the endpoint of countless nuclear families before it. It is also a way station of human reproduction en route to other future generations of nuclear families. Each nuclear family is a unit, as is the broader, multigenerational constellation of nuclear families to which it belongs. The emotional need for another, established in each individual in each nuclear family but the product of countless generations, links each generation to its past while at the same time it influences the future. It is against this background of the family as a unit that Bowen Family Systems Theory takes shape (p. 35).

From this point of view, immigrant families may often bring with them the beliefs and values that have been passed down to them from generation to generation (i.e., ideology). In the new country of residence though, they experience greater social pressure to conform and fit into mainstream society compared to non-immigrant families (Cox & Paley, 2003; Portes & Zhou, 1993). The families that are cohesive experience healthier family functioning and lower family stressors associated with assimilation, but at the same time the children are growing up within two cultures: the social world of the host society and the customs of their parents’ home country (Bacallao & Smokowski, 2009; Paat, 2013). If the child tries to disengage from being

emotionally attached to his or her family (i.e., moves toward a higher level of differentiation of self), it disturbs the equilibrium and the family “togetherness force” opposes the differentiation with vigor to restore the former togetherness equilibrium (Bowen, 1966, p. 367). He wrote that this may cause the child to seek the support of peers or other adults to help oppose the forces of the family system forming a new “undifferentiated oneness with his allies” from which it will be even harder to differentiate (p. 367).

Emotional cutoff is one way an individual may try to completely differentiate from their family of origin, and is achieved either through physical distance or through forms of emotional withdrawal (Brown, 1999). He explained that when there is an emotional cutoff from the family of origin, the current family system can experience intense emotional pressure and the tension is like ‘walking on eggshells’, as events that lead to the cutoff are carefully avoided by all the family members. Supports from outsiders (i.e., triangling) helps in providing a detour (Brown). This may be true in the case of immigrant families with children with disabilities, where, often they experience emotional cutoffs from their extended families due to the social construction of disability in their country of origin and their attempts to avoid conflicting suggestions on schooling and health care from their extended families. Hence it may be essential to provide the necessary supports from others (e.g., parents with children with disabilities, community support) in relation to the cutoffs.

Bowen expressed that sibling position could provide useful information in understanding the roles individuals tend to take in relationships (Brown, 1999). Brown (1999) explained that a parent may identify strongly with a child in the same sibling position as their own and hence that child may be most vulnerable to triangling with parents. Another aspect of the theory is the idea that the eldest children are more likely to take on responsibility and leadership in a relationship,

with younger siblings more comfortable being dependent and allowing others to make decisions when they are part of a nuclear family system (Brown). He wrote that this concept on sibling position has been used by the family theory to help family members understand how their assumptions about relationships are often fuelled by their own sibling role experience.

**Summary of the key ideas in family systems theory.** Family systems theorists consider the quality of the marital relationship to be key to overall family functioning: the spouse dyad is the 'core' of the family (Rothbaum, Rosen, Ujiie, & Uchida, 2002). They reported that the quality of the relationship is a major factor related to the caregiving provided to the child, and thus of child functioning. They explained that in a study involving a boy experiencing "fears", the researchers focused on the unresolved and unexpressed conflicts between the parents. Their goal was to "shift the relationships in the family so that mother and father are more intimately involved with each other and the boy is disengaged from them...." (p. 331).

Examining studies and literature reviews on family systems theory, Rothbaum et al. (2002) found that marital discord, more than marital distress or marital apathy, led to a variety of child development problems and that overt (i.e., not concealed) conflicts had the most damaging effects. They wrote that research by family systems theorists have indicated that children of conflicting spouses may sometimes develop emotional problems so as to stabilize the marital dyad by bringing the parents together to look after the child.

Rothbaum et al. (2002) reported that family systems theorists believe that the "enmeshed mother/disengaged father syndrome" is another common occurrence in "dysfunctional" families, where a mother's closeness to her children substitutes for closeness in the marriage. But they argued this belief is grounded in Western thought and in Asian families for example the "overinvolved" mother-child relationships are more common and less likely seen as

"dysfunctional" (p. 331). They wrote: "the evidence suggests that patterns involving extremely high levels of caregiving by wives, distancing by husbands, and lack of intimacy in the marital relationship are more common, and are less likely to be seen as maladaptive" (p. 331) in Asian countries like Japan.

Rothbaum et al. (2002) expressed that cultural differences may alter the perception of what sensitive, responsive caregiving may look like. They wrote that maternal sensitivity in the US is largely intended to provide "a secure base that promotes the child's exploration, as well as encouraging the child's assertion of personal desires and autonomous efforts to satisfy one's own needs" (p. 333), while in another culture, sensitivity largely intended to "avoid distress and to promote infants' interdependence and emotional closeness with their mothers" (p. 334). Hence when working with immigrant families, service providers should: (a) not assume that extremely close and dependent mother-child relationship or marital couple's failure to find time alone together weakens the overall family; (b) be respectful of "role-prescribed" behaviors endorsed in the wider culture (e.g., childrearing responsibilities by mothers and fathers spending long hours at work); (c) rely on nonverbal forms of communication rather than require family members to be verbally explicit; (d) be willing to forge a close relationship with family members instead of maintaining a personally disengaged stance encouraged in Western psychotherapy; and (e) allow family members to assume highly dependent and passive behaviors if that is more comfortable for them, even though it may seem counter therapeutic in the U.S. (Rothbaum et al., 2002).

## **II. Ecology Theory: Strengthening Family Systems**

"The heart of our social system is the family. If we are to maintain the health of our society, we must discover the best means of nurturing that heart" (Bronfenbrenner, 2005, p. 260). By using a family ecological approach (ecological systems theory) to study human development,

Bronfenbrenner (2005) explained certain questions like: (a) “what does a family system need to grow and succeed?” and (b) “what do children, our society’s future, need within that system to thrive?” (p. 260). Bronfenbrenner (1986) wrote that family is the “principal context” (i.e., main environment) in which human development takes place. According to Bronfenbrenner there are different ecological systems (i.e., environmental/external systems) that can serve as sources of external influence on these families, which in turn will influence the human developmental process of the child. The family ecology theory focuses on the interrelationship between the family and other ecological systems such as school, neighborhood, parental support networks, parental employment, and the community and the resulting influence on the child’s human and social development (Bronfenbrenner, 1986).

Paat (2013), writing about immigrant children and their families, observed that family is a “social institution that provides a foundation in which children learn how to navigate and fit into the society” (p. 956). Cohesive families (i.e., healthy transactions among family members) are believed to be more supportive, flexible, and responsive to their children’s needs (Henry, Robinson, Neal, & Huey, 2006; Richmond & Stocker, 2008). Even though immigrant families, just like non-immigrant families, are “open and dynamic systems” that are vulnerable to changes, they experience greater social pressure to conform and fit into mainstream society (Cox & Paley, 2003; Portes & Zhou, 1993). Immigrant families that are cohesive experience healthier family functioning, positive psychological adjustment, and lower family stressors associated with assimilation (Paat, 2013). This is crucial in regulating immigrant children’s behaviors as the children encounter various ecological systems growing up within two cultures: the social world of the host society and the customs of their parents’ home country (Bacallao & Smokowski, 2009).

Drawing on the insights of Bronfenbrenner's ecological systems theory, Paat (2013) explained that the theory could function as a guiding framework of knowledge that helps in identifying ecological risks immigrant families face. He wrote that by understanding the ecology of immigrant families and how the immigrant family process takes place, effective support and service delivery will be possible, thus helping the families stay intact and healthy. This in turn will increase the opportunity for immigrant children to succeed in the American school system and subsequent socioeconomic attainment (Portes & Zhou, 1993).

### **Ecology of the Family: External Systems Affecting the Family**

The environmental systems (e.g., employment, support networks, community) that influence families, according to Bronfenbrenner (1986), can be distinguished in terms of an interactive system that consists of the mesosystem, exosystem, and chronosystem.

**Mesosystem.** Bronfenbrenner (1979) defined mesosystem as "a set of interrelations between two or more settings in which the developing person becomes an active participant" (p. 209). Bronfenbrenner (1986) explained that the family, hospital, day care, peer group, and the school all represent microsystems (i.e., one of the several settings in which social and psychological development take place) and the processes operating in different settings are dependent of each other (e.g., events at home can affect the child's progress in school and vice versa). Bronfenbrenner noted though, that the family (microsystem) is the most important setting in which the developmental process takes place. Results of studies examining mesosystem interactions between the family and other microsystems (e.g., family and the hospital, the family and day care, the family and the peer group, and family and school) illustrated greater social and psychological development among the children when there were active interrelations (Bronfenbrenner, 1986). He explained that children were observed to have a reduction in adult

disapproved activities (such as smoking, school misbehavior, delinquency, and antisocial behavior) while demonstrating greater independence when there was greater interactions between the family and other microsystems.

Paat (2013) wrote that strong relations between immigrant families and other social institutions (e.g., school) could foster the pace of assimilation and strengthen prospects for success in the school system, and future employability. Addressing the mesosystem of the family and the children's peers, Paat noted that protective parents may monitor their children's interpersonal relations closely and enforce rigid rules limiting the free interaction with the mainstream society, while encouraging participation in ethnic activities and association with other immigrant peers in order to preserve ethnic family values. Other families may believe that wider social networks and affiliation with the dominant culture could foster assimilation and would guarantee a better future for the developing person (Paat, 2013). According to Paat, one of the main challenges for immigrant families regarding participation and understanding of various norms and values in the mainstream society is language. He wrote "consequently, they also become less involved in their children's schooling despite the fact that education is pertinent for the integration process of their children" (p. 959). Paat noted that economic hardship and stress are other factors that could shift the families' priorities affecting the mesosystem of the families and other systems.

Hence from the above discussion it seems imperative that the host society be supportive of the idea of biculturalism/multiculturalism in order to encourage interactions (mesosystem) among immigrant families and other microsystems. Biculturalism increases immigrant family's sense of well-being by decreasing social isolation (marginalization) and facilitates the children to navigate two social worlds: their parents' cultural tradition and the mainstream customs (Portes

& Zhou, 1993). Berry (1997) explained that multiculturalism leads to greater integration and reduces marginalization.

**Exosystem.** An exosystem has been defined as consisting of “one or more settings that do not involve the developing person as an active participant but in which events occur that affect, or are affected by, what happens in that setting” (Bronfenbrenner, 1979, p. 237).

Bronfenbrenner (1986) explained that the psychological development of children in the family is affected not only by what happens in the environments in which children spend their time but also by what occurs in the other settings in which their parents live their lives, especially in a domain that children rarely enter- e.g., parents’ world of work, parents’ social network (circle of friends and acquaintances), parental support networks, and relationships between the family and the community. These environments that are “external” to the developing person are referred to as “exosystems” (Bronfenbrenner, 1986, p. 723).

Examining various studies and linking them to exosystem, Bronfenbrenner (1986) found that families characterized as having ample family support, strong social networks, adequate support systems for parenting, and regular church attendance were more supportive and caring toward their children. He reported that this in turn affected the child’s social and emotional development resulting in fewer behavior problems, lesser antisocial behaviors, and higher cognitive test scores. According to the findings of these studies examined by the author, high-income families, two-parent households, and parents with strong family support reported lower levels of stress, anxiety, and depression, and better marital adjustment and positive perceptions toward themselves and their children. Also it was found that single mothers’ effectiveness in dealing with the child was directly related to the amount of support received from friends, relatives, and ex-husband (Bronfenbrenner).

Paat (2013) stated that immigrant families are “socially disadvantaged as newcomers” (p. 961) due to unfamiliarity regarding dominant cultural practices and social norms. He noted that language and difficulty adjusting to the host country might make them less privileged in regards to voicing and exercising their rights related to their children. These families are far from their home country where they were raised in non-English speaking households and in a different culture and are often torn between preserving their family identity and gaining a new national identity (Zhou, 2001). Paat wrote, “if mainstream society and the immigration laws are perceived as welcoming and friendly, immigrant families are likely to feel supported” (p. 961). Evidence has indicated that children of immigrant families will adapt better in the larger society when there is public support for cultural diversity (Paat, 2013).

**Chronosystem.** Bronfenbrenner (1986) noted that human development within individuals is influenced not just by chronological age but also by changes in the environment over time. Bronfenbrenner explained that before the 1970s most traditional longitudinal studies focused exclusively on the individual and his or her psychological changes over time. By proposing the term chronosystem, he suggested projecting the factor of time along a new axis which focuses on the changes in the environments in which the person is living and its influence on the individual's development. Bronfenbrenner noted life transition is an example of a form of chronosystem (e.g., school entry, puberty, entering the labor force, marriage, retirement). From a family ecology theory viewpoint, life transition on family processes can also influence development of the child indirectly. A death or severe illness in the family, divorce, moving, winning the sweepstakes can impact the family processes and the development of the child (Bronfenbrenner).

Immigrant children experience not only normative life transitions such as physiological, cognitive, emotional, and interpersonal changes but also non-normative life transitions resulting from their family's move to a new country (Zhou, 2001). Zhou explained they are often addressed as a "transitional generation" as they are trapped in their parents' social world and the realities of the mainstream culture. Supports that immigrant families receive, job opportunities, income, and education of the parents all exert significant impact on immigration children's assimilation trajectories and their ability to adapt to changes (Paat, 2013). He wrote that it is essential for service providers to hence consider the chronosystem of the families (i.e., various life transitions and cross-country moves) in order to deliver culturally competent supports.

### **III. Family-Centered Theory**

Family-centered theory is based on the perception of the family as the "basic social unit- the main educator, supporter, and shaper of each person" (Bamm & Rosenbaum, 2008, p. 1618). The Universal Declaration of Human Rights Article 16/3, passed by the United Nations General Assembly in 1948, stated that, "The family is the natural and fundamental group unit of society and is entitled to protection by society and the State." Bamm and Rosenbaum (2008) stated that this view of the family led to the development of family systems theory, which in turn was influential in the creation of the family-centered theory and policies. Family systems theory highlights the interactions among family members and the impact of each member upon the others, emphasizing that healthy and cohesive families are more capable of facilitating their child's development (Rosenbaum, King, Law, King, & Evans, 1998). This, according to Rosenbaum et al. (1998), promoted the view that supports and services that are family-centered can indirectly affect the children.

Bronfenbrenner (1979) wrote that the family is the primary organizing structure in the development of a young child. According to Roberts, Rule, and Innocenti (1998), family-centered care occurs when "a service provider assists a family in decision making that honors and respects family preferences. This form of assistance helps families use the informal structures that are already available and helps to make decisions about more formal systems with which they choose to interact" (p. 56). Examples of decision making can be: setting goals, choosing intervention strategies, and deciding who the service provider should be (Roberts et al., 1998).

Bamm and Rosenbaum (2008) wrote that there is no one definition for family-centeredness since the function and perception of family vary according to the cultural and political environment. They explained the definition of family-centeredness might differ from country to country and from one setting to another. The term family-centeredness, according to Dunst (2002), refers to "a particular set of beliefs, principles, values, and practices for supporting and strengthening family capacity to enhance and promote child development and learning" (p. 141). These beliefs and practices (i.e., ideologies) are individualized, flexible and responsive, treat families with dignity and respect, promote information sharing so families can make informed decisions, and encourage family choice regarding supports and resources necessary for families to care for their sons and daughters (Dunst, 2002). Dunst explained that when practices are family-centered, the family as well as the child benefits.

The CanChild Centre for Childhood Disability Research described family-centered practices as a set of values, attitudes, and approaches to services for children with special needs and their families (CanChild Centre, 2003). According to the Center, family-centered practices recognize that each family is unique; that the family is the constant in the child's life; and that

they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receives. Dempsey and Keen (2008) wrote that the four crucial beliefs that drive the implementation of family-centered practices are: (a) the family and not the professional is the constant in the child's life, (b) the family is in the best position to determine the needs and well-being of the child, (c) the child is best helped by also helping the family, and (d) emphasizing family choice and decision making in the provision of supports, respecting and affirming families' strengths, enhancing family control over the services and supports they receive, and encouraging partnerships and collaborations with families.

According to Rosenbaum et al. (1998), the guiding principles and key elements of family-centeredness are that (a) parents know their children best and want the best for their children and hence each family should have the opportunity to decide the level of involvement they wish in decision-making for their child and that parents should have ultimate responsibility for the care of their children; (b) families are different and unique and hence each family and family member should be treated with respect (as individuals) by listening to their voices, accepting diversity, trusting parents, and communicating with them early; and (c) optimal child functioning occurs within a supportive family and community context (i.e., the child is affected by the stress and coping of other family members) and hence the needs of all family members should be considered. They noted that by encouraging parent decision-making, parent satisfaction and the feeling of empowerment was present, resulting in lower child-related parenting stress and in increasing parents' psychological well-being.

#### **IV. Ecocultural Theory**

Since the abolition of the quota system in the 1965 Amendments to the Immigration and Nationality Act, there has been a rapid increase in immigrant families entering the US over the past half century (Welterlin & LaRue, 2007). They noted that this growing influx of immigrant families necessitates an understanding of culturally bound perspectives (i.e., how cultural values and beliefs influence interpretations families give to their everyday lives). This, according to the authors, allows supports and services/interventions to be "tailored to accommodate the needs, values, goals, and systems that make up the ecocultural niche of a family" (p. 749). Bernheimer, Gallimore, and Weisner (1990) wrote that ecocultural (ecological/cultural) theory attempts to provide a "conceptual framework that enables us to understand why some parents think, feel, and act entirely differently" (p. 223). The theory builds on both family systems and ecological theories and integrates a social constructivist perspective (Brookman-Fraze, 2004).

According to the ecocultural theory, actions that families take in their everyday lives, their daily routines and activities, are influenced in part by the ecology (i.e., the physical setting, the material setting, and the social setting) and in part by their beliefs and values that are personally and culturally influenced (Bernheimer, Gallimore, & Weisner, 1990). Examples of the family routines are: preparing meals, eating dinner, clearing up, mowing the lawn, repairing cars, watching television, getting ready for school and other similar adult-child interactions (Gallimore, Goldenberg, & Weisner, 1993, p. 539). They explained that these daily family routines and activities promote the development of children and families and are the architecture of everyday life.

The environmental circumstances (ecology) that influence the everyday routines in which children and adults interact (i.e., the family's niche) include geographic, demographic, and

economic presses like the climate, political economy of the region, income, public health conditions, neighborhood characteristics, housing and space, transportation, and the distance from family members or services (Bernheimer et al., 1990; Gallimore et al., 1993). Ecocultural theory proposes a family's niche is also a product of a social construction process- meanings the family place on these everyday activities and its impact on the cognitive and communicative development of the child (Bernheimer et al., 1990). This perspective that the family's niche is influenced by not just the material environment but also the sociocultural environment (e.g., beliefs relating to moral life, origins and causes of disability, culturally appropriate conduct of marriage, and family relationships) is useful when considering supports and intervention for families, especially for immigrant families with sons and daughters with disabilities (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Welterlin & LaRue, 2007).

Brookman-Frazer (2004) and Moes and Frea (2000) used an ecocultural approach to propose supports and interventions should fit into the daily routines of families with children with disabilities and incorporate the goals and meaning that the family places on such routines. This approach is based on the idea that the most important needs of the family are those that are identified by that family (Brookman-Frazer, 2004). The supports and interventions for families and children with disabilities in more "sustainable routines and activities" provide stability for the children and produce well-being among family members due to meaningfulness and value for the family (Weisner, 2002). He wrote that well-being, in ecocultural theory, consists of "engaged participation in cultural activities deemed desirable by a cultural community (e.g., kinds of play, work for the family, prayer), and the psychological experiences produced thereby (such as effectance, happiness, and trust) (p. 279).

Welterlin and LaRue (2007) wrote that an ecocultural perspective will guide western service providers on how to work effectively with immigrant families with sons and daughters with disabilities due to the differences in cultural values and beliefs of both the providers and the families. Gallimore et al. (1993) wrote that the supports should not just depend on the ecology surrounding the family (i.e., geographic factors, demographic factors, and economic factors) but also the value families place on these supports and interventions (i.e., the socially constructed meaning regarding the activity settings and routines). They noted that most times the "value" families place on the activity settings depends on cultural and personal beliefs and hence these beliefs should be considered to optimize the supports, hence making the supports and interventions effective and sustainable. By paying careful attention to a family's existing proactivity and daily routines service providers can take the family's strength into account in family intervention planning (Gallimore et al).

**Intervention planning using ecocultural theory.** Brookman-Fraze (2004) and Moes and Frea (2000) wrote that ecocultural theory is one of the leading theories in intervention planning of immigrant families with sons and daughters with disabilities. They noted that the approach includes the components of a family's social and cultural environment to create a 'best fit' intervention, and by doing so, the effectiveness and compliance with an intervention will increase sufficiently. According to Welterlin and LaRue (2007) several studies have supported the notion that family collaboration based on ecocultural theories lead to: (a) effective parent training, (b) increased child outcomes, (c) reduced parental stress, and (d) increased parent confidence in home-based programs.

Some of the recommendations put forth by the authors for service providers working with immigrant families with children with disabilities are: (a) understand immigrant families'

perceptions of disability, the diagnosis, etiology (i.e., the cause), and intervention, (b) acknowledge cultural differences among the families and service providers and differences in beliefs about disability and intervention, (c) instill a sense of sensitivity and competence when working with immigrant families by respecting their background and willingness to incorporate their cultural views into intervention planning, (d) identify and integrate immigrant families' strengths and resources (strength-based approach), and (e) recognize one's own cultural assumptions and biases, and at the same time avoid stereotyping another person's cultural beliefs. According to Welterlin and LaRue (2007) this "stance of cultural reciprocity may also allow families to be more open to explanations of the benefits of incorporating the goals of the dominant culture" (p. 756). They wrote that support/service providers can acknowledge cultural differences by asking a question such as: "I understand you are new to this country and the medical care and educational systems may work differently in your country. Can you tell me more about your country and how those systems work there?" (p. 756).

## V. Categories and Types of Family Supports for Families with Children with Disabilities

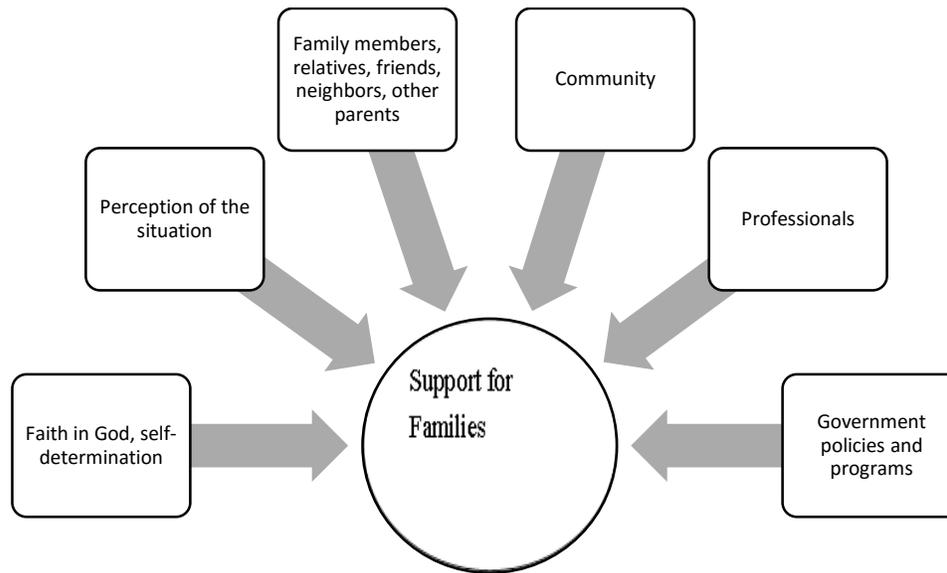


Fig 1: Supports for families (Gupta, Mehrotra, & Mehrotra, 2012)

The range of categories and types of family supports for families with sons and daughters with disabilities include the categories put forth by Canary (2008); Cooley, 1994; Gupta, Mehrotra, and Mehrotra (2012); Kyzar, Turnbull, Summers, and Gomez (2012); and the National Agenda on Family Support (2011). The common feature among all these studies were the assessment of the source of support, that is *who* provides the support for the families. The three main categories were: (a) family (natural supports- spouse, extended family, relatives/kin, mother/father, or mother-in-law/father-in-law); (b) friends (informal supports); and (c) professionals (formal supports- family or child's physician, health care providers, counselor or therapists). Additional sources of support identified were neighbors, other parents, co-workers, parent group members, social groups, church members, services (e.g., early intervention program), and school/daycare center.

Types of family support for families of sons and daughters with disabilities, that is, *what* support is provided, were classified in these articles as: (a) Emotional supports (mental health

and self-efficacy), (b) Informational and training supports (knowledge and skills), and (c) Material/Instrumental supports (day-to-day needs and physical support). According to Kyzar et al. (2012), emotional support refers to assistance related to improving psychosocial functioning in terms of reducing stress and improving a positive orientation of feelings (e.g., someone to talk with, family acceptance of disability), informational support refers to assistance related to improving knowledge from verbal or written materials presented (e.g., online, through print, information shared by another parent), and material/instrumental support refers to assistance related to improving access to adequate financial resources and completion of necessary tasks (e.g., transportation to appointments, child care enabling the parents to work, assistance with housework so the family can spend time together). They noted that it has been a timely shift to a supports paradigm in the field of disability from a deficit paradigm where the focus was deficit within the person/family. The authors indicated that the current focus on support to individuals with disabilities and families will enhance positive family outcomes (i.e., benefits experienced by families).

## VI. Building Circles of Support

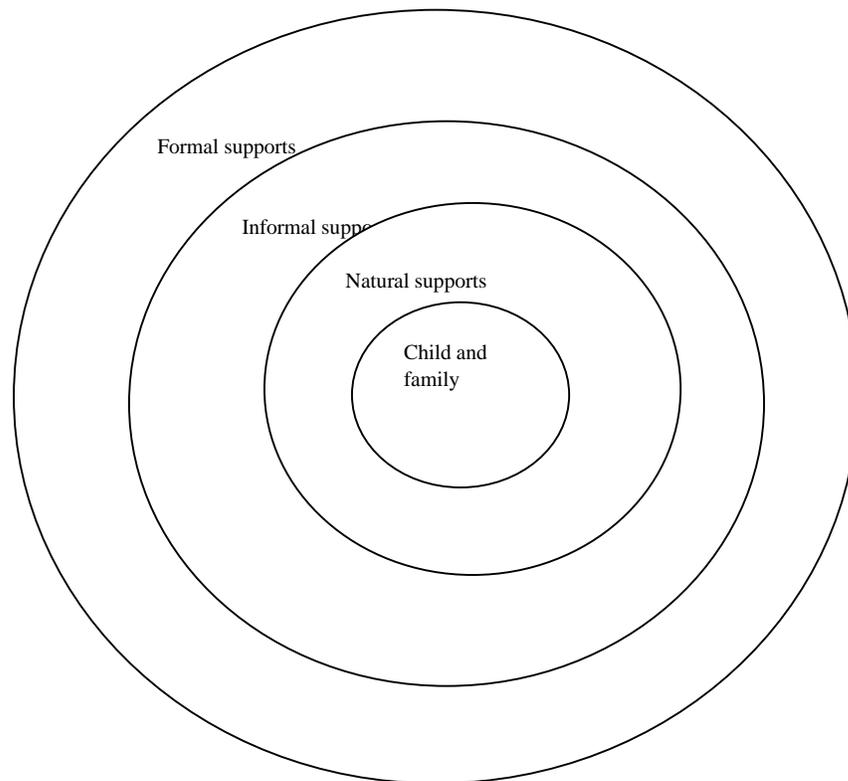


Fig 2: Ecology of Support for Families of Sons and Daughters with Disabilities

Cooley (1994) explained that a community-based, family-centered system of family supports includes three subsystems. He wrote, “the subsystems form an ecologic frame of reference with the child and the immediate family unit at the center of concentric rings of support” (p. 118). The circle of support closest to the family represent the most natural and primary sources of support for families and is referred to as natural supports and includes spouses, extended family members, friends, neighbors, churches, and other community-based systems (Cooley, 1994). At the second level are informal supports, and may include informal networking with other parents of children with disabilities, or more formal parent-to-parent

programs (Cooley). The author wrote that the outermost circle of support contains the formal supports, which includes ways to assist the family in meeting its daily needs like financial and health insurance benefits, respite care, early intervention programs, transportation.

Weinhouse and Weinhouse (1994) noted that the emotional stress of dealing with the reality of the disability, the burden of responsibility of taking care of a son or daughter who may forever require extra services, the added expense of medical and educational interventions, the guilt and doubt related to “self-blame” for the child’s disability- all these factors show the importance and need for supports at all three levels. They wrote that some of the common sources of support are: spouses, older children, other family members, friends, families of other children with similar needs, schools, agencies, churches, and religious beliefs. Weinhouse and Weinhouse wrote, “as any architect or builder knows, in order for a structure to remain standing, supports must be stronger than burdens” (p. 163).

During the early years when dealing with the reality that the child “is not like most other children” (Weinhouse & Weinhouse, 1994, p. 163), emotional stress like numbness and denial, rejection, guilt, acceptance, and wanting time alone are common (Thompson, 2000). This may be a crucial time when the young families need lots of supports at all three levels. Thompson (2000) wrote that parenting is hard work even under the best of circumstances, and for sons and daughters with disability, the work of parenting intensifies and so do the strains, stresses, and pressures. She explained parents are likely to “feel constantly tired, irritable, short-tempered, weepy, ill, discouraged, or depressed, or angry and brittle” (p. 33) and need to find a way to relieve the stress and occasionally get a break from their responsibilities to refresh themselves. If not, the emotional burden can strain the family relationship, leading to fights, separation, and divorce (Thompson, 2000). She stated that many families reported not spending time together

even for a meal after the birth of a son or daughter with a disability. According to Bailey and Smith (2000), findings of several studies have indicated higher levels of stress and/or family discord among families of children with disabilities than in comparison groups of families of children without disabilities.

### **Natural Supports**

Cooley (1994) noted that families surrounded by empty rings of natural and informal supports and who only have formal supports will often remain dependent on those formal supports and they are “at high risk for social isolation and demoralization” (p. 118). He identified natural supports as the most important supports to nourish and develop families.

**Support from Spouse.** Bruns and Foerster (2011) conducted a study on support for parents with children with rare trisomy conditions. They wrote that the majority of participants indicated their spouse was the most supportive family member. Responses like “We are a team in everything including the care of our son,” and “My husband is just there for me to listen to me and hold me when fear or grief overwhelms me...and it still does even though Nash is almost 14 years old” indicated that support was demonstrated in several ways (Bruns & Foerster, 2011, p. 365). The importance of a father’s role in supporting mothers in mitigating stress has been documented in the study by Dyson (1997). But Bruns and Foerster (2011) also reported on evidence where many husbands either did not fully understand or come to terms with the breadth of their child’s condition even years after diagnosis.

Thompson (2000) reported that often the case is that if a child has a disability the father leaves the household and no longer keeps in contact with the mother, leaving her with no emotional, physical, or financial support. Single mothers hence often are left with the responsibility of taking care of the child herself. The mother of a six-year-old girl stated, "My

husband left during [daughter's] first year at school, partly because he couldn't accept [her] condition. He buried his head in the sand" (Cigno & Burke, 1997, p. 180). Thompson suggested that in such cases single mothers should try to quickly develop a good support system of family, friends, and medical personnel. A network of close friends, especially other mothers who have children with disabilities, can mutually support each other through valuable advice and information about practical matters, energize and sustain each other, and take turns watching the children (Thompson, 2000).

In the study by Cigno and Burke (1997) with single mothers of children with disabilities, the authors noted priorities on the kinds of support services was somewhat different for single mothers compared to mothers in a two parent household. Transportation, followed by support in dealing with their sons or daughters behavior problems were the main two supports requested by single mothers. The need for more equipment for the home and financial support were also in the main priorities for the mothers. In regards to informal support, single mothers felt the need for more contact with parent groups compared to mothers in two parent households. Also the need for greater contact with the teachers, more social work visits and medical services were reported by the single mothers in this study.

**Support from Extended Family Members.** Support from grandparents, especially grandmothers in mitigating stress was documented in studies and reviews by Bruns and Foerster (2011); Trute, Worthington, and Hiebert-Murphy (2008); and Mitchell (2007). Trute et al. (2008) wrote that key findings in studies indicated that: (a) grandmothers are seen to be more supportive than grandfathers; (b) maternal grandmothers are perceived to be more supportive than paternal grandmothers; (c) grandparent support was more common than support from other relatives or friends; (d) grandparent emotional support was considered to be more valuable in reducing

parenting stress than instrumental support (e.g., practical help). For immigrant families the level of support from grandparents was lower due to geographical limitations (Mitchell, 2007). She wrote that there is little research on grandparent support and grandparent perceptions on disability among ethnic families though.

Ayon and Naddy (2013) wrote that findings in studies have indicated the importance of supports from extended family members such as in-laws, relatives, and siblings. From their study they cite a mother who said:

Well, for me, my husband supports me emotionally and financially. I depend completely on him financially . . . and when one has problems or anything there is always the family, who for me are my sisters and my mother. And when we get financially stuck there is always my husband's mom, who helps us (p. 365).

Older siblings of the children also play a crucial role in supporting their parents (e.g., cleaning, caring for younger siblings) (Ayon & Naddy, 2013). They explained that siblings of the parents were also reported to be a significant member of their support network, providing financial assistance, emotional support (their presence), instrumental support (e.g., babysitting) and moral support (e.g., accompanying to appointments).

**Support from Friends, Neighbors and the Community.** Families with children with disabilities face many disadvantages compared to families with sons and daughters without disabilities (Dowling & Dolan, 2001). The need for supports in order to participate in paid work, engage in leisure activities and enjoy social relationships within and outside the family was expressed by families in a study by Murray (2007) and to participate meaningfully in existing community activities has been discussed by parents in a study by Carter, Swedeen, Cooney, Walter, and Moss (2012). The disability of a son or daughter could threaten the family's ability

to “belong” in a community (Hall, 2010) and according to Swenson and Lakin (2014) many times individuals with a disability or their family members have felt unwelcomed at schools, at community events, public places, or in a church. A large percent of families indicated that supports were not fully available to participate in congregational activities (Ault, Collins, & Carter, 2013). The families expressed the need for a greater “welcoming” and “supportive” attitude by the faith community.

Carter et al. (2012) conducted community conversations with parents of individuals with disabilities and some concerns voiced by parents were how the community could be more welcoming of people with disabilities and the need for supports in existing activities to make them more inclusive. The families also focused on the importance of educating the community regarding the value of inclusion, and advocacy training for the parents. In another study families reported exclusion from participation in their religious community because of concerns about their child’s disruptive behaviors, and the lack of accessibility in parks and swimming pools (Murray, 2007). Social inclusion was another concern by families in the study. The researcher wrote that loss of support from friends and family members in turn often affected families own relationship with each other. Swenson and Lakin (2014) reported that families in rural areas articulated the absence of access to transportation and local necessities.

### **Informal Supports**

Cooley (1994) explained that informal supports are not a part of a statutory (i.e., constitutional, legal) system of supports but help families reduce or avoid feelings of isolation and helplessness. He wrote this may include: contact with other parents of children with disabilities through chance meetings (e.g., in a hospital waiting room), informal networking, or parent-led programs.

**Informal Networking.** Informal support networks play a unique role in families of sons and daughters with disabilities and these support networks differ from person to person (Weinhouse & Weinhouse, 1994). They wrote:

No two people, not even spouses, share the same exact network. Helene may rely on her husband, Al, for emotional support, whereas Al may rely on his buddies; Leah and John may seek assistance from their church in times of crisis, whereas Berta and Hans may turn to a counselor or social worker; Claire and Daniel may have their parents watch the kids when they need a break, whereas Patty and Ben may hire a baby-sitter (p. 162).

Parent support groups are important channels for families of children with disabilities who seek support and resources (Lo, 2010). Seeking new information and asking questions could be significantly more comfortable among parents than with school professionals (Haren & Fiedler, 2008). As children start school informal supports from other parents of children with and without disabilities can also be a key support network, where parents receive emotional support by sharing information and experiences (Bailey & Smith, 2000). Haren and Fiedler (2008) noted that parent networking is a great source of support, especially for those having new experiences in the special education system. Doctors, social service agency, the hospital social worker, or a parent-support group could help connect families together to share information and come up with fresh ideas to everyday issues (Thompson, 2000).

**Parent-Led Support Groups.** Parent-led support groups for parents who have children with disabilities are "voluntary organizations with goals to provide social support and information and to foster advocacy" (Law, King, Stewart, & King, 2001, p. 29). They wrote that the support groups provide parents with support, friendship, opportunity to share experiences, knowledge and assist in improving parents' ability to deal with childhood disability issues. Even

when there are adequate formal supports (i.e., professional supports) parents often feel a need for support from other parents (McCabe, 2008). According to McCabe (2008) parent-led support groups are highly beneficial for parents of newly diagnosed children with disabilities as they are mentored by more experienced parents.

**Concerns.** One of the concerns voiced by parent-led support groups was that immigrant families and families in the lower socioeconomic backgrounds were not utilizing the opportunity to benefit from these support groups (Mandell & Salzer, 2007). They noted for families that are uncomfortable attending support groups, 1:1 mentoring with families in similar situations may help to decrease social isolation, reduce stress, and increase access to information about appropriate care. Immigrant families often report they encounter a feeling of shame and embarrassment about having a child with a disability and the need in keeping matters involving their children's disability private (McCabe, 2008). Lo (2010) added that many immigrant families believe their sons' or daughters' disability should not be openly discussed with people other than their family members because "Asians do not often define or address disability in the same open manner as typically does the American culture" (p. 406). She wrote that language barriers added to the challenge of locating support groups for the families. For immigrant parents who reached out for support, they felt more comfortable sharing their frustrations with parents of the same culture and feel a sense of relief to "finally meet someone who understood what they were going through" (p. 413).

### **Formal Supports**

Formal systems of family support are usually developed by governments or other public agencies and these supports reflect current policy toward families (Cooley, 1994). Even though Federal and state laws attempt to bring order and consistency to formal supports for children and

families, factors that make this an elusive goal include the heavy financial burden special services place on local agencies, differing values among communities, professional burnout, short supply of professionals, greater demand than ever before (due primarily to medical advances in saving babies born prematurely and increased use of drugs in pregnant women) (Weinhouse & Weinhouse, 1994). And due to these factors many of the available services are short term and the fear of losing them is a concern families have to deal with everyday. As expressed by a parent, “I can’t get over these thoughts that we’re going to lose the services we’re getting and then I won’t be able to handle the situation anymore. How can I deal with these fears and just live my life?” (Weinhouse & Weinhouse, 1994, p. 213).

Weinhouse and Weinhouse (1994) wrote that to ensure supports from services are not lost and that further advances continue to enrich the lives of children with disabilities and families, parents need to continue their active support of existing services and lobby for new programs and increased funding. They addressed the need for families to express themselves loudly and clearly about how the services (programs) can benefit them and their children, and about services they like and those they don’t like. They argued that to be a strong advocate or lobbyist requires knowledge and understanding. They wrote:

Parents must therefore read and learn about their child’s disability, attend conferences, join support groups, and network. Through activities such as these they will become more knowledgeable about the condition of special education and be more able to suggest how it might be improved; they will prepare themselves for the numerous letters they will have to write, phone calls they will have to make, and questions they will have to answer (p. 68).

**Support from Professionals.** “The best outcomes for children and families happen when parents and professionals work as partners with mutual respect and shared decision-making power” (Naseef, 2001). Naseef (2001) wrote that families, by virtue of their bond with their child, have information no one else has access to. Professionals, on the other hand, through training and experience can offer the families a broad perspective and important skills (Naseef). He noted that “each has only partial knowledge, with complete expertise only possible in the partnership” (p. 220) and that all decisions, plans, and goals should be based on this combined perspective.

Researchers have found that formal support networks that are family-centered (e.g., provide needed information, treat parents with respect, include parental control of decision making) and specific to family needs relate to lower stress, greater well-being, and empowerment among families (Canary, 2008). She noted that several studies report that families express a desire for formal supports/intervention by professionals and rely on such supports. They could include intensive family counseling, informational programs for parents and siblings, respite care, crisis counseling, early-intervention programs, and multiagency coordinated programs (Canary, 2008).

Key characteristics of effective partnership “collaboration” according to Keen (2007) are: (a) mutual respect, trust and honesty, (b) mutually agreed-upon goals, and (c) shared planning and decision-making. According to Porter and McKenzie (2000) collaboration means “power is shared, with parents and professionals jointly determining goals and planning strategies with each other” (p. 8). The family may determine their role in the relationship: the level of responsibility they want to take and the level of involvement (Porter & McKenzie). They wrote that the families may or may not take an active part in delivering services for their sons or

daughters with disability according to their desires and other commitment, while the professionals' role is to support the families in their chosen role. The professionals, according to the authors, should not define the families' role.

**Instrumental Supports for Families.** Material supports in the areas of family income, employment, costs of caring, housing, respite care, and transportation are necessary for families with children with disabilities. Chamba et al. (1999) pointed out that the factors mentioned above are all interconnected and that caring for a child with a disability could draw heavily on families' material resources, affect employment choices and hence reduce family income, and experience extra costs associated with caring. Bailey and Smith (2000) wrote that for families struggling with stress-related issues formal supports, such as financial and health insurance benefits, respite care, early intervention programs, and other state/agency resources would be beneficial in meeting their daily needs and medical and educational needs of the child.

**Cost of caring.** Estimates for the United States indicate that there are over 3 million children aged between 5 and 17 years with disabilities living with parents (Brandon, 2007). Families with children with disabilities face on average three times the cost of families of children without disabilities (Russell, 2003). Parents reported that the need for income support and financial assistance (e.g., Medicaid, Supplementary Nutrition Aid Program) were because of high medical costs, cost for special education services, parental productivity loss, cost for residential care or supportive living accommodations, high cost of alternate care arrangements (e.g., after-school care, day care), home care modifications, cost of travel to medical appointments, and cost of specialized equipment (Buescher, Cidav, Knapp, & Mandell, 2014; Murray, 2007). The absence of affordable and appropriate child care for children with disability has resulted in them being in a financial disadvantage (Russell, 2003).

**Family income and employment.** Many families face difficulties in getting into, or retaining employment even though they reported wanting full or part-time jobs (Buescher et al., 2014). The findings of Drummond, McDonald, MacKenzie-Keating, Fleming, Feldman, and Enns (2004) suggested that the main reasons for parental stress in families having children with disabilities were as a result of juggling work and family, along with child care responsibilities. Drummond et al. (2004) reported high levels of stress were placing the health and well-being of families at risk and that appropriate supports from services could reduce these levels of stress. Formal supports help in meeting the health, educational, and social care needs of children with disabilities and their families (Chamba et al., 1999). Significant career-related decisions by family members (e.g., turning down promotion, working only part time, refusing transfers), result in direct and indirect economic costs (Swenson & Lakin, 2014). They asked a core policy question: “How do we create fair, effective, and cost-beneficial approaches to supporting families” (p. 187). According to a study conducted in Australia, families with children needing significant supports reported lower incomes, greater expenses for long periods of time, limited capacity to participate in paid work due to care activities, and higher stress trying to balance care and paid work (Murray, 2007).

**Transportation.** With a constant stream of appointments to attend (e.g., speech therapy, physiotherapy, occupational therapy, hearing tests, vision tests, dietary therapy, and social work appointments) families often have to travel considerable distances with the child and possibly siblings (Dowling & Dolan, 2001). Arranging transportation was reported by families as difficult as they encountered problems arranging the necessary seating, funding, insurance, safety, and timing (Dowling & Dolan). The authors suggested that one of the ways to reduce the burden for

the families is for the service providers and health care professionals to travel to them, at home or school.

**Respite care.** The purpose of respite care, according to Dowling and Dolan (2001), is not just for giving a break for parents from the caring role but also in providing a beneficial experience for the developing child. Findings from studies have indicated the importance of ‘short-term breaks’ as parents and children have reported they enjoyed the experience (Ward, 1999). The results of a systematic review of respite care for families of sons and daughters with disabilities by Strunk (2010) indicated: (a) need for respite care services go beyond nature of disability, income level, rural or urban demography, family size, and marital status; (b) respite care is associated with significant reductions in parental stress even if it was short-term respite care; (c) the primary value of respite care was perceived by parents as to give them a break and the chance to spend time with other family members; (d) families of children with challenging behaviors often did not receive respite supports and often when they received them the supports were not evidence based; and (e) respite care may be considered as an intervention for child abuse, especially for children with disruptive behaviors.

**Education supports and early intervention.** Naseef (2001) wrote that often parents are not in control over the education of their child. He explained that many parents report long searches to find information about their child’s disability, early intervention, preschool programs, and speech and physical therapies. The Individuals with Disabilities Education Act of 2004 (IDEA) mandates inclusion of children with disabilities with their same-age peers as much as possible and insists that parents be included in all educational decision making and planning process (Ryndak, Orlando, Storch, Denney, & Huffman, 2011). The authors noted that supports from educators and collaboration between professionals and families are paramount for planning

of the appropriate special education and placement. Examining the studies and literature on culturally diverse families' participation in the child's education process, cultural barriers do exist and impede the collaborative relationship between families and educators (Cho & Gannotti, 2005; Kalyanpur & Gowramma, 2007; Kalyanpur & Harry, 1997; Kalyanpur, Harry, & Skrtic, 2000).

***IDEA and family support.*** The main purpose of IDEA (2004) is to:

(a) ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living; (b) *to ensure that the rights of children with disabilities and parents of such children are protected*; and (c) to assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities (20 U.S.C. 1400 (d)(1)).

According to Section 1414 of IDEA (2004) the school must obtain informed parental consent before conducting an initial evaluation (i.e., to identify if the child is a child with a disability and whether he or she needs special education services) and before providing special education services. If the parent refuses consent for services, the school district is not required to develop an individualized education program (IEP) for the child.

Section 1415 of the Act describes the procedural safeguards designed to protect the rights of children with disabilities and their parents. These safeguards include an opportunity for the parents of a child with a disability to examine all records relating to such child and to participate in meetings with respect to the identification, evaluation, and educational placement of the child, and the provision of a free appropriate public education to such child, and to obtain an

independent educational evaluation of the child (20 U.S.C. Section 1415 (b) (1)). According to Section 1415 of the Act, if the school district proposes to change or refuses to change the identification, evaluation, or educational placement of a child, the school must provide the parent with prior written notice (PWN) describing the action proposed or refused and explaining why the school propose or refuse to take action (20 U. S. C. Section 1415 (b) (3)).

**FERPA.** The purpose of the Family Educational Rights and Privacy Act (FERPA) is to protect the privacy and confidentiality of parents and students. FERPA (20 U. S. C. 1232g and 1232h) is a Federal law that protects the privacy of student educational records and gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level (U.S. Department of Education, ed.gov). FERPA gives parents certain rights to inspect and review all educational records relating to their child, the right to have copies of records and to receive explanations and interpretations from school officials. Also personally identifiable information may not be disclosed without written consent of the parent (i.e., student's name, name of student's parents or other family members, address of the student or student's family, or other information that would make the student's identity easily traceable) (20 U.S. C. 1232g).

## **VII. Government Policies and Delivery Mechanisms used by the US to Address the Supports Needs of Families with Sons and Daughters with Disabilities**

According to the Families of Children with Disabilities Support Act of 2000 (42 USC 15091), the term “family support for families of children with disabilities” means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to-

- (a) support families in the efforts of such families to raise their children with disabilities in the home;
- (b) strengthen the role of the family as primary care-giver for such children;
- (c) prevent involuntary out-of-the-home placement of such children and maintain family unity; and
- (d) reunite families with children with disabilities who have been placed out of the home, whenever possible.

The findings in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 USC 15001) reported that Congress found:

- (a) family members, friends, and members of the community can play an important role in enhancing the lives of individuals with developmental disabilities, especially when the family members, friends, and community members are provided with the necessary community services, individualized supports, and other forms assistance;
- (b) current research indicates that 88 percent of individuals with developmental disabilities live with their families or in their own households;
- (c) many service delivery systems and communities are not prepared to meet the impending needs of the 479,862 adults with developmental disabilities who are living at home with parents who are 60 years old or older and who serve as the primary caregivers of the adults.

Also Congress reported the following findings in the Families of Children with Disabilities Support Act of 2000 (42 USC 15091):

- (a) It is in the best interest of our Nation to preserve, strengthen, and maintain the family;

(b) families of children with disabilities provide support, care, and training to their children that can save States millions of dollars. Without the efforts of family caregivers, many persons with disabilities would receive care through State-supported out-of-home placements;

(c) most families of children with disabilities, especially families in unserved and underserved populations, do not have access to family-centered and family-directed services to support such families in their efforts to care for such children at home;

(d) medical advances and improved health care have increased the life span of many people with disabilities, and the combination of the longer life spans and the aging of family caregivers places a continually increasing demand on the finite service delivery systems of the States;

(e) in 1996, 49 States provided family support initiatives in response to the needs of families of children with disabilities. Such initiatives included the provision of cash subsidies, respite care, and other forms of support. There is a need in each State, however, to strengthen, expand, and coordinate the activities of a system of family support services for families of children with disabilities that is easily accessible, avoids duplication, uses resources efficiently, and prevents gaps in services to families in all areas of the State;

(f) the goals of the Nation properly include the goal of providing to families of children with disabilities the family support services necessary

(A) to support the family;

(B) to enable families of children with disabilities to nurture and enjoy their children at home;

(C) to enable families of children with disabilities to make informed choices and decisions regarding the nature of supports, resources, services, and other assistance made available to such families; and

(D) to support family caregivers of adults with disabilities.

The “Purposes” of the Families of Children with Disabilities Support Act of 2000 (42 USC 15091) are:

(1) to promote and strengthen the implementation of comprehensive State systems of family support services, for families with children with disabilities, that are family-centered and family-directed, and that provide families with the greatest possible decision making authority and control regarding the nature and use of services and support;

(2) to promote leadership by families in planning, policy development, implementation, and evaluation of family support services for families of children with disabilities;

(3) to promote and develop interagency coordination and collaboration between agencies responsible for providing the services; and

(4) to increase the availability of, funding for, access to, and provision of family support services for families of children with disabilities.

And Families of Children with Disabilities Support Act of 2000 (42 USC 15091) policy statement reads:

It is the policy of the United States that all programs, projects, and activities funded under this title shall be family-centered and family-directed, and shall be provided in a manner consistent with the goal of providing families of children with disabilities with the support the families need to raise their children at home (42 USC 15092, Sec 202 (c)).

**Family integrity and unity.** Turnbull, Beegle, and Stowe (2001) explained that the key issue is whether policy and practice advanced or impeded the integrity and unity of the family. An official of a national group stated “We should try to help the family stay intact. We don’t ask [ourselves] what policies and practices make the family fragment” (Turnbull, Beegle, & Stowe, 2001, p. 142). They wrote that the goal of state support should be to make it possible for the family to raise a child with a disability and for the child to have the benefits of being raised in, and living with his or her family for as long as the family and child chose to or can remain as a single unit. A key concept the authors bring forth is family integrity and unity. According to them, family integrity and unity refers to “preserving and strengthening the family as the core unit of society” (p. 142). They noted that supports should be able to advance these key concepts (family integrity and unity) through responding to all family members and taking into account the family’s cultural, ethnic, linguistic, or other socioeconomic traits and choices. They maintained that it is important for policy makers to recognize that the family is the most fundamental unit of society and that it is usually beneficial to the child with a disability to live and grow within a family. Policies should be developed and delivered to help the family keep the child in the home and strengthen the family as the core unit of society (Turnbull et al., 2001).

**Family Centeredness: Services to the Whole Family.** The Families of Children with Disabilities Support Act of 2000 (42 USC 15091) states “It is the policy of the United States that all programs, projects, and activities funded under this title shall be family-centered and family-directed.” This according to Turnbull et al. (2001) emphasizes that supports are to be delivered to the entire family so as to advance the family’s interests even as they also advance the interests of the individual with the disability. They wrote that family-centered and family-directed programs, projects, and activities (a) support families to raise their children with disabilities in the family

home, (b) strengthen the role of the family as the primary caregiver, (c) maintain family's intactness and unity, and (d) reunite families with their children who have been placed out of the family home. But they cautioned family-centered supports are not always the same for every family and would alter depending on social conditions. A policy administrator explained:

Real cultural things affect policy....Not only do you have the effort at the policy level to use institutions less, to be more person-centered, but you also have the rise in single-parent families, both parents working, less natural community and family supports for families to rely on, and more severely involved children staying at home (Turnbull et al., 2001, p. 142).

**Culturally Responsive Policies.** Turnbull, Beegle, and Stowe (2001) noted that policies and supports are more effective when they are culturally responsive. They wrote that often families, especially those from cultural, linguistic, and ethnically diverse backgrounds and those from various socioeconomic strata may have different "values, beliefs, perspectives, expectations, interpersonal styles, language, or attitudes" (p. 142) than some policies and service/supports providers may assume or hold. They explained that providing supports in a manner that responds to the family's needs in culturally sensitive ways is essential to increase the likelihood of benefit to the family. Thus by responding to family's culture the supports will ensure family integrity, family unity, and are family-centered (Turnbull et al.).

Culturally sensitive partnership (i.e., professionals understanding and appreciating families' values, beliefs, and goals) are essential for planning and delivering effective supports for immigrant families (Lindsay, King, Klassen, Esses, & Stachel, 2012). They noted that professional collaboration with immigrant families can be challenging because of differing conceptualizations of disability between service providers and immigrant parents, lack of

training in providing culturally sensitive care, language and communication issues, building rapport, and helping parents advocate for themselves and their children. Some of the recommendations for providing culturally sensitive supports and successful collaboration with immigrant families raising a child with a disability, according to Lindsay et al. (2012), include: (a) more education and training around how to provide culturally sensitive care; (b) collecting relevant cultural background information from families when they register so that appropriate services can be provided by matching professionals with families from similar backgrounds (where feasible) and/or hiring more ethnically and linguistically diverse staff; and (c) spend more time with the immigrant families to build rapport and understand family situations, needs, concerns, worldviews, constraints, and priorities, thus, providing supports to meet their identified needs.

**Parent-led support initiatives.** Parent-led support groups for parents who have children with disabilities are "voluntary organizations with goals to provide social support and information and to foster advocacy" (Law, King, Stewart, & King, 2001, p. 29). They wrote that support groups provide parents with support, friendship, opportunity to share experiences, knowledge and assist in improving parents' ability to deal with childhood disability issues. Even when there are adequate formal supports (i.e., professional supports) parents often feel a need for support from other parents (McCabe, 2008). According to McCabe (2008) parent-led support groups are highly beneficial for parents of newly diagnosed children with disabilities as they are mentored by more experienced parents.

**Main elements of parent support groups.** Parent-led support can be either 1:1 support or support groups. Much of the parent-led support is described as programs that match trained, experienced parents (usually volunteers) with parents needing support (1:1 support) (McCabe,

2008). She noted that local Family Support Network chapters train the experienced parents to provide support and information for families (e.g., for immigrant families with a son or daughter with disabilities and are new to the U.S.). McCabe explained that across the United States there are multiple local Family Support Network chapters, organized, directed, and attended by parents. Parent support group meetings on the other hand involve more participants, thereby increasing the pool of information available and greater chances to interact with other parents who share specific experiences (Mandell & Salzer, 2007). These support groups are attended by parent members having a child with a disability and usually the group size ranges from groups of three to four members to groups over 150 members (Law et al., 2001).

### **Review on Immigration in the United States**

#### **Nation of Immigrants: History of Immigration in US**

Statistics indicate as of 2007, the United States has the largest number of immigrant population in the world-35 million (Udea, 2007). The percentage of the U.S. population that is foreign-born has increased from 5% in 1970 to 13% in 2010 (Steil & Vasi, 2014). In 2000, 1 of every 9 American residents was an immigrant, and 1 of every 5 children under the age of 18 was the child of immigrants (Waters & Udea, 2007). Skinner (2012) assessed that, as of 2009, one child in every four, aged eighteen years or younger was either born abroad or lived with their “foreign-born parent” and this ratio is expected to rise to one in three by the year 2020. He wrote that the number of children in immigrant families nearly doubled between 1990 and 2007, while there was only a 3% growth in the number of children living with “native-born” parents.

Looking back in history, prior to 1882 the most common grounds of exclusion were those who were convicted of a crime or engaged in criminal activity and may be a burden to the community. The 1882 Immigration Act excluded immigrants persons with a disability and

continued to the 1917 Immigration Act (also called the Chinese Exclusion Act). According to Section two of the Immigration Act of 1907:

All idiots, imbeciles, feeble-minded persons, epileptics, insane persons, and persons who have been insane within five years previous; persons who have had two or more attacks of insanity at any time previously; paupers; persons likely to become a public charge; professional beggars; persons afflicted with tuberculosis or with a loathsome or dangerous contagious disease; persons not comprehended within any of the foregoing excluded classes who are found to be and are certified by the examining surgeon as being mentally or physically defective, such mental or physical defect being of a nature which may affect the ability of such alien to earn a living.

Section 3 of the 1917 Immigration Act passed by Congress on February 5, 1917 stated:

That the following classes of aliens shall be excluded from admission into the United States: All idiots, imbeciles, feeble-minded persons, epileptics, insane persons; persons with chronic alcoholism; paupers; professional beggars; vagrants; persons afflicted with tuberculosis in any form or with a loathsome or dangerous contagious disease; persons not comprehended within any of the foregoing excluded classes who are found to be and are certified by the examining surgeon as being mentally or physically defective, such physical defect being of a nature which may affect the ability of such alien to earn a living; (P.L. 64, Sec 3, 1917).

Family members of the individuals with disabilities were refused admission to the United States too as stated in section 18 of the Act.

In the 1920s the Congress passed the Act of 1924 that adopted discriminatory immigration restrictions on certain nationalities also referred to as the “national origins quota

system” (Chiswick, 1982, p. 2; Waters & Ueda, 2007). The Civil Rights movement of the 1950s and 1960s demanded equality and fairness in immigration policy and in 1965 Congress amended the Immigration and Nationality Act of 1952 (INA) also known as the McCarran-Walter Act (Batalova & Terrazas, 2013). Water and Ueda (2007) explained that in 1965 Congress passed the INA Amendments also called the Hart-Celler Immigration Act, installing a new global admissions system under which the immigration reached an all-time high. Skinner (2012) wrote that the immigration surge rapidly changed the face of America. The liberalization of immigration policy created a new “social framework of multiethnic and multiracial diversity, which has reconfigured American pluralism and national identity” (Waters & Ueda, 2007, p. 3). They wrote that initiatives for multiculturalism, bilingualism, and minority empowerment of Latinos, Asians, and African immigrants started taking place as part of the assimilation process as most of the new immigrants came from countries in Latin America, the Caribbean, Asia, the Middle East, and Africa, especially from Mexico, the Dominican Republic, Haiti, India, China, and the Philippians.

### **The U.S. Immigration Policy Post-1965: Effects of Immigration Surge**

Post-1965 to 2001, 27 million immigrants were admitted into the U.S. in addition to an estimated 3 million undocumented immigrants (Ueda, 2007). He noted they came in one of two major socioeconomic groups: human capital migrants (i.e., highly educated white-collar and professional employees) and labor migrants (i.e., undereducated). Espenshade (1995) wrote that due to the surge in arrival of immigrants a new wave of “neo-restrictionist” sentiment was being advanced and promoted by the early 1980s. He explained that this rise in “neo-restrictionism” by the early 1980s was grounded on fears associated with economic insecurity, concerns over immigrants’ “undesirable culture traits”, and concerns over “unauthorized immigration” (p. 202).

The federal government enacted “a policy of managed admissions” to regulate its intake of immigrants (Ueda).

The 1990s and 2000s were marked by state and federal legislation that limited access of immigrants, especially unauthorized immigrants, to social services and public benefits (Batalova & Terrazas, 2013). They summed up that three of the major federal legislation Congress passed regarding immigrants in general, and undocumented immigrants in particular, were (a) The Welfare Reform Act of 1996; (b) The Illegal Immigration Reform and Immigrant Responsibility Act (IIRIRA) of 1996; and (c) The Anti-Terrorism and Effective Death Penalty Act (AEDPA) of 1996. The Welfare Reform Act of 1996 restricted access of legal and unauthorized immigrants to federal public benefits, such as Medicaid, Supplemental Security Income (SSI), and food stamps; IIRIRA speeded up deportation of undocumented immigrants who were convicted of crimes; and AEDPA made it easier to arrest, detain, and deport immigrant population in general (Batalova & Terrazas, 2013).

**Unauthorized Immigration.** Since the mid-1990s, annual arrivals of undocumented immigrants have exceeded those arriving under legal categories and undocumented immigration is estimated to have increased from about 3.2 million in 1986 to about 12 million as of 2013 (Batalova & Terrazas, 2013; Sadowski-Smith, 2008). Sadowski-Smith (2008) explained that there is a tendency to equate undocumented immigration with Mexican nationals. According to her in the 1970s Mexican nationals represented 90 percent of the “unauthorized population” but by 2002 they made up only half of this population. She wrote that it is often ignored that some of today’s undocumented migrants arrive from Ireland, Poland, Russia, and Asia.

Between 1942 and 1964 the U.S. engaged with Mexico in an agreement called the bracero program, which permitted the admission of temporary guest workers from Mexico to

relieve wartime labor shortages and to legalize and control the flow of Mexican agricultural workers (Espenshade, 1995; Sadowski-Smith, 2008; Ueda, 2007). In 1964, Congress terminated the program in the face of public opposition to conditions under which migrant workers lived, the influence of the U.S. Civil Rights movement, and the effective lobbying of labor, church, and ethnic groups (Espenshade, 1995). He explained that this resulted in a substantial rise in undocumented immigration as job-seeking individuals from Mexico, who had grown accustomed to working in the United States, no longer had any legal means of entry.

To tackle the issue of the growing unauthorized population post-1965, Congress passed the Immigration Reform and Control Act (IRCA) of 1986 (Batalova & Terrazas, 2013). They wrote that IRCA made it illegal for employers to hire unauthorized workers and established sanctions for violators in the form of fees and criminal charges. Also the surge in immigrant population arriving in the US since the 1960s resulted in new government legislation that placed numerical limits on immigration, which in turn has led to growing number of undocumented immigrants in the US (Waters & Udea, 2007).

Batalova and Terrazas (2013) wrote that at the state level, Proposition 187 (1994), also known as “Save Our State” initiative, denied unauthorized immigrants access to public education, health care, and other social benefits in California. “Protect Arizona Now” (Proposition 200) was passed in 2004, requiring state residents to prove their U.S. Citizenship before registering to vote or applying for government services (Batalova & Terrazas, 2013). They noted in 2010 Arizona’s “Safe Neighborhoods Act (SB 1070) legislation was signed into law, requiring state police to verify immigration status of anyone stopped during their routine law enforcement activity.

### **Current Immigration Law**

For more than a decade the United States immigration system has been overshadowed by a list of other events- national crises like foreign wars, national security, and financial crisis that threatened to bring down the world economy, years of partisan political fighting, and the resurgence of a volatile restrictionist movement (Giovagnoli, 2013). The author noted that as a result of these events and more, both political parties (i.e., Republican and Democratic) opted for political strategy that emphasized immigration enforcement over immigration reform.

Immigration enforcement was supported by the argument that effectively deporting non-citizens would reduce undocumented immigration and pave the way for more sensible outcomes in the future (Giovagnoli). However, according to the author, the results were: unprecedented spending on immigration enforcement, extraordinary rise in deportations, the passage of state anti-immigration laws, and anecdotes of separated families and discrimination. In the 2012 federal elections voters voiced their opinion that they were tired of enforcement-only immigration policies and the senseless pain these policies caused and that it was time the immigration policies reflected American values (Giovagnoli).

According to Giovagnoli (2013) the vast majority of Americans support reforms that permit legal status and ultimately citizenship, if the immigrant establishes commitment to the United States. The commitment may be in the form of initial registration, a willingness to learn English, and full payment of any outstanding taxes. Voters also voiced their desire that the immigration policies supported families and American values. She wrote "while the economics of unauthorized immigration is frequently the focus of the immigration debate, the breakdown of the family immigration system is equally destabilizing and also spurs a significant amount of unauthorized immigration" (p. 5). According to data there is a current backlog of up to 20 years

in family-based immigration (i.e., for the legal migration of family members). While there have been shifts in public support away from immigration enforcement, the author explained that those supporting immigration reforms also desire that the policies (a) ensure national security and community safety, (b) ensure that the legal immigration system is sufficiently robust to meet the needs of the American economy, (c) does not put native-born workers at a disadvantage, and (d) does not encourage new waves of illegal immigration when job demand is high.

### **Perspectives on Immigrants**

Sevillano and Fiske (2013) explained that mass media often use terms such as “aliens”, “strangers”, “invaders”, “illegal”, or “enemies” to describe immigrants. Elovitz (1997) wrote that immigrants are perceived as: a cultural hero, an outsider, a dangerous alien, and as a human being. As a cultural hero, the immigrant represents the outsider who becomes an insider usually through economic, cultural, or political success (e.g., Andrew Carnegie, Henry Kissinger) (Elovitz, 1997). He wrote that as an outsider, the immigrant is perceived as someone suitable to do tasks in the society that others are not willing to perform, while as a dangerous alien, the immigrant is viewed as a criminal, terrorist, etc. The link between immigration and national security has been fueled by post-September 11th fears that undocumented immigration constitutes a breach in national security (Batalova & Terrazas, 2013). Finally as a fellow American, the immigrant is viewed as one of the citizens, can be empathized with, suitable as a marriage partner and elected leader (Elovitz).

Some of the terms commonly associated with perspectives on immigrants and refugees are:

#### **(a) Prejudice**

Banks (2009) defined prejudice as “a set of rigid and unfavorable attitudes toward a particular group or groups that are formed in disregard of facts” (p. 70).

### **(b) Discrimination**

According to Banks (2009) discrimination consists of “differential behavior directed toward a stigmatized group. Discrimination exists when individuals are treated differently because they belong to a particular social category or group” (p. 70). Discrimination accounts for both the level (individual or structural) that discrimination occurs at and the intensity (overt or subtle) of discrimination (Perreira, Kiang, & Potochnick, 2013). They wrote that an example of structural discrimination is segregation in “English Language Learners” program, minority schools, and low-income schools.

### **(c) Racism**

Banks (2009) defined racism as the “belief that human groups can be validly grouped on the basis of their biological traits and that these identifiable groups inherit certain mental, personality, and cultural characteristics that determine their behavior” (p. 72).

### **(d) Values**

Banks (2009) explained the term values as “those elements within a culture to which individuals and groups attach a high worth are called values” (p. 74).

## **Review of Research on Immigrant Families with Sons and Daughters with Disabilities**

Immigrant families are one of the fastest growing populations in the United States (Jegatheesan, 2009) and according to the U.S. Department of Education, the number of immigrant students with disabilities continues to increase and form the third largest group to receive special education services (Antony & Banks, 2010; Lo, 2008). The U.S. Census Bureau (2006) reported 33% of the nation’s population is culturally and linguistically diverse (CLD) and

the number of people who have immigrated to the United States rose 16% over the last 5 years (Lee, Turnbull, & Zan, 2009). Lee et al. (2009) wrote that out of the 6.6 million children who received services under the Individuals with Disabilities Education Improvement Act (IDEA, 2004) about 40% were students from CLD backgrounds.

Disability and diversity is a double-edged sword (Jegatheesan, 2009) and barriers to meaningful family participation can frustrate families and can cause anguish on their expectations and aspirations for their child identified with a disability. And because each immigrant family may have distinct traditions, cultures, customs, religions and languages, as well as unique life circumstances based upon how recently they immigrated (Kim, Lee, & Morningstar, 2007), it often is difficult for policy makers, educators and the community to understand their expectations and aspirations.

**Immigrant Families' Perceptions toward Disability.** Immigrant families' perceptions of their child's disability and their willingness to seek supports are influenced by parents' assumptions regarding the etiology of disability (i.e., causes), their understanding of child development, and their personal, religious, and cultural beliefs (King, Esses, & Solomon, 2013). Disabilities are often viewed by immigrant families, especially Asian families, as a punishment for sins committed by the parents (often the mother) or their ancestors (Lo, 2010; McCabe, 2008). Other perceived causes of disability are: a result of some supernatural fate, violations of certain taboos during pregnancy (e.g., construction work done around the house, father's involvement in an extramarital affair), and inappropriate dietary practices (Lo, 2010). Examining studies of Asian families with children with disabilities, especially Chinese and Vietnamese families, Huer, Saenz, and Doan (2001) reported that for some families the professional

diagnoses of disability are relatively unimportant because “family members had made their own determination of cause and often looked to past events or careless acts as related” (p. 31).

Immigrant families reported that they encounter a feeling of shame and embarrassment about having a child with a disability and the need to keep matters involving their children’s disability private (McCabe, 2008). Huer et al. (2001) wrote that Asian parents frequently avoided taking their children to public places to avoid unfriendly stares, rejection, and excessively sympathetic reactions. Lo (2010) added that many immigrant families believe their sons’ or daughters’ disability should not be openly discussed with people other than their family members because “Asians do not often define or address disability in the same open manner as typically does the American culture” (p. 406). With these cultural beliefs, immigrant families rarely share information about their child’s disabilities with others (Lo, 2010) often resulting in challenges in receiving information regarding informal and formal supports (McCabe, 2008).

Lo (2010) wrote that parent support groups (professional-led and parent-led) provide families of children with disabilities many benefits, such as allowing parents to gain knowledge and skills in coping with their sons or daughters special needs, improving parent perceptions and skills at parenting, increasing parent use of communication resources, and developing positive relationships between families and schools. Perceptions on disabilities and the consequences of traditions can affect the utilization of these supports resulting in further isolation and disempowerment for the families (Lo). She wrote that language barriers added to the challenge of locating support groups for the families. For parents who reached out for support, they felt more comfortable sharing their frustrations with parents of the same culture and feel a sense of relief to “finally meet someone who understood what they were going through” (p. 413). Through group participation the parents received emotional and psychological support from each

other; they developed friendships, had a sense of belonging, and felt empowered and confident when working with their own children with disabilities (Lo, 2010).

### **Unique Needs and Support for First Generation Immigrant Families**

Parents new to the United States have little to no knowledge about the education system, community supports and the special education policies which makes it difficult for them to be equal participants in the decision making processes (Lo, 2012). The literature has pointed out that the needs of families of children with disabilities are greater than the needs of families of children without disabilities (Dowling & Dolan, 2001). If this is true across most families then it is likely to be the case with immigrant families too. Immigrant families may face greater difficulties due to difference in culture, language, understanding of the society, distance from extended families, education, and learning about the supports available. Also many of the policies supporting families address the native population of the United States (Antony & Banks, 2010; Lo, 2008). With the increase in immigrant population, there will be an increase in immigrant families with children with disabilities (Jegatheesan, 2009).

First generation immigrant parents have reported that their limited English proficiency has hampered their understanding of the disability diagnosis and obtaining information regarding the disability, and also has resulted in receiving lower levels of formal support from professionals (Cho & Gannotti, 2005). Also the expectation that families should address and advocate for supports comes from a mainstream culture of the U. S. and may contradict the values of many immigrant families (Kalyanpur, Harry, & Skrtic, 2000). The rights-based individualistic society found currently in western culture, and societal expectations that families will advocate for supports, are often difficult for immigrant families to understand and accept (Kalyanpur & Gowramma, 2007).

The No Child Left Behind Act (NCLB) and IDEA (2004) stress the importance of parental participation in their children's educational process as literature has shown family and school collaboration is paramount in children's success (McLeod, 2012). The IDEA (2004) mandates that parents be included in all educational decision making and planning process and recommends collaboration between professionals and families for planning of the appropriate special education and placement (Ryndak, Orlando, Storch, Denney, & Huffman, 2011). The education lawmakers who put forth the education laws regarding parental participation understood that when there is a good working parent-professional relationship, the needs of children are more successfully met and the outcomes are satisfying (Jegatheesan, 2009). But though well intentioned regarding parental participation, the laws do not consider key differences in cultural practices (McLeod, 2012).

Frequently educators have assumed low parental participation in the educational-decision-making process as lack of interest or they believe that parents are satisfied with the decisions being made for their child (Jung, 2011). But Jung wrote that for first generation immigrant families it could be a cultural norm that arguing with authorities is considered wrong and it shows disrespect. He explained that often times even when schools or agencies fail to meet families' expectations for the individual with disabilities, first generation immigrant families may hesitate to address the specific issues. The notion that the authorities are the experts and that it may be offensive to question them or advocate for services that rightfully belong to their son or daughter exist among the first generation families (Kalyanpur & Gowramma, 2007). This in turn may hamper collaboration and be a barrier to their hopes and expectations for the success of their child.

The studies reported above mostly focused on the education of the child with disabilities, supports for families in the school system and special education programs (Cho & Gannotti, 2005; Hughes, Valle-Riestra, & Arguelles, 2008; Parette, Chuang, & Huer, 2004); the importance of parent-teacher collaboration (Jegatheesan, 2009; Olivos, Gallagher, & Aguilar, 2010; Lo, 2008); perceptions of parents toward disability and special education (Antony & Banks-Joseph, 2011; Kim, Lee, & Morningstar, 2007; Lo, 2010; McLeod, 2012); the difficulties parents face in the individualized education program (IEP) meeting for their child (Fish, 2008; Lo, 2012; Zhang & Bennett, 2003); decision making regarding the educational placement of the child (Jung, 2011; Kalyanpur & Gowramma, 2007; Spann, Kohler, & Soenksen, 2003), and language and cultural issues parents face in the schools (Kalyanpur & Gowramma, 2007; Zhang & Bennett, 2003). Very few studies reported on the needs of immigrant families outside the educational sphere. And most of the studies focused on the individual with the disability and not on the family and their needs. It will be motivating to hear the voice of first generation immigrant families living in the United States to identify needs and supports related to raising their son or daughter with a disability.

A study by Ayon and Naddy (2013) reported Latino immigrant families relied heavily on their family, friends, neighbors, and the community for emotional, moral, and financial support. A study conducted in China reported the importance of parent-to-parent support (McCabe, 2008). A similar study conducted in the United States among immigrant Chinese families of children with disabilities examined the benefits experienced in support groups among the families (Lo, 2010). She reported families expounded on the need to meet other families who would understand their culture and the cultural pressure they were facing from family members,

relatives, and friends regarding disability. They expressed the importance of support groups for sharing resources and supports with each other.

Research on understanding the needs of immigrant families, especially first generation immigrant families in areas such as social support networks, access to medical and insurance coverage, financial needs, community support, and opportunities for work, leisure, and travel along with cultural barriers they face is essential. Studies that examined cultural barriers that impede the collaborative relationship between immigrant families and educators in the school setting (Cho & Gannotti, 2005; Kalyanpur & Gowramma, 2007; Kalyanpur & Harry, 1997; Kalyanpur, Harry, & Skrtic, 2000) reported barriers, including: (a) conveying information about services and parental rights through written material in English higher than a fifth-grade level to families with limited literacy skills or to non-English speaking immigrants who may not be literate even in their native language; (b) communication and language; (c) families' economic and cultural circumstances; (d) perceptions about professionals as experts whose opinion cannot be opposed; and (e) unfamiliarity with the educational system that results in a lack of knowledge about service availability or legal rights.

Kalyanpur and Gowramma (2007) wrote that a South Indian parent refused to question the school about the lack of academic progress she observed in her child and when asked about that she said "Because there was no other option, even if I felt there was no improvement, I could not actually say this to the professionals. If I told them, I was afraid they would say, don't come" (p. 74). They wrote that in South Indian culture, parents have no rights, legally or socio-culturally in making educational goals and decisions for their children. They explained that parental participation is one of the main principles of IDEA that emerges from the rights-based individualistic environment of American society and that for many cultures it may be difficult to

accept. Kalyanpur and Gowramma wrote that the societal expectations are that families will advocate on behalf of their child. When first generation families struggle with advocacy, and allow professionals to lead the meetings, there is no equity, which often leads to not obtaining the services they desire for their children in special education (Cho & Gannotti, 2005).

Also negative ancestral attitudes towards disability (i.e., feeling of shame or embarrassment) could be another barrier that could cause low participation among South Indian families (Kalyanpur & Gowramma, 2007). Language and cultural differences prevent the parents from understanding diagnoses regarding the disability, restricting their use of services like early intervention, free public special education, and use of specialists for their children (Cho & Gannotti, 2005). The authors expounded that Asian parents reported receiving lower levels of formal support from schools. Jung (2011) wrote that culturally and linguistically diverse families have difficulty in gaining appropriate educational services as well as in accessing, understanding, and making full use of their legal rights, and in advocating their children's rights. It is hence a necessity to address the need of culturally responsive and family centered supports and services and recognize cultural barriers and the feeling of isolation faced by immigrant families with sons and daughters with disabilities.

### **Summary: Immigrant Families with Sons and Daughters Disabilities**

By 2050, it is predicted 50% of the U.S. population will comprise of ethnic minority families (King, Esses, & Solomon, 2013). Also data from studies have indicated an increasing numbers of children having significant needs due to disabilities (Sloper & Beresford, 2006). With growing number of immigrant families who have sons and daughters with disabilities in the United States there needs to be new information to guide service and support providers and inform policy makers about the best ways to meet the needs of these families (Cho, Singer, &

Brenner, 2003). King, Esses, and Solomon (2013) reported there is little literature on support and service utilization experiences of immigrant/refugee families with children with disabilities. A review on research by the authors on immigrant/refugee families brought forth issues of poverty, single parenthood, social exclusion, resettlement, unemployment, and underemployment. They face social and economic marginalization and have limited access to health and social services due to their eligibility status (e.g., Supplemental Nutrition Assistance Program) (Skinner, 2012).

These vulnerabilities are compounded when raising a child with a disability (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999). Immigrant families with sons and daughters with disabilities face high levels of unmet needs, significant barriers to health care for their child, and the uncertainty of their child's health, well-being, and educational success (King et al., 2013). In addition to the emotional, physical, and financial demands of caring for a son or daughter with a disability (Chamba et al., 1999), many immigrant families experience difficulties trying to obtain supports due to lack of information of available supports, lack of access to these supports, and the fragmented service/support delivery policies (Sloper & Beresford, 2006).

## Chapter 3

### Research Methodology

#### Qualitative Interviewing Research Approach

This qualitative study examined the support needs of first generation immigrant families with children with disabilities. I chose qualitative interviewing to understand the support needs of the immigrant families. I used an open-ended interviewing approach to interview four first generation immigrant parents and allowed them to express richly the meaning they make of their experiences- their thoughts and feelings, their frustrations and confusions, and their joys and praises. Seidman (2013) wrote, “I interview because I am interested in other people’s stories” (p.7). The purpose of interviewing according to Van Manen (1990) is because the researcher is interested in understanding the lived experience of other people and the meaning they make of that experience. Seidman wrote that a researcher can understand the experience of people through examining personal and institutional documents, through observation, through exploring history, through experimentation, through questionnaires and surveys, and through a review of existing literature, but to understand the meaning people make of their experience, then interview is the correct avenue of inquiry. Kvale and Brinkmann (2009) wrote that interviews attempt to (a) understand the world from the participants’ point of view, (b) unfold the meaning of their experiences, and (c) uncover their lived world. They explained that an interview is literally “an *inter view*, an inter-change of views between two persons conversing about a theme of mutual interest” (p.2). These views resonated with my ideology and encouraged me to take interviewing as my approach.

Asking families the grand tour question “tell me about your experiences in the United States, your needs, and the supports you have received” may limit their responses due to the lack

of “context” in that approach. Instead I wanted them to look at their experiences through the lens they grew up with and are most comfortable with: their experience in their home country or culture. Being able to compare what they had or might have had to their current situation in the United States allowed families to provide a richer and more complete narrative. They used their background and foundation as they talked about their current needs and supports.

### **Target Population and Inclusion/Exclusion Criteria**

The research sample included 4 first generation immigrant families with children with disabilities from an urban city in the Southwest. I, the researcher, contacted two prominent support centers in a large metropolitan city serving families with sons and daughters with disabilities. Letters of invitation (*Appendix A*) were given to the family centers with instructions to distribute them to first generation immigrant families with sons and daughters with disabilities. The letter explained the purpose of the research (i.e., the focus of the in-depth interview will be on hearing the life stories of first generation immigrant families with children with disabilities, mainly their support needs in the US). Also, recruitment flyers were placed in these centers with their permission. One of the support centers communicated my interest to a group of families in another city, which is a much smaller city. These families spoke Spanish and English. Three of the families came from Mexico and one of the families came from Puerto Rico. Even though the families that showed interest to take part in the study were all first generation immigrant families, there were differences among them including the length of time spent in the United States, culture, religion and beliefs, education, socio-economic status, job, extended family support, number of children in the family, disability of the child, and age of the child. A purposeful sampling procedure was hence used to select this study’s participants. Snowball sampling strategy, many times referred to as network sampling (Bloomberg and Volpe, 2012),

was also employed, whereby participants were asked to refer other first generation immigrant families whom they know with children with disabilities.

The families responding to the invitation were further contacted by phone and the inclusion/exclusion criteria were discussed followed by the location of the interview (i.e., deciding on the setting for the interview). The inclusion criteria for participants included first generation immigrant families with sons and daughters with disabilities and participants whose English is sufficient for an interview in that language. The first four families that were willing to participate and meet the inclusion criteria were selected for the study.

The families understood that if they agree to participate then the following will happen: 1) participation in one 60 to 90 minute in-depth interview (seeking deep information and understanding) and 2) participation in one 30-minute interview in person or by telephone giving them an opportunity to respond or react to a brief report of the themes identified. The second interview would also be used as a follow-up to the first and allow for greater elaboration and clarification of initial responses.

### **Informed Consent Process**

Informed consent involved informing the research participants about the overall purpose of the investigation, the main features of the design, and any possible risks and benefits from participation in the research project (Brinkmann & Kvale, 2015). Consent entailed obtaining the voluntary participation of the participants involved and informing them of their right to withdraw from the study at any time. The informed consent also included information about confidentiality, who will have access to the interview or other material, the researcher's right to publish the whole interview or parts of it, and the possibility for the participants to access the transcription and the analysis of the data.

**Ethics in the design of the study.** Ethical issues of design involved obtaining the interviewee's informed consent to participate in the study, securing confidentiality, and considering the possible consequences of the study for the participants. First, participants in the study were provided a letter explaining the research procedures and requesting their consent to participate before beginning the interviews (*Appendix A*). The consent form clearly explained the right of each participant to withdraw from the study at any point in time including during the interview. Second, every effort was made to avoid deception by clearly outlining the intent of the study and the parameters involved in participation through the letter of invitation (*Appendix B*).

Six ethical considerations addressed by Brinkmann and Kvale (2015) were used to address this study involving the research, the participants, and finally the society in general (i.e., thematizing, designing, interview situation, transcription, analysis, verification, and reporting). In regards to thematizing, Brinkmann and Kvale wrote, the purpose of an interview study should, beyond the scientific value of the knowledge sought, also be considered with regard to improvement of the human situation investigated. The why and what of the investigation should be clarified before the question of how method is posed. Designing the study is undertaken with regard to obtaining the intended knowledge and taking into account the moral implications of the study. The personal consequences of the interview interaction for the participants need to be taken into account, such as stress during the interview and changes in self-understanding. Also the confidentiality of the interviewees needs to be protected and there is also the question of whether a transcribed text is loyal to the interviewee's oral statements. Ethical issues in analysis involve the question of how accurately the interviews can be analyzed and of whether the participants should have a say in how their statements are interpreted. Finally, it is the researcher's ethical responsibility to report knowledge that is as accurate and verified as possible.

The researcher will consider the issue of confidentiality when communicating the finding of the study, and of the consequences of the published findings for the interviewees and for the groups they belong to.

**Benefits of participating in this interview study.** The findings could assist special educators, policy makers and implementers here in the United States to look at support needs through the lens of immigrant families and to be more culturally sensitive. This is important as the number of immigrant families in the United States has been growing exponentially. Also the findings will inform the home countries on the perceptions of families of children with disabilities regarding their needs and supports they desire. I feel it will be important for parents to be able to examine their needs and the supports available in the United States while reflecting what it might have been like in their home country. This will bring their story (the data) in context and the findings will report the needs and opportunities with greater richness and passion. Some other benefits may include, as Hutchinson, Wilson, and Wilson (1994) pointed out, (a) opportunity to express personal feelings, thoughts, and problems (catharsis), (b) feeling of validation as an individual with integrity and worth (self-acknowledgment), (c) sense of purpose, (d) self-awareness, (e) empowerment, (f) healing, and (g) providing a voice for the disenfranchised.

**Potential risks in unstructured interactive interviews.** Open-ended interactive interviews are “shared experiences in which the researchers and the interviewees come together to create a context of conversational intimacy in which participants feel comfortable telling their story” (Corbin & Morse, 2003, p. 338). These interviews, according to Corbin and Morse (2003), are not interrogation sessions where the interviewer is asking a series of questions to which participants are expected to respond. Due to the nature of the interviews, participants are not

always aware of the course that an interview might take. Consent forms make it clear that persons are free to choose whether to participate or not and that they can withdraw from the study at any time without penalty. The topic of the research will be explained clearly before the participant agrees to be interviewed and once the agreement is made, the researcher and participant together should negotiate the time and place to meet.

### **Data Collection Procedures**

#### **Qualitative Interview Research Methodology**

I began the interviews by explaining the purpose of the study, securing informed consent, answering any questions the family may have, and eliciting permission from the participant to use an audio recorder. Often times even before I asked a question, the participant started her narrative addressing what was in her heart. The interviews concluded with me (i.e., the interviewer) summarizing some of the main points I understood and asking follow up questions to clarify issues. An audio recorder was used to record the in-depth interviews so as to obtain verbatim records of those interviews. At the completion of the interview we discussed possible times and dates for the follow up to complete the interview process. Also I provided the family with a journal to write down any thoughts that came up later that they would like to add to the interview. I used the second interview for member checking. I conducted member checking by providing the participants a brief summary of the major findings and asking them to share their perceptions regarding the themes that have emerged. This gave participants the opportunity to respond my report.

The interviews began with the participants filling out a demographic form (*Appendix D*). Participants shared their life history, details of their present lived experiences (not opinions but rather the details of the participants' experiences), and concluded with them reflecting on their

experiences and the meaning they make of these experiences. *Appendix C* lists questions I planned to ask during the interviews. The interview questions (*Appendix C*) are descriptive and open-ended, allowing the participants to talk about their experiences, their support needs, and the meaning they make of these experiences.

All the interviews were digitally recorded. I then transcribed the digital recordings manually by typing the recorded interviews on my personal computer which is password protected. Handwritten notes were taken, noting observations and thoughts that occur while conducting the interviews.

**Setting.** I suggested interviewing family members (e.g., father, mother, grandparents) together and the location of their preference, if possible. Most of the studies on caregiver roles, stress levels, parent need, and marital satisfaction focused on mothers' experiences and their voice and almost none looked at the father's experiences and voice (Mueller & Buckley, 2014). Mueller and Buckley (2014) wrote that fathers were the "odd man out" and their experiences were often ignored because of employment, fathers' lack of knowledge and unfamiliarity regarding the system, and educators and professionals treating the mothers as the informants and collaborators.

### **Plan and Timelines**

The first step was to complete the necessary application and gain permission to conduct the interviews from the Institutional Research Board (IRB) by December 2016. Contacting the support groups and the selection of participants took place in January 2017. Interviews were conducted in February of the same year. Data analysis began after transcription of the first interview and continued until finalization of results in December 2017. In between the families were contacted with the themes that emerged and their input was solicited.

### **Data Management Procedures and Confidentiality**

By organizing the material throughout the research process (e.g., keeping track of participants through the participant information forms, making sure that the written consent forms are filed in a safe place, labeling audio recordings of interviews accurately so as to be able to trace the interview data to the original source, managing the extensive files that develop in the course of working with the transcripts of interviews), I as the researcher made the data more accessible so as to work with it efficiently. Seidman (2013) wrote that the goal of this administrative work is to be able to trace interview data to the original source at all stages of the research.

**Confidentiality.** Confidentiality in research denotes agreements with participants about what may be done with the data that arise from their participation (Brinkmann & Kvale, 2015). Private data that may result in the identification of the participants were always locked in a secure location separate from consent forms and the study data. All the transcribed material was stored in a password protected personal computer. Identifiable data and the consent forms were stored in separate cabinets in the researcher's office. The Institutional Review Board (IRB) that oversees human subject research had access to the interview data to access records. The participants' names were not used in any published reports about this study. Confidentiality is important as it protects participants and is an ethical demand.

### **Data Analysis**

The process of identifying, coding, and categorizing the primary patterns in the data (persistent words, phrases, and concepts) is referred to as content or thematic analysis (Mayan, 2009). She differentiated between just going over the text and counting the number of times a word or phrase appears (manifest content analysis) and taking the context of the words or

phrases into consideration (latent content analysis). She gave a clear example, where the researcher can either count the number of times the word “stress” appears or examine the context of the stress (is the reference of stress indicative of something going on in the person’s life or is it because of number of hours worked, relationships between coworkers, etc). The categories emerge from the data (open coding) or the researcher uses predetermined categories (selective coding) and tries to fit the data into those categories (Strauss, 1987). Open coding is a grounded theory concept and this form of analysis is often referred to as inductive analysis (Riessman, 2008). This study used an open coding approach.

### **Important Concepts and Principles in Thematic Analysis in Qualitative Studies**

**(a) Coding:** Coding can be defined as “the process of identifying persistent images, words, phrases, concepts, or sounds within the data so that the underlying patterns can be identified and analyzed” (Mayan, 2009, p. 94). She explained that coding is not the process of assigning labels or categorizing the data but is simply the first step by which the researcher becomes familiar with the data and starts to organize the data. Mayan wrote that the process of coding the text involves the researcher reading all the data, rereading and highlighting sections of the text, and making comments in the margins regarding anything that is striking.

**(b) Categorizing:** Once the transcript is coded (persistent phrases or concepts are identified and highlighted), the researcher will arrange the highlighted sections of the text into various categories (Mayan, 2009). Thus categorizing is actually grouping data into categories. Mayan (2009) wrote that the researcher should restrict the number of categories to ten or twelve. The author explained that the researcher then should read the data in each category, make sure the excerpt “fits” within the category, be willing to move excerpts around, relabel or dissolve

categories, or develop subcategories. She noted that subcategories are created if there are two distinct ideas/perspectives within one category.

The criteria a researcher should use to judge categories are, according to Mayan (2009), internal homogeneity and external homogeneity. Internal homogeneity refers to the individual categories: (a) do all of the data reflect the category and fit nicely into it? and (b) does the category make sense? External homogeneity refers to the relationships among the categories: (a) are they all distinct and separate? and (b) are the differences among categories bold and clear.

**(c) Forming Themes and Making Conclusions:** To form themes, Mayan (2009) explained the researcher looks at the “big picture” and determines how the categories are related. Theming is the process of “determining the thread(s) that integrate and anchor all of the categories” (p. 97).

Mayan explained that they are thoughts that weave throughout and tie the categories together.

She wrote there should typically be only one to three themes and that making use of the

categories and then the themes, the researcher can make overall conclusions about the research.

Ferguson and Ferguson (2000) referred to the process of forming themes as "contextualizing

narrative data." They wrote that by contextualizing, the researcher's goal is in finding the

overarching story by analyzing the text for “meaning and voice” rather than careful “dissection

and reduction” (p. 182). He or she finds the story that links all the categories together into a

coherent whole (Ferguson & Ferguson, 2000).

### **Data Analysis Procedure: Studying, Reducing, and Analyzing the Text**

Once the interviews were recorded and carefully transcribed by me manually, the next step was to study, reduce, and analyze the text. These interviews generated an enormous amount of text. The vast array of words, sentences, paragraphs, and pages were reduced to what is of most interest. By coming to the transcripts with an open attitude, seeking what emerges as

important and of interest from the text (i.e., inductive) I reduced the data. This is contrary to approaching the text with a set of hypotheses to test (i.e., deductive) as suggested by Glaser and Strauss (1967). As Seidman suggested, my desire was to come to the transcript prepared to "let the interview breathe and speak for itself" (p. 120) rather than approach it with any bias or prejudice.

First step in reducing the text was to read the transcript and mark with brackets the passages that seemed significant and interesting. This winnowing process helped in reducing the text into meaningful chunks of transcript. In this stage I exercised judgment about what was significant in the transcript and what was not. Later I checked with the participants to see if what was marked as important seemed that way to the participants too (i.e., member check).

**Making thematic connections.** The goal in marking what was of interest in the interview transcripts was to reduce the interview data and make it easier to group them in thematic categories and then to study the categories for thematic connections within and among them. After organizing the excerpts from the transcripts into categories, I then searched for connecting threads and patterns among the excerpts within those categories and for connections between the various categories that might be called themes. As authors of qualitative research point out, it is important for researchers to remember not to begin reading the transcripts with a set of categories in mind; the categories arise out of the passages. One of the members of the dissertation committee reviewed the themes I had identified to examine whether the themes are appropriate and relevant to my research questions (i.e., peer debriefing).

### **Standards for Assessing Interview Research: The Evaluation Criteria**

Patton (2002) wrote that qualitative inquiry, because the human being is the instrument of data collection, requires that the investigator carefully reflect on, deal with, and report potential

sources of bias and error. And in order to produce high-quality qualitative data that are “credible, trustworthy, authentic, balanced about the phenomenon under study, and fair to the people studied” a researcher needs to follow systematic data collection procedures, have rigorous training, collect data from multiple data sources, follow triangulation, and have external reviews (Patton, 2002, p. 51). He addressed the terms “objectivity” and “subjectivity” and wrote that they are ideological and the best solution is for a researcher to avoid using either word and to stay out of futile debates about subjectivity versus objectivity. According to Patton, it is better for researchers to move toward language such as trustworthiness, balance, fairness, completeness, and authenticity.

### **Trustworthiness**

This study used the quality criterion established by Lincoln and Guba (1985) to validate data collection, analysis, and interpretation. They used the terms credibility, transferability, dependability to operationalize trustworthiness. Bloomberg and Volpe (2012) agreed that the criteria for evaluating the trustworthiness of interview research are mainly through (a) credibility, (b) dependability, and (c) transferability.

**Credibility.** The question I asked myself throughout the study was “am I accurately describing the participants’ thoughts, feelings, and actions?” Bloomberg and Volpe (2012) wrote that in research the researcher can increase the credibility of the study by (a) clarifying up front the bias the researcher brings to the study, (b) engaging in repeated and substantial involvement in the field and then conveying the details about the site and the participants, (c) collecting multiple sources of data and comparing the information provided by these different sources (triangulation), (d) be willing to discuss contrary information (i.e., discrepant findings), (e) have participants reviewed the researcher’s summaries and conclusions (member check), and (f)

asking colleagues to examine data and analysis of the data so as to examine the researcher's assumptions (peer debriefing). Also if the researcher and the participants are using different languages or dialects, it will be important for the researcher to carry out frequent "member check" of the findings to ensure accuracy of the study.

**Dependability.** In this study dependability was maintained by providing detailed and thorough explanation regarding the processes and procedures used to collect data and analyze the data. Through peer-debriefing I was able to reduce the bias of a single researcher, who himself is a first generation immigrant.

**Transferability.** Throughout the study the question I asked myself was, "can the lessons learned in the current setting be useful in other settings or communities?" In qualitative studies this is very important as generalizability of the findings of a study may not be possible to all other settings, but what was learned in one setting might be useful for another researcher in his/her own setting. Bloomberg and Volpe (2012) wrote that the researcher can increase the transferability of the findings by richly describing his/her study's context and background. I presented a portrait of each parent to help in increasing the transferability of the findings.

## **Chapter 4**

### **Data Analysis**

Qualitative analysis is primarily an inductive activity, where the researcher must try to make sense of the data. He/she will be guided by the literature and experience, but otherwise the picture is there, waiting to be rendered (Mayan, 2009). By reading, rereading, and reducing the data, I was able to present the transcripts as portraits of the families, a window to their experience and their challenges and their joys and hope. In this chapter I present a summary of the different portraits and my analysis of the data. More complete content of the portraits is included in Appendix E. As I created the picture, I understood that there can be more than one picture/truth coming from the data. The experience and knowledge of each reader will help in creating a different picture, but the ultimate goal is not the creation of the picture, but what one will do with it.

As mentioned in the previous chapter the purpose of this study was to explore the support needs of first generation immigrant families with children with disabilities. And, as there is little literature on the experiences of these families and given the growing number of first generation immigrant families in the United States, a better understanding of their support needs can add to the knowledge base that can inform the development of supports and policies for families. During the analysis I exercised judgment about what is significant in the portraits. I also checked with the participants to see if what was highlighted as being of interest seemed that way to them. Member checking and peer review helped to inform the accuracy and the trustworthiness of the analysis.

## **Presenting the Portraits**

### **Portrait 1: Portrait of Erica and her family**

My first interview was with a single mother, Erica, who came from Mexico to the US when she was 12 years old. Her primary language is Spanish. Erica reported that she did not have any extended family here in the US. Her daughter, Rebecca has intellectual disability and is diagnosed with autism and dyslexia and was born in the US. She is currently 9 years old. Erica has not gone to any school in Mexico nor here in the United States. When asked if Erica had family here she reported “after my husband knew that my daughter was autistic, he told me that in his family they don’t have that “dumb people” and so he decided to divorce me and blame me that the disability she has is because of my fault.” Erica described her early life experience in Mexico as:

We were three sisters, my dad, he was an alcoholic. And I never went to school in Mexico. My Mom sent me to sell food or to ask for money in the streets. And I grew up like that till I was twelve years old. After that my Mom decided to sell me to one man, to here to the United States. And I went to that house when it was summer. When I get out of the house it was winter. Men came in and came out from the room. And I always wanted to remember everything. And they told me “no” to block whatever had happened. I went back to Mexico and when I found my Mom I thought she will be happy to see me. But she was mad and she beat me and she told me how you got out from there. And I told I escaped. And...she sold me again and I come back again to the United States. I decided I don’t want to live in the same way I was living after all. So, I escaped again, I don’t know how long I stayed there. But I decided not to go back to my country, and I decided not to go back to my family anymore.

Regarding her present challenges, Erica spent a major portion of the narrative describing her struggles with the professionals at the school. She explained:

And I know they still have a lot to work with her. And of course, I found a lot of things at school that they don't do what they have to do. And I knew, but I didn't know my rights. And when I found this Parent Support Group, they give me a book. I can speak English and read, but I have more problems to write. So, I found out the rights of the kids and rights of the parents. And when I found out I said "Oh my God, there is a lot of things that are wrong in the school." So when I went to school I said "you know what, I think this is wrong." But they say "no, this is the way things work here."

Erica's advice to other first generation immigrant families is:

We have rights. That is the first thing I would like to tell them. Our group is not just a group for support-parent support. It is not just that. It is a group from legal, legal information. Because, if you don't know your rights you never going to know what you can do.

On the importance of being part of a parent support group Erica noted:

Nothing is easy in this life. And maybe they don't see what the group is now. So that is the same thing. Maybe I am not going to see a big office. Maybe I am not going to see there is a lot of doctors here. But it is the other people who can see it. And I would like to be working for these kids and why not maybe for the other ones who came. If I don't see it that is fine. But I would like to help to help a little bit. This information you want to take it to other places and maybe one place we cannot reach but you can do it. And I am sure that you are going to do it. So, you are helping us. I am just so happy you are here. I really appreciate that you came here.

### **Portrait 2: Portrait of Veronica and her family**

My second interview was with Veronica. She came from Mexico to the United States when she was 16 years old along with her parents and extended family. She is living with her husband and three children. Her extended family (parents and sister) is also close by. Veronica's primary language is Spanish. Her daughter has been identified as having cerebral palsy (speech impairment/ developmental delay) and she is 18 years old. Veronica's education background is high school, two years college, and attended massage school. She works currently as a massage therapist.

On her early years in Mexico and coming to the United States, Veronica noted:

I was a worker child. I worked at a very early age. My dad, he always had a business at the home and I usually worked with him at his business, pretty much. I went to elementary- I finished elementary and I did a training career in computers there. And when I graduated from the computers I went to California with my grandma. So, I lived there for six years and met my husband there, and we got married. And my older boy, he was born in California. Then we moved here. It was good in Mexico. I miss those times. It was lot of work but we were a family, you know.

Regarding the family's challenges and needs, Veronica stated:

We need more help. I think, medical information on the disabilities. And, schooling. And school- I think we need a lot of help and support in schools. Because, with my own experience at schools- she is in 12<sup>th</sup> grade right now. She is a senior. She will graduate this year. But all her academic time in school- I don't think it is being fair and justice for her. I don't think she's been receiving what she deserves, what she needs. And her needs become my needs too. And it is very frustrating when you go and ask for help and they

just close the door and say “no, we cannot do this. We cannot do this.” Always denying the services. When you know there is your child’s needs. So, I started fighting with them. Meetings, meetings, meetings, talk, talk, talk, raise the voice. That is the only way I find out more help from them.

But it is-there is a lot of needs here. We need more information. Especially in our language. Because it is almost nothing. Even though when we request a translator, they say they don’t have it. We need the law. It is the regulation. We should receive the help. All meetings in our native language. So, they deny sometimes. This is one of the principal needs. You know, if we don’t have good communication, how we going to help this kid, how we going to improve as parents and teachers and make a good team to work for this kid.

Regarding the importance of parent support groups Veronica noted:

The Parent Support Group here is Hispanic, one hundred percent (laughs). Oh, I love it. I love it. That is what, I am the leader of the group, here in our city. The “leader mom.” Because now we feel that we have a family. Because you have your family of blood, right, but they don’t understand your needs, and your daughter’s need, your child’s needs. And when you get close to another family who have the same needs, we can understand each other. We are in the same ship. It is a lot easier to help, to find support, to feel like a family. I think in any people- with disability or who has something, who has hard time- maybe illness or something- it is very important to find the support, one way or other. We have the support. Yeah, because I feel like I am not alone anymore. I feel like there is some other people, like me- they feel the same way we feel. We feel challenges, happiness, blessed, different feelings that regular people don’t even think about it.

### **Portrait 3: Portrait of Venessa and her family**

My third interview was with Venessa. She came from Mexico to the United States in 2005. She is living with her husband, their three children, and her mother. Her husband's parents live close by. Venessa's primary language is Spanish. She has a son with learning disability and speech impairment. Her son is 16 years old and was born in Mexico. Venessa has a bachelor's degree in architecture, did course work for two master's degrees (real estate appraisal and managerial engineering). On her early years in Mexico and coming to the United States, Venessa noted:

I was born in Mexico City. My daddy was pursuing his MD. So back in the days, in Juarez, they didn't have a college. So, he went to Mexico City. As soon as he got his MD degree, we moved back to the border-which is Juarez. I was like five. And, since five, I was raised in Juarez-in the border land. In the US I cannot make the same money I used to make there. I am not the typical immigrant (laughs). My kid was born in El Paso, but I was living in Juarez. So, it is kind of not easy to take him to therapy, like three times a week because I was working. So, in Mexico if you have the money to pay for the services you will get them.

When we moved here I told myself, "Services should be better." And the thing is there is no information. I wasn't aware that it was the early intervention. My mistake is that I aim for private schools. And I knew that he was going to struggle because he, at that point in time, Spanish was his first language. And I kept asking them, but nobody tell you the truth, like "we are private, we don't have any responsibility, or it is not mandatory for us." They just won't tell me. "Oh, yeah, we will search on it, we will look on it." But nobody that I knew told me "Oh, there is such a thing as early intervention

and he is so serious and he can go.” Not even the private school principal- he never told me. So that was my mistake. And I was thinking that, well if the private school cannot do it then the public school cannot. It was my mistake not do more research because I was ignorant.

Venessa noted her advice to first generation immigrant families with sons and daughters with disabilities is to fight and search from the very beginning. Don't let the time go by. She noted:

That was my mistake. If somebody else, it could be a family member, it could be a teacher, if somebody else tells you there is something not right with your kid, you should check onto it because, as parents we don't want to see our kid is different. But once somebody else tells you, follow up and search for more information because sometimes the resources are there but you don't know to obtain them or how to ask for help. Like in my case my mistake is I didn't check both- private and public. You know, I bang my head against the wall because if only I had checked. If I just do more research and I just crossed the street and ask that school, maybe they will- if they don't have the information, they will tell me where to get the information. So, my advice will be to check all your choices. And the sooner the better. Don't wait. If somebody else told you your kids is different, maybe it is because he or she is (laughs). With our new President, I am concerned because- just talking about special education- not all the other craziness he has. If they start making disappear the bilingual fliers, bilingual information in this region- it is common that you will have this information. But, how I see, his nationalism and English only policy kind of thing- I am afraid that it will disappear.

#### **Portrait 4: Portrait of Negroni and her family**

My fourth interview was with Negroni and her daughter Vero (pseudonym). They are natives of Puerto Rico and came to the United States in 1999-2000. Negroni and her husband have three children with ages of 21, 19, and 18. All her children were born in Puerto Rico and have been identified as having dyslexia. Negroni's primary language is Spanish. Negroni has a bachelor's in criminology. They do not have any extended family members living close by.

When asked about Negroni's early life experience, she narrated:

Puerto Rico is beautiful, is nice, I am happy there. But the reason we moved is my husband is a policeman in Puerto Rico. We are, you know, try always to improve. I tell him "Okay, Puerto Rico not pay more for the college." Move to the United States, because my father and others moved to Minnesota. From there we moved here. The move is for improve, not because I not happy in Puerto Rico, it is to improve. We have the three kids, I finished my university, I married, I graduate in criminology, and I never working in that because you know, my husband work always for provide. We are fine. For us it is more important. No Mom in the house, the kids are no, no. We have values-Christian ones, you know, going in the Bible. That is my guide. I don't care the population, what the people are doing. I have my- my husband and me- we are purpose in life.

But I not learning good English. Because the school, only one period in English in the day and the rest in Spanish. But the rich people in Puerto Rico go to the private school-all in English. Parents are doctors. If parents have the money to afford the tuition. Many people say, "Puerto Ricans speak English." But that is if we can afford we can get the education. Academic, pay a lot. Two thousand or more. Too much. But, the status of

us affect me because I have college degree in the university but no work because I feel like no secure to speak. But now I feel like I need to maintain my Spanish for my kids. That is why no, no, no speaking English in home. Because I am proud about Spanish. I like Spanish better. I am proud to be a Puerto Rican and proud to be American.

When asked about what supports her family needs, Negroni narrated:

I think, parent resources are not here. We have no resource- what happen with my kid, where I do get it. I think the parents here are not fighting. Maybe one or two parents are fighting for the kids' education. That is why the schools say "No" because we don't have support. We do not have an office for disability rights here. But I think the community- the Spanish ones are more.....the Mexicans, they don't have study over there. They are a little ignorant. It is too hard to provide- they thinking different. They always been thinking no education but money for them. In my family education more important. I don't want to be rich, I want like- good life. Rich is not happier. Rich people, you know. Education is your freedom for me. That is why I am thinking- that happen in Puerto Rico. You come to here when you are educated. That is why the education give you power to do something different. That is why I am here, it is different but I am power. You know, I have confidence here. That is why I don't need more support. I try to find the best for my family. But I thinking this community need education, they need rights, they need hope, and maybe the problem is with the- I can't imagine stay here without the paper. For me thinking it is hard-hard time.

### **Presenting Themes: The Big Picture**

By contextualizing the narrative data my goal was to find the overarching story that came out- the theme that linked at the categories together into a coherent whole. The meaning and voice that breathed out by analyzing the text was that immigrant families with children with disabilities, like any other family, are on a journey; but, what was unique in their journey as immigrant parents was the building up of relationships with other immigrant parents: the feeling of helplessness in a new country and overcoming that through relationship with other families. The journey included coming to awareness that there are rights and procuring that information in a social context. Information about their rights, about services, and resources that can support the families were not obtained in isolation (e.g., schools and agencies handing out fliers, pamphlets) but by building relationships with other families, often speaking the same language (e.g., Spanish) and coming from the same country (e.g., Mexico).

As mentioned by the participants, the families “carry each other’s cross,” support one another, and provide each other with valuable information (e.g., on guardianship, long waiting list, parent rights). The journey from having no rights to having many rights- the coming to awareness of rights, according to the participants, occurred through relationships. The coming together and sharing of experience with one another and being connected was what made the difference. Social networks were crucial and thus the formation of a parent support group, where everyone felt safe to share their experiences and learn together about their rights, was vital according to each family.

#### **A Sense of We-ness**

As language was a key barrier in receiving information and supports, families reported a sense of belonging (i.e., culture) with other families from the same country and speaking the

same language. It seemed socioeconomic status and education of the parents were not that much of a factor compared to the language and country of birth. Culture refers to different elements that influence “one’s sense of ‘we-ness’” (Turnbull & Turnbull, 2001, p. 61). As one parent noted:

The Parent Support Group here is Hispanic, one hundred percent (laughs). Oh, I love it. I love it. That is what, I am the leader of the group, here in our city. The “leader mom.” Because now we feel that we have a family. Because you have your family of blood, right, but they don’t understand your needs, and your daughter’s need, your child’s needs. And when you get close to another family who have the same needs, we can understand each other. We are in the same ship. It is a lot easier to help, to find support, to feel like a family. I think in any people- with disability or who has something, who has hard time- maybe illness or something- it is very important to find the support, one way or other. We have the support. Yeah, because I feel like I am not alone anymore. I feel like there is some other people, like me- they feel the same way we feel. We feel challenges, happiness, blessed, different feelings that regular people don’t even think about it.

It is mainly in this context that families reported they got the epiphany that they have rights and about the resources available in this country. This coming to awareness of their rights and the available supports came in a social context and not in isolation. One parent noted how her friend did not know about the services:

I knew another friend, her child, they moved from Arizona here, and her child was 20.....20 some years old. And they did not know about the DD Waiver. And they were living here already for 5 years. And they didn’t know about it. So sad, because the waiting list also, to get into the DD Waiver is more than 10 years. Ten years!!!

The school never told me about it. The school, did not tell about it. And I knew other parents who say, “what’s that.” From the Support Group I learned about our rights, basically we focus on the IEP’s, and to know our rights, and parents’ laws, and group support.

This indicated the importance of informal parent networking. As a parent mentioned there is not much time to lose and families need to start looking from the very beginning. This parent, who has a son with disability, was paying for services in Mexico when they were residing there. When they moved to the United States she assumed services would be better in a private school, as she had to pay for the education. She still regrets that decision and about not knowing public schools provide the special education services free of charge. She said:

Like in my case my mistake is I didn’t check both- private and public. You know, I bang my head against the wall because if only I had checked. If I just do more research and I just crossed the street and ask that school, maybe they will- if they don’t have the information, they will tell me where to get the information. So, my advice will be to check all your choices. And the sooner the better. Don’t wait.

The need to unite quickly with other families and be informed, according to the narratives, were important, especially as the families are coming from a country where services and resources are different. There was a sense of urgency. The narratives included:

We have rights. That is the first thing I would like to tell them [new families]. The Parent Support Group is not just a group for support-parent support. It is not just that. It is a group for legal information. Because, if you don’t know your rights you never going to know what you can do.

Know the rights, request them, speak out, never stay quiet, never be afraid, for once you know the rights you do have to follow them, request until they provide the service to your child. It is only way the child will improve. It is the only way the child will have skills, life skills. That way they will feel more confident, they feel more independent, which is goal. Yes, so speak up. Speaking up and request, and request, and if they deny [the school], then send complaint to whatever agency you need to send it.

Fight and search from the very beginning. Don't let the time go by. That was my mistake. Follow up and search for more information because sometimes the resources are there but you don't know to obtain them or how to ask for help.

Throughout the narratives the theme on the importance of receiving information in a social context and the awareness of rights kept reappearing. One of the participants explained:

I found this group- they give me a book. I can speak English and read, but I have more problems to write. So, I found out the rights of the kids and rights of the parents. And when I found out I said, "Oh my God, there is a lot of things that are wrong in the school." So, when I went to school I said "you know what, I think this is wrong." Because I didn't know the rights Rebecca have, I didn't know my rights. If I didn't be in that Group-Parent Support Group, I still will be thinking like, "Oh, I don't like the way they are treating my daughter but what can I do." But now I feel like the same way when I came to this country, when they teach me these are your rights. Like, if you are in the wheelchair, always you are going to be in that chair and you not going to be moved, because you don't know you can move from the chair. But after you know your rights, you have that feeling, you have that anger to get up and say, "you know what, that is it. No more." So, that happened in my life when I know my rights here. And this is what

happened with Rebecca now that I know her rights. Of course, I don't know everything because I am still learning.

The parent support group mentioned by Erica above was started by a couple of mothers in a large city in the southwestern part of the United States. Erica noted that the group has been a huge blessing for her, especially it being a Spanish speaking parent group. Workers from the group come once a month and provide information and support for the families in Erica's city. Erica noted that they are also helping the families to start their own Parent Support Group. Paat, (2013) stated that immigrant families are "socially disadvantaged as newcomers" (p. 961) due to unfamiliarity regarding dominant cultural practices and social norms. Hence, it seemed important for the parents to come together as a family and help one another.

Another parent explained how she became aware of her families' rights. Having difficulties with formal supports and feeling isolated, one of her friends referred her to the parent support group. She narrated her experience:

"Do you know who can help me because I am going through this problem?" She [the friend] said, "Call this Parent Support Group. I have been receiving help from them." So, I did, and I found they are going to have an annual conference. I went to the conference and that is where I learned how to defend myself and how to defend my daughter because there they told me, "you have rights, your daughter have rights, the school has obligations. The school receives money to provide services to your daughter." And I said, "really. And they treat me that way. That is the way they think." No, no, it has to change.

As first generation immigrant families are in a social disadvantage due to not knowing their rights and the dearth of information, another aspect in which they find themselves in a disadvantage is the limited natural supports available to them. The circle of support closest to the

family represent the most natural and primary sources of support for families and is referred to as natural supports and includes spouses, extended family members, friends, neighbors, churches, and other community-based systems (Cooley, 1994). Often the families are separated from extended families and hence greater the need to connect with other families. According to the narrative of Erica, the importance of these informal supports are multiplied for first generation immigrant families when the parent is by herself. Her husband left her after she had her daughter, leaving her by herself to take care of her daughter. She explained:

After my husband knew that my daughter was autistic, he told me that in his family they don't have that "dumb people" and so he decided to divorce me and blame me that the disability she has is because of my fault. So, for me that was a lot, because coming from this kind of life I had before and then to see one kid like that and then the divorce came with no job, that was *too much* for me. A lot, a lot. And I have cancer and I lost my hair, I lost my everything, I lost my house, I lost everything. So, it is a lot when you know you are a single parent, that you have a special kid and you have to get up, you have to keep going and keep going. You not going to stop. Because you not going to be in this life, for the rest of their lives. We are going to die and we have to prepare them to be a good person and to defend themselves. And to learn, they have to learn. We are here to teach them how to learn. And because one day they are going to be by themselves.

Sometimes I don't have enough money-like now I don't have any insurance for my truck and I have to take Rebecca to the City next month for two appointments. So, it is like- I feel sometimes frustrated because, at work we don't have enough hours. I was feeling **so** guilty and I was starting to feel that I am not doing nothing right. So, having a special kids, we carry a lot of feelings and sometimes we feel guilty. Because we feel that

we don't do enough for the kids. I feel sometimes in that way- I don't do enough for Rebecca, I don't give her enough time. I would like to be with her [starts crying] and I would like to take her to school every morning and I would like to take her to therapy, but I cannot do it because I have to work. And to be a single mom and to be like, what I am, I am having no education, I always get the minimum wage. And I told my older daughter, "go to school. It is the only way you want to defend yourself and you know your rights. Because I didn't know the rights Rebecca have, I didn't know my rights. My biggest dream was to go to school. And I try but when Rebecca came everything stopped.

Erica's narrative confirmed what Thompson (2000) reported, that often the case is that if a child has a disability the father leaves the household and no longer keeps in contact with the mother, leaving her with no emotional, physical, or financial support. Single mothers hence often are left with the responsibility of taking care of the child herself. Thompson suggested that in such cases single mothers should try to quickly develop a good support system of family, friends, and medical personnel. A network of close friends, especially other mothers who have children with disabilities, can mutually support each other through valuable advice and information about practical matters, energize and sustain each other, and take turns watching the children (Thompson, 2000). For immigrant families often this network is small and place them in a disadvantage. In addition, communication in a language that is not their first language adds to the feeling of helplessness. Another participant echoed the sentiment of their family being lonely. She noted:

When I move to Minnesota my family was there. Mommy, Pappi, my sister live there, friends from Puerto Rico live there. When one move, everyone moves. We do not have problem. The kids are supported with cousins, grand pa, uncle, my grand ma. But, we

move here I feel lost, most alone, or different. I feel sad- my mother just have her happy birthday, all my aunt in Puerto Rico. Me, I can't touch my mom. They come but it is enough you know, it is expensive. I feel depressed in the beginning because.....I go to the church on Sunday- I go to the Pentecost type close to my house. That support is like family.

This journey from helplessness and loneliness to being empowered and having a family was highlighted in the narratives. The importance of having a network of informal supports, especially when extended family or the spouse was absent was a theme that was voiced.

### **Be the Change you want to see**

As I searched for threads and patterns among the narratives to connect them in creating the overarching story, determination among the families to be the change and the desire to advocate on behalf of their child and on behalf of other families kept appearing. The families were embracing the rights-based environment of American society and accepting the societal expectations on advocacy and empowerment. The drive to be a voice and be the change is what encouraged the mothers to be part of this study, regardless of the barriers related to language and culture. One of the participants pointed out:

When they told me that you want to come, they told me "but he speaks English, he don't speak Spanish. My group is in Spanish. And I tell them, "yes, I want to go." And everybody was laughing because they say, "there has to be Erica"- yes there has to be me. Because I am not ashamed of nothing. That is something that teach you. You not going to be shamed, no way. So, for me to be here with you, I hope, like I tell you, I hope somebody can hear this and to see the necessity that we have here-like the parents. And

maybe we will be like the Parent Support Group, I know the group came from two parents- two mothers. And that did not come easy. That did not come that easy.

So nothing is easy in this life. And maybe they don't see what the group is now. So that is the same thing. Maybe I am not going to see a big office. Maybe I am not going to see there is a lot of doctors here. But it is the other people who can see it. If I don't see it that is fine. But I would like to help. You are helping us. Because this information you want to take it to other places and maybe one place we cannot reach but you can do it. And I am sure that you are going to do it. So, you are helping us. I am just so happy you are here. I really appreciate that you came here. I don't know if you have heard this: If something that not kill you will make you strong.

The common thread again seemed to be the "sense of we-ness." The parents advocated in the social context and not in isolation. When they helped each other and advocated together they had a feeling of empowerment and success. One of the participants spoke about her difficulties with the school system and how she did not feel part of the team. After talking about the lack of inclusiveness in the school district and the families' helplessness her narrative changed to what she is doing to help create the change. She explained:

But, now I, I help the district.....they know me more because I work in the program called "Parents Involved in the Education." It is a new program. I am facilitator for the Spanish speaker. I am working with them-Superintendent. I am working with them because I know what happens there. They say "Okay." For me no more parents pass my experience. That is why I help in "Parents Involved in the Education." That is my passion. I am not working but I do this for the community. They say okay. And support emotionally. But, I do fight and it is working. I tell them the truth. Now I'm working with

them. Because they have that good program to involve in the parents. We give everything to it. Because I know it is not personal, district is not personal. They try to do less for the kids, because, you know the budget. The budget, that is important. But, the law is appropriate education for everyone. Doesn't matter you are immigrant or no. Status nothing. That is the law. Federal law help. And that is my passion, you know. I want to help people.

In the midst of her helplessness, instead of feeling self-pity, Negroni started working with the schools, became a facilitator, and is helping in creating change. She learned the “law-appropriate education for everyone regardless of status,” and is transforming herself to be a leader. This resonated with all parents- they wanted to help parents “new” to the system and be a support for them. Difficulties have been stepping stones according to Erica. She noted:

And I start thinking well, there has to be something else. I was thinking to myself. And I was thinking, the support group, all the support groups are in English. They don't have any Spanish. So, I thought there has to be something else. And, I don't know nothing about computers. If you told me “go and look here,” forget it. I don't know nothing. So I started thinking and thinking there has to be something else. The language because this is what I noticed. It is a lot of people but they do not know their rights because they are in English.

And every time they send help [Parent Support Group from the City], send us help to give us information I am in those meetings and I learn a lot. And important of this is that it is in Spanish. Because it is a lot of people that they don't go to the meetings because they say “well, I don't speak English” or “I don't understand nothing.” So, I think that is the reason parents, they don't show up at schools because they don't know, they don't

their rights because they don't know how to read, they don't know how to write, they don't understand. But if we have a group in Spanish, I am more than sure that we can have a big office and a big group (laughs loudly). Yes.

Erica understood information transfer took place best in a social context that was comfortable to the families. Lo (2010) wrote that parents who reached out for support felt more comfortable sharing their frustrations with parents of the same culture and feel a sense of relief to "finally meet someone who understood what they were going through" (p. 413). Through group participation the parents received emotional and psychological support from each other; they developed friendships, had a sense of belonging, and felt empowered and confident when working with their own children with disabilities (Lo, 2010). Being a leader and stepping out to help other families proved to be a blessing, giving them a sense of belonging. Throughout the narratives I sensed a change in tone and countenance as their conversation changed from anger and helplessness with the schools and other service providers to being a support to other families.

### **The need to advocate for resources in the community**

According to the participants there is a need to advocate for resources and have their voices heard. Again the theme that emerged from the narratives is building up relations and together making the changes needed. Being aware of rights was the first step and that is achieved in a social context. Helping each other in overcoming barriers was the second step. In doing so, the parents became leaders and have a vision. The final step according to the families was to be proactive and to speak up for the resources. The participants all had the same opinion that the community where they lived in lacked services and resources and they felt less fortunate compared to those families living in bigger cities and hence the need to speak up together. One

of the parents noted that services are limited because most of the recipients do not speak English.

She noted:

To have doctors!! Doctors, because we don't have doctors for the kids. We have to go to the city which is 3 hours away. I would like to call the attentions to the State and say, "you know what, we need money, we need doctors, we need more help here because there is a lot of necessity. But they are not going to see it because, a lot of people, they don't speak English. Everybody is going to the city. More therapists. Evaluations, Rebecca has to go to take evaluation in the city. So each evaluation that they take we have to go over there. And we would like to have that here. And it is a lot of people, I never thought, I never thought till now and parents-rich parents, I never thought that there was so many people with special kids. And the thing is that these people, they don't speak English. That is the reason I think nobody knows that we are here.

Another parent agreed on what Erica spoke regarding the supports needed in their city.

Regarding having to travel to the big city for medical services, Veronica stated:

For specialist we have to go to the city all the time. That is something that is a big necessity here- we can have more specialists here. Because to see a good specialist, to see a good clinic or specialty, in medical we have to travel to the city, which is 3 hours and 3 hours one way. And before, we can go to another city close by, but it is in the next State. But with Medicaid rules, policies, we can't. They are another State and are not accepting Medicaid there from our State. So, now the only choice we have is for us to go to the city that is 3 hours away. Like my daughter, she has cardiologist in there in the city. For everything we have to go there. So, I had to find another orthopedic here-orthopedic doctor. He is not specialized in kids and he is not specialized with kids with disability. He

is a regular orthopedic doctor. Right, but it is the choice I have here. So I took, I like it anyways, I like it, he is working with my daughter. But cardiologists, is still in the city 3 hours away. My daughter has, she needs jaw correction surgery and the surgeon is there. So, every time we have to travel three hours just to see the specialist.

When asked about what supports her family needs, Negroni narrated:

I think, parent resources are not here. We have no resource- what happen with my kid, where I do get it. I think the parents here are not fighting. Maybe one or two parents are fighting for the kids' education. That is why the schools say "No" because we don't have support. We do not have an office for disability rights here. Here I go to the office, but the lady working there tell me, "I help more the veterans, less schools." We are so desperate. She say's not here but in the big city- but it is far away. We need people here. The parents continue not to find the support. We need more in my language. Many people say, "But study English." But in my case I'm US citizen, I am born speaking Spanish, it is not my fault they give me Spanish in all my years-in the University-twelve years, with my Bachelor's degree. My Bachelor degree is good here but I know my English is not. They no provide a good education in English to us.

According to Negroni, the reason for limited services and resources, especially in Spanish is because parents are not advocating for their families. And as mentioned earlier, parents felt that when are together they can make a difference; start an office; train other parents; promote the availability of information in their native language; have their voice heard. Together there is the feeling of empowerment and courage.

## Chapter 5

### Discussion, Findings and Recommendations

The relative lack of current literature on the experiences of first generation immigrant families with sons and daughters with disabilities in the United States led to my research question: What are the support needs reported by first generation immigrant families with sons and daughters with disabilities? Given the growing number of first generation immigrant families in the United States, a better understanding of their support needs can add to the knowledge base that can inform the development of supports and policies for families. Four immigrant parents with children with disabilities in the Southwest of the United States were interviewed to hear first-hand about their experiences, the existing forms of supports, and the families' needs and their concerns, worries, and challenges as caretakers. The interviews were transcribed for review and thematic analysis.

Using inductive analysis, the theme or the overarching story identified was that the immigrant families were on a journey- journey from no rights to awareness of their rights; journey from no information to information in a social context; journey from loneliness and helplessness to having a "family" and being empowered together with the family. The sense of we-ness and the sense of determination came about with the help from other parents speaking the same language and having the same culture. All participants expressed the importance of building up of relationships with other parents and the importance of family and friends. They indicated that it was difficult trying to understand the needs of their child alone- they felt much secure when they received supports from family, friends, other parents, and caring professionals. Participants also spoke about the ecological factors playing a crucial role in meeting the needs of the families- external factors like location of their city and language influenced their needs. All

four participants expressed that it has been a difficult road for them but they also indicated they have hope for the future and want to be part of that future. Following is a discussion of the major findings and conclusions drawn from this research. This is followed by recommendations and a final reflection of this study.

### **Findings**

(a) Being separated from extended families and often times alone in an unfamiliar country can be difficult and requires a lot of strength and support. Needs are not often met- financial, emotional, and day-to-day needs. Spouse and children may be the closest forms of support. But if abandoned by the spouse, the needs multiply and it is imperative to look for other forms of support. They could be in the form of other parents, church, or support centers. On being a single first generation immigrant parent, one of the participants noted:

It is hard. And, like I said, to be a single mom with a special kid is a lot. Because sometimes you don't have nobody to talk to, the person who is supposed to be with you, or with your kids, saying, "I understand you, I feel the same way as you. Don't worry, we going to do it together." So, it is like my elder daughter say, "you are very strong, mom, you, for the kind of life you had. And I say, "yes, I can do it." Though, sometimes when, you are the head of your family, you have to be the example, you have to be the stronger. And.....your kids, they look like that, you are very strong, you know everything, like, everything what you do, everything that you do is right. But it is not. I am not that strong. I have my moments and when I feel like the way I feel now [crying] I just tell my kids I am tired, I am going to take a shower and I take a shower and I cry a lot. Because it is a lot of responsibility.

It is difficult being a single mother, but this maybe especially true for an immigrant family, especially if there is no extended family close by to help out and provide the support.

(b) Another finding in this study was that the participants interviewed found comfort in connecting with other families speaking the same language and coming from the same country.

There was a feeling of camaraderie and willingness to help each other. The participant mentioned above had very little natural support and hence she and her family started thriving when she discovered the support group and when she started helping other families.

One of the participants noted:

So, I learned a lot through the parents. And I thought it was me, I thought it was me who is weak. The way I feel, "I am so weak." And "no," all the parents-you can see a group of parents and everybody is happy and we are smiling and happy to see each other and happy to see other kids. But it is like, like a mirror. It is like you looking yourself. You look the other people and you look, "well, she is me." So, if she is me that means that she has problems too. And I have to take care her, because I have problems and I would like that somebody came and do something for me or say, "you look good" or "you can do it." So, we do that because we have that feeling that we have to help each other.

Another parent explained:

You have your family of blood, right, but they don't understand your needs, and your daughters need, your child's needs. And when you get close to another family who have the same needs, we can understand each other. We are in the same ship. It is a lot easier to help, to find support, to feel like a family. I think in any people- with disability or who has something, who has hard time- maybe illness or something- it is very important to find the support, one way or other. We have the support. Yes, because I feel like I am not

alone anymore. I feel like there is some other people, like me- they feel the same way we feel. We feel challenges, happiness, blessed, different feelings that regular people don't even think about it.

This resonates with what Naseef (2000) wrote, "A special kind of camaraderie exists among parents of children with disabilities. Although not related by blood, we are deeply related by our circumstances and can offer each other much comfort and understanding" (p. 205).

(c) Another finding was that immigrant parents often struggled with English and felt much more comfortable when information was available in their native language. Most of the participants interviewed had a bachelor's degree or similar education, but they all desired information in Spanish. As mentioned earlier parents prefer to be in support groups where communication is in their native language. One of the mothers noted that families do not attend some of the parent support groups because they are all in English. She said:

A lot of people don't go to the meetings because they say "well, I don't speak English" or "I don't understand nothing." So, I think that is the reason parents, they don't show up at schools because they don't know, they don't their rights because they don't know how to read, they don't know how to write, they don't understand. But if we have a group in Spanish, I am more than sure that we can have a big office and a big group. Yes. What I noticed is that a lot of people do not know their rights because they are in English.

This lack of information creates fear and worry among families followed by guilt for not being able to take action sooner, as noted by one of the parents:

"What will happen when I will die?" My other kids I know they will go on with their lives-they will marry, and be like any other people. But with him that's my main concern. And, nobody will tell me. What I need somebody when I ask direct questions I can get

answers and tell me, “you can do this, this and that.” In this country they don’t tell you face to face.

One of the parents talked about the changes that she fears might occur with the change in the administration in the country. She explained:

Our new President, I am concerned because if they start making disappear the bilingual fliers, bilingual information. In this region it is common that you will have this information in Spanish, but now, his nationalism and English only policy kind of thing- I am afraid that it will disappear. Because you know that the website of the Presidents, they used to have everything in English and Spanish. And then as January 20, they disappear from the website-all the Spanish information. If they disappear or they cut funds then it will be less and less information in Spanish.

(d) One of the findings was that participants suggested it important to learn the system immediately after coming to the United States. According to the participants, new immigrant families need to be informed and not waste any time in getting the right information. One of the mothers gave some valuable advice to immigrant families moving to the United States and said this is because she still regrets not having the right information when she and her family moved here to the U.S. She said:

Fight and search from the very beginning. Don’t let the time go by. That was my mistake. Follow up and search for more information because sometimes the resources are there but you don’t know to obtain them or how to ask for help. I bang my head against the wall, because if I just do more research. So, my advice will be to check all your choices. And the sooner the better.

Lot of parents let time go by before they realize the long waiting list and the availability of resources and services. She noted that even native families face the same difficulties first generation immigrant families face. She said that if the situation is new for a family, having a child with a disability, then they are in the same boat as immigrants coming to the United States for the first time. There is no information and you learn more from other families having a son or daughter with a disability than from anybody else.

In this age of information and technology, even if there are information and resources, for immigrant families finding them will be an issue. Many parents are not computer savvy and unless they come in contact with other parents and communicate with them, often times valuable information, especially those that need urgent attention will be hidden. Studies have indicated many of the immigrant parents do not communicate with authorities or other parents due to a feeling of shame or guilt. Also not knowing your rights, the school system, and your child's rights put these parents in a disadvantage. If schools and other professionals assume parents already are familiar with their rights or that it is the parents' duty to attain information, then there are no active supports. Also, as one of the mothers pointed out, here professionals might be fearful that if they provide the information, then they are also responsible in providing the support, and thereby not communicate the information. The fear of families suing the provider of the information may keep providers of valuable information silent. But as the mother pointed out that is the last thought going through the families' minds, especially when they are desperate to receive help and support.

(e) As I analyzed the results, another finding I realized was that most of the participants felt strongly that they did not know their rights and as a result they felt they were not part of the team in the school setting. Information about the families' rights, especially in the language they are

well versed in is crucial according to the participants. The participants noted that it is through the Parent Support Group they knew about their rights as a parent. All parents spoke a lot about the challenges they faced with the school system. They also spoke about long waiting list for evaluation, guardianship, absence of medical professionals, specialists, and therapists. One of the parents noted, “And when I found this Parent Support Group, they give me a book. I found out the rights of the kids and rights of the parents. And when I found out I said “Oh my God, there is a lot of things that are wrong.”

Weinhouse and Weinhouse (1994) addressed the need for families to express themselves loudly and clearly about how the services (programs) can benefit them and their children, and about services they like and those they don't like. They argued that to be a strong advocate or lobbyist requires knowledge and understanding. They wrote:

Parents must therefore read and learn about their child's disability, attend conferences, join support groups, and network. Through activities such as these they will become more knowledgeable about the condition of special education and be more able to suggest how it might be improved; they will prepare themselves for the numerous letters they will have to write, phone calls they will have to make, and questions they will have to answer (p. 68).

(f) Parents also spoke about the difference in supports in the United States compared to their home countries. Here, according to the participants, the supports are better but the issue is on knowing how to access them. One of them noted that:

Yes, yes, here the supports are much better. There is a lot more supports here than in Mexico. In Mexico, for kids, they don't even go to school because they don't have any

program, and they don't have teachers certified in special education, nothing like that.

Doesn't exist there in Mexico.

Another parent explained:

The bad thing in Mexico is if you don't have the money, like, parents with special education kids, I don't know what they will do. Right now I don't know, but back in those days when I left Juarez, it was one special education school and they were all together, like, Down syndrome, all the disabilities. I am thinking if you don't have the money and that school won't have a spot for your kid then you will be on your own. Back on the days if I hadn't had the money to pay for the session-the speech therapy sessions, we would have struggled. I am thinking that is the bad part of my country. The good part is the communication. But the resources are so limited. Here, they have more, but they don't have the information available. For somebody that doesn't speak English, that is illegal, and are not computer savvy, they will have more disadvantage. That is the disadvantage of this country.

(g) The environment played a large role in this study. This issue may affect not just immigrant families but also native families. For families in large urban cities this may not be an issue that may not arise, as there would be greater resources like medical specialists, therapists, disability rights offices, and parent support groups. Resources and information in languages parents are familiar in will also be in abundance there but not in smaller towns. Unless more and more service providers are willing to branch out or transfer to smaller towns and rural parts of the country it would be difficult to deal with this problem. For every major appointment with a specialist families had to travel more than 3 hours one way. Parents felt they need more supports where they are and more professionals. One of the parents addressed the needs as:

To have doctors!! Doctors, because we don't have doctors for the kids. We have to go to the city which is 3 hours away. I would like to call the attentions to the State and say, "you know what, we need money, we need doctors, we need more help here because there is a lot of necessity. But they are not going to see it because, a lot of people, they don't speak English. Everybody is going to the city. And the thing is that these people, they don't speak English. That is the reason I think nobody knows that we are here.

Another parent responded:

Parent resources are not here. We have no resource- what happen with my kid, where I do get it. I think the parents here are not fighting. Maybe one or two parents are fighting for the kids' education. That is why the schools say "No" because we don't have support. We do not have an office for disability rights here. We are so desperate. Parents continue not to find the support. I'm working, we need more in my language. Many people say, "But study English." I am born speaking Spanish, it is not my fault they give me Spanish in all my years-in the University-twelve years, with my Bachelor's degree. My Bachelor degree is good here but I know my English is not. They no provide a good education in English to us.

(h) Another important finding was that as difficulties arose parents found solace in helping one another and making sure no one had to go through what they went. Out of all the struggles with the school system and professionals there was much good that came about. The parents came together and started a Parent Support Center in the city. They call themselves the "leader mom" and are proud of their achievements. They are ready to step out of their comfort zone and bring out the changes they desire. One of the mothers who has difficulty with English had no problem taking part in this study because she felt it important that her voice be heard. When she was told I

was interested in interviewing families she readily agreed for the interview, even when she was told that I will be interviewing in English. Other parents laughed and said, “Erica is there in everything.”

As I analyzed the results, I realized more and more that the parents wanted change and that change started with them. They wanted to change the outlook on disability, support one another and carry each other’s load. They realized this is not an individual journey, but a corporate one, in which all families were included, all families had a role to play. If they wanted their voice to be heard, they wanted it to be a collective voice not individual voices trying to make changes. They were the change, and there was no backing down. It did not matter if language was a factor, or education, or financial difficulties, or worries about the future- change is coming, and it is starting right at the epicenter- the families together being support to one another.

(i) Understanding American culture was another issue some mentioned. One of the parents noted:

In this country is that they don’t tell you face to face. They tell you like, don’t mention my name... And then everything takes forever. The main thoughts is “What will happen when I will die?” -well to me. That is my- you know, my other kids I know they will go on with their lives-they will marry, and be like any other people. But with him that’s my main concern. And, nobody will tell me. I am thinking what I need somebody when I ask direct questions I can get answers and tell me, “you can do this, this and that.” Like in the private school-the secretary, not the main teacher, not the principal, not the assistant principal-a secretary with the same case, she was compassionate enough to tell me when nobody else was there and, “Please don’t tell anybody I told you.” And I was like, “No, I

won't do that." It is different because down there [Mexico] nobody is afraid to talk, because we don't sue everybody for small stuff. And, if we sue each other, that won't go within the court. The communication is more direct.

## **Recommendations**

Based on the findings, analysis, and conclusions of this study, some of the recommendations I humbly present are for (a) the schools and professionals; (b) first generation immigrant families of children with disabilities; and (c) further research.

### **A. Recommendations for Formal Support Providers**

1. Provide timely and valuable information. Families of children with disabilities, especially those new to the country, have minimum to no information on special education laws, supports available, their rights as parents, their child's rights, and the often long waiting lists. If information is not available, families lose valuable time and forever regret the lost time. They feel guilty and, as a mother said, "I bang my head against the wall for not doing research on the available supports." Providing information is the key, and if possible in the language the families are fluent in. Parents will ultimately get the information from other parents or support groups, but as time is precious for the families, timely help and support is appreciated by these parents.

2. Encourage the formation of Parent Support Groups. Families feel a real bond with each other and learn from one another, and as a parent noted, help carry each other's "cross." These support groups can help in educating one another on their rights, what an IEP meeting is, and how they can work as a team for the success of their child.

3. Communicate with families. Bronfenbrenner (1986) noted that the family (microsystem) is the most important setting in which the developmental process takes place. Results of studies examining mesosystem interactions between the family and other

microsystems (e.g., family and the hospital, the family and day care, and family and school) illustrated greater social and psychological development among the children when there were active interrelations (Bronfenbrenner). When there is a lack of “team,” it affects the child and the family. Hence, it is important to communicate with families on current policies, their rights as parents, and available resources.

4. Be sensitive to the culture of the immigrant families. According to the ecocultural theory, actions that families take in their everyday lives and their daily routines and activities (i.e., family niche), are influenced in part by the ecology (i.e., the physical setting, the material setting, and the social setting) and in part by their beliefs and values that are personally and culturally influenced (Bernheimer, Gallimore, & Weisner, 1990). Examples of the family routines are: preparing meals, eating dinner, clearing up, getting ready for school and other similar adult-child interactions (Gallimore, Goldenberg, & Weisner, 1993, p. 539). This perspective that the family's niche is influenced by not just the material environment but also the sociocultural environment (e.g., beliefs relating to moral life, origins and causes of disability, culturally appropriate conduct of marriage, and family relationships) is useful when considering supports and intervention for families, especially for immigrant families with sons and daughters with disabilities (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Welterlin & LaRue, 2007). Hearing families' stories and understanding their past culture and beliefs will be very helpful and would make a great difference. Being subjective is a plus here in this case, talking about their feelings, the hurt, and helping in mending the hurt is what parents desire.

5. Create parent-led support groups. Make family support groups and resources family-centered, led by parents, or include families in the planning and decision making. By encouraging parent decision-making, parent satisfaction and the feeling of empowerment will be

present, and the feeling of being part of the team will be there. This may result in increased knowledge, lower child-related parenting stress and an increase in parents' psychological well-being.

### **B. Recommendations for First Generation Immigrant Families of Children with Disabilities**

1. Be part of a parent-led support group. Parents of children with disabilities have a feeling of togetherness and feel the need to support one another. What parents are saying is that they do not want other parents to go through what they had to face, especially when they are new to the country. Parent led support groups, especially in a language immigrant parents are most comfortable in, are most beneficial, according to the participants. McCabe (2008) wrote that parent-led support groups are highly beneficial for parents of newly diagnosed children with disabilities as they are mentored by more experienced parents.

2. Be informed. Attend conferences and reach out to family support groups. A lot of times information of these groups and conferences come from other parents with sons and daughters with disabilities. Participants noted that the most effective Support Groups are those that have action items, like, education on important legal matters (e.g., what is an IEP), or on what can be done to support one another (e.g., send a letter to the State requesting more medical specialists or more therapists).

3. Support groups should embrace families of different cultures. The parent-led groups should be diverse and all-inclusive. They should be willing to embrace families from other cultures. One of the participants reported she did not always feel comfortable with other families because of differences in their culture. Mandell and Salzer (2007) suggested for families that are uncomfortable attending support groups, 1:1 mentoring with families in similar situations may

help to decrease social isolation, reduce stress, and increase access to information about appropriate care.

4. Know that you have rights. It is important to know you and your family have rights and act upon them. And the best way to know the rights and act upon it is in a social context, together with other families, not in isolation.

### **C. Recommendations for Further Research**

1. Include families of different ethnicities. In this study families from Hispanic background were interviewed. All had Spanish language as their first language and spoke Spanish fluently. It would be interesting to interview families of different ethnicities and different backgrounds in one study to examine if the families' narratives are similar or their perceptions are different. In this study the parent from Puerto Rico had a slightly different narrative compared to the parents from Mexico.

2. Research the needs of single parent families. In this study, three of the mothers interviewed were married and spoke about the support they received from their husbands. It was seen through the interview that the support needs of the single mother seemed much greater. A comparative study to examine the differences in the support needs of homes of single parents to the needs of two parent homes would bring about issues single parents face.

3. Voices of fathers are missing. Much needed is the voice of fathers of children with disabilities. In this study both parents were invited for the interviews but only mothers showed up. This does not mean fathers do not care for the needs of the family and the well-being of the child, but the social construct seems to be that mothers take care of support groups, communication with schools and doctors, therapists and evaluation specialists, while the fathers take care of the daily needs. Fathers are often times hidden from the picture. It seems to be odd

for both parents to be equally involved- or at least it looks like that. Mueller and Buckley (2014) wrote that fathers were the “odd man out” and their experiences were often ignored because of employment, fathers’ lack of knowledge and unfamiliarity regarding the system, and educators and professionals treating the mothers as the informants and collaborators.

4. Hear the voice of support providers. In all the interviews the parents noted that school personnel do not want to be a team, they do not communicate and give much needed information, are hostile because the parents do not speak fluent English, and are often considered as enemies by the families. This narrative is common in a lot of studies (Cho & Gannotti, 2005; Kalyanpur & Gowramma, 2007; Kalyanpur & Harry, 1997; Kalyanpur, Harry, & Skrtic, 2000) and this study revealed the same results. I would like to know from teachers and administrator’s perspectives why families make such a claim and what can be done to heal the hurt. I feel it is essential to hear the school personnel’s voices too and understand their situation too- the pressures of being a modern day school teacher/administrator. Or is it cultural barriers that impede the collaborative relationship between immigrant families and educators in the school setting?

### **Limitations**

**(a) Number of participants:** In this study only four parents were interviewed. Though there were only four participants, this limitation was overcome through deep interviews. Participants were allowed to narrate their experiences without me asking questions in between.

**(b) Same school district:** The personal narratives from first generation immigrant families with sons and daughters with disabilities highlighted the lack of formal support from schools and the lack of team work. It would be interesting to hear from families from other school districts to see if there are similar issues or not.

**(c) Support center connection:** As I recruited parents through a parent support center, the families interviewed assumed I represented the support center, even though I made it clear that I was a student from the University. But on the flip side, I felt the participants were more open and willing to share more. They were not suspicious or cautious.

**(d) Absence of the fathers' voice:** All the participants were mothers. There has always been a scarcity to fathers' voices and my hope was to hear their stories too.

### **Researcher Reflections**

*Do nothing from rivalry or conceit, but in humility count others more significant than yourselves. Let each of you look not only to his own interests, but also to the interests of others (Philippians 2:3-4)*

As I come to the close of this study, I want to pause and reflect on the journey undertaken. I am a first generation immigrant who arrived here with absolutely no experience in the field of disability. But as I was thrust into the field of special education and disability, I found myself enjoying every bit of my experience, learning from experts in the field, wanting more of what they had to share, hoping one day I will be part of their story too. When asked what I would like to pursue in this vast field that is progressing each day, my thoughts were immediately on the "families of sons and daughters with disabilities." I just love to hear their voice and so far have just done that. But now I feel it is time to flow out what I have been hearing.

My hope is that this study will reinforce what is being told all along by families- "thank you for taking time to hear us." Most times families are resilient, native families or immigrant families. They will find a way to support one another and receive support from one another. But most times they feel unheard, feel ignored, feel left out of all decision making. If they are the experts in regards to their child, why are they left out? Why is communication the last and the

least effort? Why is passing of information not a priority? That is what parents asked in this study. Especially if you are new to the country, especially if English is a daunting language to learn and understand, especially if you are not familiar with the computer, especially if you don't know anyone. Are we service providers in such a rush to provide the supports that we often forget to stop and talk to the beneficiaries of these services? Let us start with families and their sons and daughters with disabilities before we do anything else. If they have needs, we need to listen to them before we start becoming providers of these supports. Stop and wait for their counsel.

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## Appendix A

### Letter of Invitation

Dear Family Members:

I would like to invite you to participate in a research study. The purpose of this study is to understand the support needs of first generation immigrant families with sons and daughters with disabilities. Through this study my hope is that you get an opportunity to express your families' support needs and share your experiences as a parent of a son or daughter with disabilities in the US and the meaning you make of these experiences. You are asked to participate in this study because you are a first generation immigrant and a family member of a child with a disability.

If you agree to participate, the following things will happen: 1) participation in one 60 to 90 minute in-depth interview (seeking deep information and understanding) and 2) participation in one 30-minute interview to respond to the accuracy of themes that emerged. The focus of the in-depth interview will be on hearing the life stories of first generation immigrant families with children with disabilities, mainly their support needs in the US.

Participation in this study will assist in adding to the knowledge base than can inform the development of supports and policies for families with children with disabilities. Participation in this study will provide you an opportunity to narrate your stories that will hopefully help in the development and implementation of family-centered policies that meet the support needs of immigrant families. A long-range benefit of this line of work is that it might help to increase the availability of information and outreach services and at the same time encourage the provision of culturally appropriate supports.

All personal information is confidential and will not be shared with others. Real names will not be used and all participants will be assigned a pseudonym (fake name). Pseudonyms will be used in the reporting of results.

If you decide to participate in this study, please contact me via email at [gjacob01@unm.edu](mailto:gjacob01@unm.edu) or phone at (505)721-6670. Additional information regarding your consent to participate will be given to you through a consent form at the beginning of the interview. If you have questions or concerns, Prof. Ruth Luckasson, Chair of Special Education in the College of Education will be glad to answer them at (505)277-6510. If you would like to speak with someone other than the research team, regarding complaints or your rights as a participant, you may call the UNM Institutional Review Board (IRB) at (505)277-2644.

Sincerely,

George Jacob,  
Ph D Candidate,  
University of New Mexico, Albuquerque

## Appendix B

### Consent Form

#### **Exploring the Support Needs of First Generation Immigrant Families with Sons and Daughters with Disabilities through Qualitative Interviewing Consent to Participate in Research**

**Purpose of the study:** The purpose of this study is to understand the support needs of first generation immigrant families with sons and daughters with disabilities. Through this study you will get an opportunity to express your families' support needs and share your experiences as a parent of a son or daughter with disabilities in the US and the meaning you make of these experiences. You are asked to participate in this study because you are a first generation immigrant and a family member of a child with a disability.

This form will explain what to expect when joining the research, as well as the possible risks and benefits of participation. If you have any questions, please ask one of the study researchers.

**What you will do in the study:** Participation in this study will take a total of about 1.5 to 2 hours over a period of 6-9 months and involves two separate meetings. The first time involves a 60 to 90 minute interview held at a mutually agreeable location. The second is a follow up 30-minute interview to member check the themes (i.e., an opportunity to respond to the themes identified by the researcher) and can be used as a follow-up to the first interview to allow for greater elaboration and clarification of initial responses. Also participants will fill out a demographic form (verbally or written).

You may skip any question that makes you uncomfortable or stop the interview at any time. The interview will be digitally recorded. Each recorded interview will then be transcribed manually as a word document on my personal computer that is password protected. I will take notes on observations and thoughts that occur while conducting the interview. The transcripts and notes will be stored in a locked filing cabinet in my office.

**Risks:** There are potential risks of stress, emotional distress, inconvenience, and possible loss of privacy and confidentiality associated with participating in a research study.

Interviews on certain topics might arouse powerful emotions causing distress. The narrative may provoke feelings of loss and grief, anger, causing the interviewee to become too overwhelmed to carry on with the interview. As a participant, you will retain considerable control over the process and can stop the interview if it becomes too painful to talk about the topic.

Every effort will be made to minimize the loss of privacy through the use of pseudonyms on all materials including the results of the study. The risk will be minimized through scrupulous attention to record handling and the concealing of identifying information so as to minimize the chances of linking specific records with specific persons.

**Benefits:** Interviews allow participants to express their inner thoughts and feelings providing a sense of emotional relief. Many participants, after qualitative interviews, have reported increased self-esteem, feeling of adequacy, and a sense of being heard. In addition, telling one's story and feeling heard can often be empowering and able to use one's own voice and create changes creates a sense of empowerment.

Participation in this study will assist in adding to the knowledge base than can inform the development of supports and policies for families with children with disabilities. Participation in this study will provide you an opportunity to narrate your stories that will hopefully help in the development and implementation of family-centered policies that meet the support needs of immigrant families. The study can assist in increasing the availability of information and outreach services and at the same time encourage the provision of culturally appropriate supports.

**Payment:** You will not be paid for participating in this study.

**Right to withdraw from the study:** Your participation in this study is completely voluntary. You have the right to choose not to participate at any point in this study without penalty. You may withdraw participation in writing via email or personal contact by phone or in person. If you withdraw from the study no data gathered will be used for the research. The digital file of the interview will be destroyed.

As the researcher I will take measures to protect the security of all your personal information, but I cannot guarantee confidentiality of all study data. The University of New Mexico Institutional Review Board (IRB) that oversees human subject research may be permitted to access your records. Your name will not be used in any published reports about this study.

If you decide to participate in this study, please contact me via email at [gjacob01@unm.edu](mailto:gjacob01@unm.edu) or phone at (505)721-6670. Additional information regarding your consent to participate will be given to you through a consent form at the beginning of the interview. If you have questions or concerns, Prof. Ruth Luckasson, Chair of Special Education in the College of Education will be glad to answer them at (505)277-6510. If you would like to speak with someone other than the research team, regarding complaints or your rights as a participant, you may call the UNM Institutional Review Board (IRB) at (505)277-2644 or email them at the address: [irbmaincampus@unm.edu](mailto:irbmaincampus@unm.edu). Website: <http://irb.unm.edu/>

**CONSENT**

You are making a decision whether to participate in this study. Your signature below indicates that you have read this form (or the form was read to you) and that all questions have been answered to your satisfaction. By signing the consent form, you are not waiving any of your legal rights as a research participant. A copy of this consent form will be provided to you.

I agree to participate in this study.

_____	_____	_____
Name of Adult Participant	Signature of Adult Participant	Date
Researcher signature (to be completed at the time of informed consent)		

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

_____	_____	_____
Name of the Researcher	Signature of Researcher	Date

## Appendix C

### Main Interview Questions

#### **1. Introduction: Sharing your life history (Goal: in order to understand the meaning the families are making of their current experiences in regards to support needs)**

- (a) Please tell me about your early life-you were born in...?"
- (b) Can you share your and your families' experiences at your home country?

#### **2. The details of your present lived experiences (not opinions but rather the details of the participants' experiences)**

- (a) Please tell me about your needs related to having a child with a disability?
- (b) What do you need most help with?
- (c) What kinds of help do you receive currently?
- (d) What kinds of supports are you aware of here in the United States?
- (e) How have you been able to access these supports?
- (f) In the community, who provides you with most supports?
- (g) What areas do you still need help in?
- (h) What are your concerns, worries, and challenges in relation to your son/daughter?

#### **3. Reflecting on their experiences and meaning they make of these experiences**

- (a) Looking back on your experiences here, how does life in the US compare to life back home?
- (b) What things you would like to change here?
- (c) Which supports do you wish were easily available?
- (d) What advice would you give to other first generation immigrant families with children with disabilities?

## **Appendix D**

### **Demographic Information**

1. Which is your home country?
2. What is your primary language?
3. When did you and your family move here to the United States?
4. Who are the members of your family?
5. Do you have any of your extended family members (e.g., child's grandparents, uncle, aunt) living with you or close by?
6. Was your child with disabilities born before you moved to the United States or after you settled here?
7. The age of your child?
8. The disability eligibility criteria (e.g., intellectual disability, autism, specific learning disability)?
9. Highest educational degree you have earned?

## **Appendix E**

### **Portraits**

The purpose of this qualitative study was to explore the support needs of first generation immigrant families with children with disabilities. I, as the researcher, believed that, as there is little literature on the experiences of first generation immigrant families caring for children with disabilities and given the growing number of first generation immigrant families in the United States, a better understanding of their support needs can inform policy makers and service providers in the development of supports and policies for families with sons and daughters with disabilities. This appendix presents the voices of four first generation immigrant families, a portrait of their lives. My hope is that each of the portraits capture the richness, complexity, and dimensionality of human experience as mentioned by Golsteijn and Wright (2013). As suggested by these authors, these portraits include large, verbatim chunks of interview data, documenting “their voices and visions- their authority, knowledge, and wisdom” (p. 308).

According to Lawrence-Lightfoot (2005), for the creation of a portrait, the data must be scrutinized carefully, searching for the story line that emerges from the material. The author noted that there will be many stories that can be told, not just one from each interview, and so the portraitist is active in selecting the themes that will be used to tell the story, strategic in deciding on points of focus and emphasis, and creative in defining the sequence and rhythm of the narrative. My hope is that these portraits will be a window to their lives, opening up the lives of the four immigrant families- their hopes, worries, anger, joys, and regrets, and their emotional and physical needs. I chose to present the data as portraits because I am optimistic that the narratives will speak to each reader- may the portraits speak for themselves and create a lasting impression in the reader. And, based on the readers’ experiences and paradigm, my confidence is

themes will develop in his or her their mind and propel the person into action- wanting to do something, wanting to make a change, and wanting to speak up for immigrant families with children with disabilities.

### **Portrait 1: Portrait of Erica and her family**

#### **Overview**

My first interview was with a single mother, Erica, who came from Mexico to the US when she was 12 years old. Her primary language is Spanish. Erica reported that she did not have any extended family here in the US. Her daughter, Rebecca has intellectual disability and is diagnosed with autism and dyslexia and was born in the US. She is currently 9 years old. Erica has not gone to any school in Mexico nor here in the United States. When asked if Erica had family here she reported “after my husband knew that my daughter was autistic, he told me that in his family they don’t have that “dumb people” and so he decided to divorce me and blame me that the disability she has is because of my fault.”

#### **The Beginning: Early Life of Erica**

Erica described her early life experience in Mexico and the United States as:

We were three sisters, my dad, he was an alcoholic. And I never went to school in Mexico. My Mom sent me to sell food or to ask for money in the streets. And I grew up like that till I was twelve years old. After that my Mom decided to sell me to one man, to here to the United States. And I went to that house when it was summer. When I get out of the house it was winter. Men came in and came out from the room. And I always wanted to remember everything. And they told me “no” to block whatever had happened. I went back to Mexico and when I found my Mom I thought she will be happy to see me. But she was mad and she beat me and she told me how you got out from there. And I told

I escaped. And...she sold me again and I come back again to the United States. I decided I don't want to live in the same way I was living after all. So, I escaped again, I don't know how long I stayed there. But I decided not to go back to my country, and I decided not to go back to my family anymore.

Regarding her early life in the United States, Erica narrated:

I started going to the fields. And I was trying to look for older people than me because I knew I couldn't take care of myself. So, I was living in the streets for three years. So, I have I think lots of experience on how to survive. And I think that helped me a lot because I was trying to help the older people, like help them to pick up onions and that way they could see that I was a good worker, I was a good kid. And that way they can take me to their homes and take me back and forth. So most of my life I was living with people I never knew. Because people who works in the fields move from one country to another. And I lived like that till I grew up to be twenty years. And then I have my older daughter when I was twenty-six.

Erica narrated how she had her first daughter and the challenges she faced:

I found this man, I meet this man older than me. So I thought, well he is older and he is going to take care of me, and....I was wrong. Things go bad. My daughter born one way that she is not supposed to. He beat me a lot and he raped me too many times till I get pregnant. He always say "I am going to sent you to your country, I am going to take the kid from you," till he called the police- he knew I was scared of the police. So, he called the police. He slapped me because of what I did one day and I got tired. I said, "You know what, take me to wherever you want-my country, to police station, to immigration- I don't care." But if he left me here he wants to kill me. Because I was not able to get off

from the house. He counted the cans, he count the milk, he mark the milk, he mark the juice, he count everything because he don't let me do nothing. And, I was pregnant and I want to eat, so most of the argument we have that was because of him miss food from the house. But it was because I was hungry. Till I found a way- I decided to put water-I want to drink milk-I put water to the milk. But of course, he found out. So, after we, the police found everything that was going on in the house, he took me to the shelter. And I stay there till I have my daughter. And I became resident of the United States because of the abuse I found with him. And after that I learned a lot- how to use a credit card, for what was the social security number, because I thought the number was just for work. And they teach me, they teach me a lot of things. So when I get out of that place I was feeling stronger. So I start working. I put my daughter in a daycare. And I became an independent person.

Erica continued her narrative:

After that I meet this man- the father of Rebecca. And we were living for 4 years together. And then I decided to get married with him because he didn't have papers. And after he found that Rebecca was autistic he said "you know what, I just was waiting this couple of months because I need my residency but I don't want to stay here with you. I just married you for the resident." And he said "Well, you came from one place and you don't have education, you don't have family. So, I think Rebecca is autistic because of your fault."

In summary to her early life experience Erica noted:

So, life to me to be in this country was very difficult. But at the same time, I feel very blessed. Because my kids, they are not living that life I was living in Mexico. And they

are not living the life I live here in the United States. My oldest daughter I have is 18 years old- she is going to college. And I do everything for Rebecca. And like I told you- the minimum thing she learns I feel so proud.

### **The Middle: Present Challenges**

#### **The School System and My Rights**

Regarding her present challenges, Erica spent a major portion of the narrative describing her struggles with the professionals at the school. She explained:

And I know they still have a lot to work with her. And of course, I found a lot of things at school that they don't do what they have to do. And I knew, but I didn't know my rights. And when I found this Parent Support Group, they give me a book. I can speak English and read, but I have more problems to write. So, I found out the rights of the kids and rights of the parents. And when I found out I said "Oh my God, there is a lot of things that are wrong in the school." So when I went to school I said "you know what, I think this is wrong." But they say "no, this is the way things work here."

Erica continued:

And then I go back home and I read the book and I say "no, no, no, no." I did not understand wrong. This is right. So, I decided to talk with the teacher and with the principal on all the stuff from school. And I told them "you know what I need an IEP." And they say why you want an IEP. Well, because there is a lot of things that I have proof. But they are not right. I said "I have all these kind of papers you are sending home that say that you are putting Rebecca in the wall because she is not focused and because sometimes she talks a lot." And I tell them from what I understand here you are working with special kids. You have to know that these are some of the characteristics of an

autistic kid. And I told them okay, “if you are in the chair for 8 hours how you feel if you are in front of the computer. You don’t have a disability how you want to feel. Of course, you want to try to get up, maybe to drink a cup of water, I don’t know. So that is what Rebecca needs- she needs a break.” But they say “no” because she is not the only one. And I told them “Just wait! I have read here that she has the right for individual education.” So, I told them I want an IEP.

Regarding her continual struggles with the school system Erica continued:

And I ask them I want interpreter. And they say “no, we do not have anybody to interpret.” And I say I read here, that I have the right, that you have to provide me with somebody to speak in my own language because there are a lot of things. I can understand a lot but I want to soak myself of all this information because they are very important for me. So, I have the right. And after six months they told me “no, we don’t have nobody.” And I told them “you don’t have nobody” and they said “no, we don’t have money to pay somebody.” And I said, “you know what, I waited six months for this, I really need the IEP. You have nobody else...you don’t have a teacher. Okay, I hope that teacher will stay with me till the end of the IEP.” And they say, don’t worry, the IEP will only take forty minutes. And I say “okay that is fine,” but I knew that the IEP will not take forty minutes. No, because there is a lot of things I want to discuss with them. And that took us 4 hours. And after 4 hours they said “well, we are going to stop the IEP, because the teacher has something else to do.” I said, “No, I am not here waiting for you for six months. When I ask you for some professional person who be interpreting each word of what you say and each word of what I am saying- when you bring me a teacher, yes, I appreciate her that she be here. But you can see that she was asking me or she was

asking somebody else about one word because she is not a professional. When I know they have the right. And you told me that “well, we don’t have money, we don’t have money.” Okay you don’t have money but I hope that you have time to finish this IEP.

Erica continued telling me her concerns with the school. She noted that there were not enough staff to help the students in the classroom. She said:

I told them, “It is okay, look you feel uncomfortable with me because I am here saying this is what I want for my daughter, this is what my daughter needs, these are the rights of my daughter. You only have got away with one parent who came here and tell you the rights, to remind you of the rights of my daughter. How you want to feel when you have thirteen parents here asking you for the same thing like I am asking you. You want to feel crazy, okay you know what, somebody have to do something and I talk to the principal and I think you have to be pushing the button in the principal office. I said “because you are the principal, you have to see this teacher have a lot of work with 13 kids. And with just two persons who is helping him. So, that took me six months and I have to take them all the proofs I have, write everything. You can see, here..... (shows me the documentation she has been collecting).

### **How it Started**

Rebecca, when they found this to Rebecca, they found when she was 3 years old. But before that Rebecca was able to walk, to speak, to put some clothes on, to eat by herself. She was, we can say, a normal kid. But after a couple of years I started noticing, I was talking to her and she don’t hear me. So I thought she has a problem with her ears. But no, they tell me she is fine. And I started noticing she was not focused. So I started taking her to the doctors and the doctors say, “no, something else with her.” They sent me to the

big City (it takes more than 3 hours by car to reach the City) and they said, “well you have to wait....,we have waiting list for one year.” So I started calling them. And I was calling two or three times a week to the lady from the office. She knew who I was (started laughing), so they called me, you know what, after six months. In six months Rebecca was not able to walk, she was not able to speak, she was not able to eat by herself. If she eats something she was just grabbing whatever she found. And she started eating whatever she found. It doesn’t matter- animals, anything, anything. And, when I went to the big City it was crazy because it was like you have a kid who know how to do everything and then in six months she was not able to do anything. When they told me she is autistic, the first words that came out of my mouth was “what is that.” (Pause). Because I did not know. And I told them, “I don’t care what she has. I don’t care what you told me, I know that she going to do what she knew to do before.” And I asked them if she can learn again? And they say, “yes, but it is going to be with a lot of therapy, and it has to be very often,....you have to remind her of everything, everything, everything, everything. So, when I came here I started looking for help- office and people who can help her. And..... I still remember the name of the first therapist that she had- Anna. And she told me, “I want to be here for 1 hour. But 1 hour is not enough for her. You have to be doing everything and talking to her every moment. And, don’t treat her different. You have to treat her like the other kids. She can do a lot of things.”

Erica continued her narrative:

She was not able to grab one cup, she was not able to grab nothing. That was like her mind, that was like somebody wash her mind- she just was like that. And she started beating herself and screaming and I did not know why she was doing that. And I say,

because she is starting to feel frustrated and she started rocking a lot. So, for me that was a lot, because coming from this kind of life I had before and then to see one kid like that and then the divorce came with no job, that was *too much* for me. A lot, a lot. But when I start looking that Rebecca have an interest to learn and every time that she do something, every time she learn something we always make like a party for her, like, “Yea Rebecca, she did it” and she start making some noises and make big eyes and faces-very happy. So we started notice she start having expressions because she had lost her expressions too. And with time she started speaking and then she started smiling and then she started trying to speak with other kids. But that took us years.

Struggles with the school came back into the narrative. Erica explained:

And then when I went to school, you can see, just because she was talking with somebody else they put her facing the wall. And I told them something like, “we have lot of years working for this and now you are punishing her for talking, when we are working, you know, teaching her how to socialize.” Yeah, that was part, one of her therapy. So, I had to explain them everything, how Rebecca came, how she stop walking and eating. And I told them “she can do a lot of things, maybe you not can see it, maybe you just see she just sit, or she just look you and smile and talking and you say, well, she is smiling a lot, she is talking a lot, she is not focused, but it is part of Rebecca, that is part of the disability that she has. Why are you punishing my daughter with something she knows how to do? The only thing that we have to do is explain her, like the way I explain her- “You know what, it is not the time to be doing what you are doing-let us wait.” And they told me, “well, how you do it and that way we can do it,” but when they ask me that they ask me that like sarcastic. Like, “okay how you do it. Because *now* you

have to teach us how to do it.” And I told them “you know what, the professionals are you guys and the mother is me. I know my daughter and like professionals, I think I don’t know how school works, I don’t know, I don’t know nothing about school. Like, I am not going to put myself in one level like you guys are. I don’t have a title. I don’t have nothing. I just have the feeling like any mother can have.” And I think, .....and I told them I am not come here to make a war. I am not here to make a war. I came here because I want we work like a team. And a team for me works, work together. So that is what I want. I want that we work together. The same way I work all these years with all those therapists and we finally....Rebecca learns a lot. That is what *I want*.

### **Physical and Emotional Challenges**

Regarding Erica’s support needs in having a child with a disability, Erica explained:

I was looking for somebody to take care of Rebecca. So, I went to this place where I was working before. And the owner was there. And he said, “Oh, you came back to work,” and I told him “No, I am looking for somebody to take care of my daughter.” And I have my daughter with me. And he said, “why, just put her in a daycare and come to work for me.” And I told him, “no, because she has this disability.” And he said, “I didn’t know that you have a special kid.” And he say “you know what, go with the manager, tell him that I send you and tell him to work with your schedule”- because Rebecca have a lot of therapies at that time. So, I asked him “really. So, I started working for him. And they gave me permission and they know the permission I get is just for Rebecca. And I work Saturdays. A lot of people don’t like to work Saturdays. But I work Saturdays because I need the days in the middle of the week.

Erica continued her narrative:

So, it is like always, you always are going to find somebody to bother you. So, that was this lady who was saying, well, saying things about me. And I talked to the other ladies, “you know what, don’t tell me nothing. If she has something to say to me, she can talk to the boss or she can tell me.” And she started saying a lot of things about me. Anyway, one day I noticed Rebecca in the morning, that she didn’t feel good. I see her eyes, I see her face, you know what, something is wrong. But I have to work, I took her to school and I go back to work maybe like 10 o’clock. And when I passed close to the lady I told her “good morning”- like always I say good morning. And she say “good morning...good night.” And I looked at her and told her, “no, good morning” and she say “no, good night- if I had a dumb daughter like you have, I can come at the time you have any day and anytime. And when she said that I was feeling like...till now I don’t know what I felt. I was feeling like, mad and sad, and when she said that, that was like my body and my mind froze (laughs). But after a while I have a bad reaction. And I say bad reaction, because I go back to where she was, and I beat her. And when I say “I beat her,” I beat her (laughs). But I was so mad and I tell her “you know what, you not, never ever going to say nothing bad about my daughter. You don’t know nothing about her, you don’t know nothing about me.” But I was so mad and I was keep beating her and beating her till somebody pick me up. And I almost lost my job for that. And that is something that I learned. That like, parents we have to control ourselves. But sometimes like humans, we care a lot.

And by the time that happened they called us to the office and told me that somebody was in the front is asking for me. And when I went there, there was the therapist. At school Rebecca had an attack over there. So, I was feeling like, lost.

Because, leaving my daughter at school, knowing and seeing her that she was not feeling good and then going back to work and did what I did and then to find, know that she was at the hospital. I was feeling so guilty and I was starting to feel that I am not doing nothing right. So, having a special kids, we carry a lot of feelings and sometimes we feel guilty. Because we feel that we don't do enough for the kids. I feel sometimes in that way- I don't do enough for Rebecca, I don't give her enough time. I would like to be with her [starts crying] and I would like to take her to school every morning and I would like to take her to therapy, but I cannot do it because I have to work. And to be a single mom and to be like, what I am, I am having no education, I always get the minimum wage- I never have the hope to say, well, this week I want to get more money or get a raise. I don't apply for food stamps because they say I make a lot of money. So, sometimes I have enough and sometimes I have not.

Continuing on her support needs, Erica noted:

I apply for social security for Rebecca. That helped me a lot. But it is hard. And, like I said, to be a single mom with a special kid is a lot. Because sometimes you don't have nobody to talk to the person, who is supposed to be with you, or with your kids, saying "I understand you, I feel the same way as you. Don't worry, we going to do it together." So, it is like my elder daughter say, "you are very strong, mom, you, for the kind of life you had, I never see you take drug, I never see you do nothing like that." So, she say "you can do it." And I say, "yes, I can do it." Though, sometimes when, you are the head of your family, you have to be the example, you have to be the stronger. And.....your kids, they look like that, you are very strong, you know everything, like, everything what you do, everything that you do is right. But it is not. I am not that strong. I have my moments and

when I feel like the way I feel now [crying] I just tell my kids I am tired, I am going to take a shower and I take a shower and I cry a lot. Because it is a lot of responsibility. Sometimes I don't have enough money-like now I don't have any insurance for my truck and I have to take Rebecca to the City next month for two appointments. So it is like- I feel sometimes frustrated because, at work we don't have enough hours. We have other years that work goes down but not like this year. This year it is a lot, so it is hard, it is very hard, it is very hard. And more, when you don't have the information. And I told my older daughter, "go to school. It is the only way you want to defend yourself and you know your rights. Because I didn't know the rights Rebecca have, I didn't know my rights.

Also, on Erica's dreams on education she said, "My biggest dreams is to go to school. And I try but when Rebecca came and everything stop."

### **Parents Supporting Each Other**

If I didn't be in that group-Parent Support Group, I still will be thinking like, "Oh, I don't like the way they are treating my daughter but what can I do." But now I feel like the same way when I came to this country, when they teach me these are your rights. Like, if you are in the wheelchair, always you are going to be in that chair and you not going to be moved, because you don't know you can move from the chair. But after you know your rights, you have that feeling, you have that anger to get up and say, "you know what, that is it. No more."

So, that happened in my life when I know my rights here. And this is what happened with Rebecca now that I know her rights. Of course, I don't know everything because I am still learning. And it is hard, it is hard because I am a single mom, I have to

take her to the therapies, I have to take my son to the practice, because of course they have other things to do, I have to work. I have too many things, pay bills, groceries. And I still try to give time to be with this group and to learn. Because I need to *learn*, to know more on how to help Rebecca. And I feel very proud to be in that group. Because I came here, you came here, the parents and everybody have their own cross, Cross? - and like you are carrying something....And sometimes you grab that cross, you put it down and you rest for a little while and when you see that cross again you just put it back again. And when I say cross, it is not our kids. It is the whole problem that we have. It is the whole problem because....I am more than sure you have problems. Everybody have problems. And you have to go to school, you have to give 100% for your own benefit. If you have a problem you have to have that faith, you know, that nothing happens, nothing wrong. But when you are by yourself, you feel sad. Because there is so much.

So, I learned a lot through the parents. And I thought it was me, I thought it was me who is weak. The way I feel this way, "I am so weak." And "no," all the parents-you can see a group of parents and everybody is happy and we are smiling and happy to see each other and happy to see other kids. But it is like, like a mirror. It is like you looking yourself. You look the other people and you look, "well, she is me." So, if she is me that means that she has problems too. And I have to take care her, because I have problems and I would like that somebody came and do something for me or say, "you look good" or "you can do it." So, we do that, and not because we have that in our paper, but because we have that feeling that we have to help each other.

## **The End: Hope for the Future**

### **Determination Amidst the Challenges**

And I have cancer and I lost my hair, I lost my everything, I lost my house, I lost everything. So it is a lot when you know you are a single parent, that you have a special kid and you have to get up, you have to keep going and keep going. You not going to stop. Because you not going to be in this life, for the rest of their lives. We are going to die and we have to prepare them to be a good person and to defend themselves. And to learn, they have to learn. We are here to teach them how to learn. And because one day they are going to be by themselves. And something I would like to see is that, that socially people look them as what they are- they are persons, they are not dumbs. They do learn different. And they learn slow, because I told my daughter, she knows- she is 9 years old and she knows she is autistic. When I went to the office of social security, when I went to apply, they asked me what disability does she have. And I tell them- and at that time she was able to talk a little bit- and she asked me, when we get out of the office she asked me, “mom, what mean autistic.” And when she ask me that she asked me with a lot of difficulty. And when she say that, when she ask me that, I didn’t know what to say to her. Because I never thought that her mind want to retain something like that. So I told her, “autistic means a very special person who learns everything what they want to learn. But, they learn different. You learn different, you learn more slowly, take more time for you. But that doesn’t mean you cannot do it.” Until now she knows that she is autistic. You ask her, “what does it mean autistic,” and she say, “O, it is a beautiful person who learn whatever they want, but different. It is slow but I can do it.” That is something that she has in her mind.

With the challenges Erica and her family is facing, her focus is on helping other families with children with disabilities. She said:

We are trying to have an office here, and the City Support Group tells us that they can help us, they can give us the training, they can train us to be leaders and to have an office and to help parents with questions or how to tell the parents, “you have the right to do this,” or “you can go to this office, you can apply there.” And I think that is one of the biggest dream I have. I would like to help other parents.

Because it is not just a support group, it is for legal information- where the people can get. And the word “ignorant” comes from- is because you don’t know your rights. So, if you don’t know, you never going to do something because we ignore that. But, if you know something you going to do what you have to do about the rights that you know you have. So that is something that we are trying to do, to have an office. And every time they send help, send us help to give us information I am in those meetings and I learn a lot. And important of this is that it is in Spanish. Because it is a lot of people that they don’t go to the meetings because they say “well, I don’t speak English” or “I don’t understand nothing.” So I think that is the reason parents, they don’t show up at schools because they don’t know, they don’t their rights because they don’t know how to read, they don’t know how to write, they don’t understand. But if we have a group in Spanish, I am more than sure that we can have a big office and a big group (laughs loudly). And yes, that is one of my goals, I would like to be a leader.

### **Needs of the Family**

When asked about the needs of the family, Erica responded:

To have doctors!! Doctors, because we don't have doctors for the kids. We have to go to the City. I would like to call the attentions to the State and say, "you know what, we need money, we need doctors, we need more help here because there is a lot of necessity. But they are not going to see it because, a lot of people, they don't speak English. Everybody is going to the City, to the City. But if you have the information here legally, we hope we can have doctors.

More therapists because, here the services are till six years old- the service till six years old. But if we have a kid, let's say, that they start showing signs of autism after four, after five years you just going to have one year with them. If that kid is like Rebecca then everything disappear.

Evaluations, Rebecca has to go to take one evaluation to the City. So each evaluation that they take we have to go over there. And we would like to have that here. And it is a lot of people, I never thought, I never thought till now and parents-rich parents, I never thought that there was so many people with special kids. And the thing is that these people, they don't speak English. That is the reason I think nobody knows that we are here.

Regarding her experience with support groups Erica stated:

So, for families,.....we have a support group, it is support for parents with special kids. And I started going there. And that help you. Because you can hear the problems of other people. But I started feeling like "locked," because I thought, "okay, we have all these kinds of problems, but we are still in the same," -it is like in a circle, in a circle, in a circle. "Well, they don't do this to the kids, the schools, oh, we don't have enough help-economic help, or we don't have enough doctors." And I start feeling like locked. And I

am not that kind of person. I came from the streets, so street help, teach you a lot- how to solve problems. And teach you how to be not angry but angry with life. Like, the street push you to keep going- it is like I am not going to stop because I don't have a choice. And I start thinking well, there has to be something else. I was thinking to myself. And I was thinking, the support group, all the support groups are in English. They don't have any Spanish. So, I thought there has to be something else. And, I don't know nothing about computers. If you told me "go and look here," forget it. I don't know nothing. So I started thinking and thinking there has to be something else.

Then one friend told me, I have a friend and she have a special kid. And she..., and I told, "Oh, I know a lot of people with special kids but everybody speaks English. And we speak of the same things and I don't see, like we don't resolve nothing because we don't have help." And she said that she knows somebody from the City, that is this group. She said, "let me give you her phone number and you can talk with her." So, when she told me that she say, "we get together, we talk about certain things and somebody else came from the City." The first question that came from me was "do you guys resolve anything- what kind of help." And she said, "well, it is in Spanish and they taught us our rights." And I told her, "our rights." And I told her we are not going to be sitting there and talking about our problems. And she said, "Well, it is our problems, but legally." And when she said "legally," I said, "okay, I want to be there." (laughs). Yeah, because if you don't know, it is like saying, "I am hungry, I am hungry, I am hungry." Yes, you are hungry, but you don't get up and start looking for something to eat you still going to be the same thing.

Erica's advice to other first generation immigrant families is:

**We have rights.** That is the first thing I would like to tell them. Our group is not just a group for support-parent support. It is not just that. It is a group from legal, legal information. Because, if you don't know your rights you never going to know what you can do.

### **Concluding Words: Hope**

I feel that if we keep going with this group we can do it. And for me when they told me that you want to come, they told me "but he speaks English, he don't speak Spanish. My group is in Spanish. And I tell them, "yes, I want to go." And everybody was laughing because they say, "there has to be Erica"- yes there has to be me. Because I am not ashamed of nothing. That is something that teach you. You not going to be shamed, no way. So, for me to be here with you, I hope, like I tell you, I hope somebody can hear this and to see the necessity that we have here-like the parents. And maybe we will be like the Parent Support Group, I know the group came from two parents- two mothers. And that did not come easy. That did not come that easy.

So nothing is easy in this life. And maybe they don't see what the group is now. So that is the same thing. Maybe I am not going to see a big office. Maybe I am not going to see there is a lot of doctors here. But it is the other people who can see it. And I would like to be working for these kids and why not maybe for the other ones who came. If I don't see it that is fine. But I would like to help to help a little bit. Because if you are here because for your school, you are here for us too. You are helping us. Because this information you want to take it to other places and maybe one place we cannot reach but you can do it. And I am sure that you are going to do it. So, you are helping us. I am just so happy you are here. I really appreciate that you came here.

I would like to have more time for my daughter. Being a single mom is difficult, difficult, but we can do it, we can do it. I don't know if you have heard this: If something that not kill you will make you strong.

## **Portrait 2: Portrait of Veronica and her family**

### **Overview**

My second interview was with Veronica. She came from Mexico to the United States when she was 16 years old along with her parents and extended family. She is living with her husband and three children. Her extended family (parents and sister) is also close by. Veronica's primary language is Spanish. Her daughter has been identified as having cerebral palsy (speech impairment/ developmental delay) and she is 18 years old. Veronica's education background is high school, two years college, and attended massage school. She works currently as a massage therapist.

### **The Beginning: Early Life of Veronica**

On her early years in Mexico and coming to the United States, Veronica noted:

I was a worker child. I worked at a very early age. My dad, he always had a business at the home and I usually worked with him at his business, pretty much. I went to elementary- I finished elementary and I did a training career in computers there. And when I graduated from the computers I went to California with my grandma. So, I lived there for six years and met my husband there, and we got married. And my older boy, he was born in California. Then we moved here.

It was good in Mexico. I miss those times. It was lot of work but we were a family, you know. I moved to Los Angeles because I want to learn English. That is why I

moved with my grandma to Los Angeles. Then I like it here and I got used to- you know, it is totally different life. So, I started working. And I went to high school for a year and I didn't like it. Because I find out from my village to big city like Los Angeles, another world. So, I feel myself kind of lost. And alone. I feel like this is not a place for me. I didn't feel like I was learning what I was supposed to. Well, I had an idea I can learn English in six months (laughs). And I don't see that was happening so I told my grandma, "no, I have to get out, I have to leave the school and I want to work." Because I am used to work. So, that is what I did. I started working and then I have been learning English pretty much talking with people more than in school. That is interesting-wow. That is why my English is not too good as well (laughs). It is not very good at all. But, reading books, that is the way I learn more. So, when I went to college, the same thing. I went to college for a year and a half- almost two years. But it was the same thing- I didn't feel comfortable with the teachers. Or maybe it is the problem that I had. And I don't learn from the teachers, I don't know. Or in a school base, but I pretty much learn what I know reading and talking with people (laughs), it is weird (laughs).

### **The Middle: Present Challenges and Needs of the Family**

Regarding the family's challenges and needs, Veronica stated:

My needs- it's (pause and sighs).....it's, (pause), I don't know how can I say it. That it's opposite feelings. They are opposite.....it is weird. Because I think my daughter is a big blessing for me, to our family, to the whole family- especially my husband, my kids- my two older boys. And then when she came, with the heart problems, (pause), it changed our lives-forever, (laughs) in all sense. But, it is a lot of work. It is a lot of worries. It's

challenges every day. But- I love it. I enjoy it. I don't see my life without doing what I am doing for her.

We need more help. I think, medical information on the disabilities. And, schooling. And school- I think we need a lot of help and support in schools. Because, with my own experience at schools- she is in 12<sup>th</sup> grade right now. She is a senior. She will graduate this year. But all her academic time in school- I don't think it is being fair and justice for her. I don't think she's been receiving what she deserves, what she needs. And her needs become my needs too. And it is very frustrating when you go and ask for help and they just close the door and say "no, we cannot do this. We cannot do this." Always denying the services. When you know there is your child's needs. So, I started fighting with them. Meetings, meetings, meetings, talk, talk, talk, raise the voice. That is the only way I find out more help from them.

But it is- there is a lot of needs here. We need more information. Especially in our language. Because it is almost nothing. Even though when we request a translator, they say they don't have it. We need the law. It is the regulation. We should receive the help. All meetings in our native language. So, they deny sometimes. This is one of the principal needs. You know, if we don't have good communication, how we going to help this kid, how we going to improve as parents and teachers and make a good team to work for this kid.

### **Medical Services**

For specialist we have to go to the big City all the time. If not that City, another City which is in another State. That is something that is a big necessity- we can have more specialists here. Because to see a good specialist, to see a good clinic or specialty, in

medical we have to travel to the City, which is 3 hours and 3 hours one way. And before we can go to the City in the other State, but with Medicaid rules, policies, we can't. They are another State and are not accepting Medicaid there from our State. So, now the only choice we have is for us to go to the City which is more than 3 hours away. Like my daughter, she has cardiologist in the City. For everything we have to go there. So, I had to find another orthopedic here-orthopedic doctor. He is not specialized in kids and he is not specialized with kids with disability. He is a regular orthopedic doctor. Right, but it is the choice I have here. So I took, I like it anyways, I like it, he is working with my daughter. And I stay here. But cardiologists, is still in the City. My daughter has, she needs jaw correction surgery and the surgeon is in the City. So, every time we have to travel there to see the specialist.

### **Informational Needs**

I go and ask, and then receive the information. But I have to go and ask. You know, nobody tells you, "Yea, you can go to this agency for this or that and we are kind of lost and lonely, every family. I feel that way many years until, when my daughter was in high school, I have lot of issues with the public schools. Because I started to know more and more of my rights and her rights. And when I started asking for those rights and services, they deny it. Then I started looking for supports. And 2015, I went to a conference in the City from Parent Support Group. And there my eyes were opened (laughs). They helped me to open my eyes, when I know more rights, more services.

I didn't know much; no. I didn't know DVR. I knew DD Waiver program from the social worker but not from the school, not from the medical.....right. So, I had to find out this from the agency where I find out about DD waiver program. Otherwise nobody

told me in the school or medical-doctors, hospitals, no one told me. Also, right now we started this group- Parent Support Group here two years ago. Now we have support for families- each other, from this group. But before, no, I never hear anything about any support group or program.

### **Main Concern Right Now**

Veronica talked about her main concerns in detail- Guardianship and the School System. She said:

My daughter is now in the transition from child to adult life. We have to look to the guardianship for her. And, the lawyers, what they charge just to do the paperwork and to be in the court for 10 to 15 minutes- I think that is the longest, that is what I hear from other parents- is the longest they be in the court, they charge too ridiculous. So expensive. I have been calling from the list, the list I found out online, and also from references from other parents- they charge from 3000 to 5000 dollars to do that. I mean, that is something we really need. Right!! The guardianships of our kids. And we have to have that money, because the guardianship program they have in the City, the waiting list is 18 months or more. And we cannot apply until the kid is 17 ½ years old. So, we have six months to get the guardianship for our kids, but the waiting list is 18 months or more. It's ridiculous.

So, we have to wait all that time to be legally guardians of our kids. If we wanted not to wait, we have to pay from 3000 to 5000 dollars. If we pay it is faster, you can be legally guardian of your child when they turn 18. And, I think we need more support on that. The agency needs more budget to move the processes faster. And oh, I don't know, do something else, like get more lawyers involved in the programs so we can go faster in the list. Because it is ridiculous, we cannot take a decision for our kids until we are

guardians, legal guardians. And to be guardians we have to wait so long. I will just say start saving money. And the interesting thing is, many parents, many families, as we find out, they don't know about the guardianship. They don't know yet. And what I tell them is start saving now. When your kid is fourteen, when your kid is ten, because when they are going to turn 18 you are going to have money already in the pocket. Because this is the only way you are going to get the guardianship fast. And what I understand is they will pay only part of the money. So anyway, we need to have the savings. And many families don't know about it. I always tell them-"do you know about the DD waiver program; do you know about guardianship when your child turns eighteen, because you need to know, (laughs) be prepared ahead of time. Yeah, many parents.

I knew another friend, her child, they moved from another State here, and her child was 20.....20 some years old. And they did not know about the DD Waiver. And they were living here already for 5 years. And they didn't know about it. So sad, because the waiting list also, to get into the DD Waiver is more than 10 years. Ten years!!! The school never told me about it. The school, did not tell about it. And I knew other parents who say, "what's that." From the Support Group I learned about our rights, basically we focus on the IEP's, and to know our rights, and parent's laws, and group support.

### **The School System and Our Rights**

Regarding her challenges with the school system, Veronica, just like Erica spent a major portion of the narrative describing her struggles with the professionals at the school. She explained:

I did not know what my rights are, which are my daughters' rights are, what is real in an IEP. We did not know about it. When you get to the school, they are just sitting down and they just read the IEP. And they say it is okay- "We going to do this and this and that

with your child. We did this, and this, and that with your child. Everything is good.” So, you are the parent. They are the professionals, right. You as the parent say, “oh, ok, good, yeah I didn’t see this progress.” “Oh no, your child is progressing in this and this and these area.” You didn’t notice but if they say then it should be that way. “So, you just need to sign, maybe here, we agree with this, we are going to continue working with your child. *Oh, he is a wonderful kid, he behaves very well.*” They tell you always good things. Positive. So, what you going to do. Just sign it and okay, keep working with my kid.

Veronica continued her narrative:

But, they never tell you, “we are in a team. You are the most important part of the team. Because you are the parent. You know your child, you know their needs, you know their disabilities, and you know more than anybody, and you know their strengths also.” So, what I was focusing on my daughter was her strengths more than her disabilities. But disabilities is something she will carry all her life. We learned to live with that. But her strengths, that is something that she can improve every day. So, if we don’t address the area, nothing is going to change. She is not going to improve in that area. So, when I knew the rights, I went to the school and said, “You know what, *no*, my daughter can do more of that.” “*Oh, no, she has this disability.*” “Yeah, I know, but she has this strength.” They focus on the disability and they do more of that. So, we need more parents to be prepared to know their rights, and to know how the IEP works. So, in that way those kids will improve more. Not only academically but in their living skills. Daily living skills. Because I have seen that in my daughter since I started requesting services.

### **The End: Hope for the Future**

Even though Veronica talked about the challenges her family has been going through, when asked to look back at their experience here in the US and how that compared to her life back home, she said:

Yes, yes. It is much better. There is a lot more supports here than in Mexico. In Mexico, for kids, they don't even go to school because they don't have any program, and they don't have teachers certified in special education, nothing like that. Doesn't exist there in Mexico.

Veronica's hope for changes in policy was reiterated through these words:

To distribute more information about different agencies and work with different agencies and the teachers, from the administration- all the district. Give more trainings on special education. More trainings- because a lot of teachers, they don't know about autism for example. They don't know what autism symptoms are. They don't know about the different kinds of disabilities. Also, even though we are in a bilingual state, there is a lot of agencies, but they don't provide bilingual information in Spanish. I have seen many agencies where they say, "Oh, I should have it in Spanish, I don't have it right now." Every time. "Oh, we don't have it right now." So, they never have it. I think it is very important to have bilingual people here in all schools. So, when people come from Mexico or another country- Latin America, they can find somebody who speak their language. So, that way they can start understanding. But no, they force them to learn English at once. It's impossible.

## Circle of Support

**Parent Support Group.** The Parent Support Group here is Hispanic, one hundred percent (laughs). Oh, I love it. I love it. That is what, I am the leader of the group, here in our city. The “leader mom.” Because now we feel that we have a family. Because you have your family of blood, right, but they don’t understand your needs, and your daughter’s need, your child’s needs. And when you get close to another family who have the same needs, we can understand each other. We are in the same ship. It is a lot easier to help, to find support, to feel like a family. I think in any people- with disability or who has something, who has hard time- maybe illness or something- it is very important to find the support, one way or other. We have the support. Yeah, because I feel like I am not alone anymore. I feel like there is some other people, like me- they feel the same way we feel. We feel challenges, happiness, blessed, different feelings that regular people don’t even think about it.

**Extended family.** They don’t understand. It’s hard for people to understand what your needs, what you are going through. They think, “ah, just do it,” you know. “That’s okay you have that-that is nothing, there is a lot of people with disabilities.” They don’t know inside your house what is going on. That way they don’t understand.

**Spouse.** Support from my husband is very important. It is a base, I mean, another pillar- big support there. Because why do you think the house is like that. We need two supports- husband and wife. When one is not in there it is hard to hold the whole house. And especially when you have a child with a disability. It is big challenges- medically, mental, emotional. We pass through all emotions in one day. In one hour (laughs) with our kids. Like right now he is at home taking care of my daughter. He said, “okay, don’t

take too long.” I said, “No, no I’ll be back in an hour” (laughs). But, yeah, it is big, it makes a difference, it makes a difference.

### **Advice for other First Generation Immigrant Families**

Language. That is the first thing. The culture. After school meetings I get so angry. So frustrated. I feel like an ant; you know (laughs). Our child’s needs, that is what the school should be about. That is why so many parents have the same issues with the kids- especially Latinos. They don’t want to provide bilingual services because they say it costs money. They don’t want to provide enough EA’s, enough help with these kids because they are not going to hire more people. It costs money. Everything is about money. So sad. But yeah, that is when I said “no.,” I got information from another parent about the Parent Support Group. I went to the conference and that is where I learned how to defend myself and how to defend my daughter because there they told me, “you have rights, your daughter has rights, the school has obligations. The school receives money to provide services to your daughter.” And I said, “really. And they treat me that way. That is the way they think.” No, no, it has to change. So, I started the group here and somebody from the City comes once a month to our meetings and we receive a lot of support and also lot of trainings. Knowledge. And that made the change, because they know that parents know now- our kids’ rights. I sent a complaint to the State about that. I sent a complaint to the State, I sent a complaint to the office of the General Attorney of our State. I received a letter from the General Office-oh, my gosh, that letter was very encouraging. I think that made the change.

**Concluding Words: Speak Up**

So, know the rights, request them, speak out, never stay quiet, never be afraid, for once you know the rights you do have to follow them, request until they provide the service to your child. It is only way the child will improve. It is the only way the child will have skills, life skills. That way they will feel more confident, they feel more independent, which is goal, which is the goal from the school, which is the goal from the parents, which is the goal from everybody-to more independent. But we don't provide the tools how they going to do that. If we don't show, "yeah, you can do this, you can do that," how they going to find out how to do it? Yes, so speak up. Speaking up and request, and request, and if they deny, then send complaint to whatever agency you need to send it.

**Portrait 3: Portrait of Venessa and her family****Overview**

My third interview was with Venessa. She came from Mexico to the United States in 2005. She is living with her husband, their three children, and her mother. Her husband's parents live close by. Venessa's primary language is Spanish. She has a son with learning disability and speech impairment. Her son is 16 years old and was born in Mexico. Venessa has a bachelor's degree in architecture, did course work for two master's degrees (real estate appraisal and managerial engineering).

**The Beginning: The Early Life**

On her early years in Mexico and coming to the United States, Venessa noted:

I was born in Mexico City. My daddy was pursuing his MD. So back in the days, in Juarez, they didn't have a college. So, he went to Mexico City. As soon as he got his MD degree, we moved back to the border-which is Juarez. I was like five. And, since five, I was raised in Juarez-in the border land. In the US I cannot make the same money I used to make there. I am not the typical immigrant (laughs). When I was young we used to own a couple of pharmacies in town. My daddy had his practice. When I was an adult, I had my architecture license, so I was able to sign for construction. And then I used to teach in the college. And I have my license as a real estate appraisal. Our problem there though was that my husband didn't speak any Spanish. For him opportunities in Juarez was limited. Back on those days he was finishing his Public Administration Masters. So, as soon as he finished then we decided that it was easier to move here as my English was better- middle school English, and that we can do better here.

She continued her narrative with these words of guilt and doubts:

My kid was born in El Paso, but I was living in Juarez. So, it is kind of not easy to take him to therapy, like three times a week because I was working. So, in Mexico if you have the money to pay for the services you will get them. I had a speech therapist working with him three times a week. At school, there he never got any services, so when I started noticing that like he was different or his development was delayed I asked his teachers and they told me like, "Oh, let them grow, not all the kids are the same," because I told them I have a nephew that is exactly the same age and my kid is not talking like him. So....., he had the services there that I was able to pay. When we moved here I told myself, "Services should be better." And the thing is there is no information. I wasn't aware that it was the early intervention. My mistake is that I aim for private schools. And

I knew that he was going to struggle because he, at that point in time, Spanish was his first language. And I kept asking them, but nobody tell you the truth, like “we are private, we don’t have any responsibility, or it is not mandatory for us.” They just won’t tell me. “Oh, yeah, we will search on it, we will look on it.” But nobody that I knew told me “Oh, there is such a thing as early intervention and he is so serious and he can go.” Not even the private school principal- he never told me. So that was my mistake. And I was thinking that, well if the private school cannot do it then the public school cannot. It was my mistake not do more research because I was ignorant.

Venessa noted how she received her first important information that helped her:

One of the secretaries of the private school pulled me apart and she told me, “Venessa, I have a kid with disabilities. Go to Child Find. They will help you.” So, that was my first step. And in his first years he was labeled as “bilingual,” - they have, I don’t know, like twenty English therapist, they have just two bilingual therapists. So, he couldn’t get services and by the time we finished- and then the evaluation, it is not an English one. But I keep telling them, I don’t care if he speaks English or Spanish, I just want him to be able to communicate.

### **The Middle: Present Challenges and Needs of the Family**

#### **Challenges with Formal Support**

Regarding the family’s challenges with professionals and unmet needs, Venessa stated:

And they told me “no, we cannot allow the English lady to do the testing-it must be the bilingual evaluator.” And for those the waiting list are like longer. So, by the time they decided that he will need the services he was six. But then the Child Find services I am thinking ends at five, so he was not able to get any services (laughs) because he was

reaching that age. And then, when I enrolled him in the private school, it was the same thing. I went and talked to the speech therapist and she told me, “but I am the English SLP, I cannot help you.” And I was like “Oh, my God.” Then, I enrolled him in the English kindergarten and they told me “No, he needs to be in dual language program.” So they make me switch. I was patient and I waited. The English therapist won’t see him, it was some bilingual therapist that came to the school and worked with the bilingual kids. It’s when he started getting services, but at that point in time I say to myself, “Venessa, you need to do something for your kid.” When I learned that I wasted those two years or year and a half then I started searching and then I find out that the University has the speech and language program. I also learned they have a long waiting list but I put him on that waiting list.

Venessa continued:

In this country they don’t tell you face to face. They tell you like, don’t mention my name. And then everything takes forever. So, by the time he got tested, they told me like, “yeah, he has some signs but not enough for him to qualify for services.” So, in all these stages, you know, we have internet but there is not enough information there. In my house if I am on my own I will be speaking in Spanish. If my family is there we will be speaking in Spanish. If my in-laws are there they will speak English. So, what they explained to me is that those kind of kids is harder because like the other kids they will know “Oh, we are home, we will speak Spanish. When we are in school we will speak English.” But in my case I confuse him. The other factor is that the thing is he was my first. If he will be my second child, then I will know the milestones and I can prepare. Like, he was my first and then the very first time the teachers told you, “Oh, he is

different, give him time,” then you kind of-on that regard it was my fault because I say “Yeah”- like, you want your kid to be normal. So, if the teacher give you the hope that not all the kids are the same, give him time then, but I should do more research, but it was more they say “Oh no, he will pick up.”

**Source of Information.** In this country they don’t tell face to face. The secretary, not the main teacher, not the principal, not the assistant principal-a secretary with the same case, she was compassionate enough to tell me when nobody else was. And she said, “Please don’t tell anybody I told you.” And I was like, “No, I won’t do that.” It is when she like, in the scratch piece of paper, she told me to go to Child Find and this the phone number and she knew that I will go and I will do it. But, before her, I did not know the name.

### **Worries Regarding the Future**

When asked what her family needs are at present and what supports do they need, Venessa explained:

Right now, I want that somebody will give more training for the parents because like right now he is going to be an adult and I don’t think he is ready to live on his own. I do not know that he is able to think about cause and effect. It took me so much to tell him, “Hey, if you don’t stop in the sidewalk when the cars are coming they won’t stop for you. You don’t have the right of way.” So he will walk and I mean, I won’t let him go out all the time by himself because he cannot say “Oh, if I cross here, a car is coming, he can hit me.” Also right now he already took the driving class and he passed, and like I know the other kids are ready for that but with him I am- I won’t feel safe and the I don’t know what to do. I am thinking maybe the instructor just want to pass as much as they can.

**Uncertainty and fear.** I hope somebody with the expertise will help me. The diagnosis is learning disability. But that tells me nothing. At least the mother who has a kid with autism, well there is a bunch of studies and they know what's the prognosis. Because that is my question to every people that I see, "What is the prognosis? Could he be able to live on his own and do his own thing? The main thoughts is "What will happen when I will die?" -well to me. That is my- you know, my other kids I know they will go on with their lives-they will marry, and be like any other people. But with him that's my main concern. And, nobody will tell me. What I need is somebody to answer me directly when I ask direct questions. Like, "you can do this, this and that." Because I don't know if he will qualify for the DD waiver. I learned that the waiting list is 10 years. So, he is 16 right now. So, if I apply right now he is going to have it when he is 26 and some teachers told me, "No, he won't qualify" and others "Yes, he will." And I am thinking if we don't have information for when they are young, we have less information for right now that they become adults.

Venessa continued her narrative on her fear about the future. She narrated on her fears of her son joining the army:

You know the army recruiters are so bad with their tongues- they can convince anybody. My son came and told me, "Oh, I want to enroll to the army," and I was scared to death because I know if you are breathing they want you (laughs). They cannot know-if he cannot decide between vanilla and chocolate ice cream, how he can decide between should I shoot or should I not. So, that scared me to death and then I started looking for should I ask for his- you know like full custody to the judge when he is eighteen. Because I know that if my son tells an army officer that he wants to enroll but mom doesn't want

to, they will find a way. He also told me that somebody told him that he can emancipate if he went to the judge. So, the only thing is that he is overweight. So, he approached-the last time he went to the army recruiters-he approached them and then they told him, "Oh, you need to lose like 30 pounds." And then I was happy, "thank you God" (laughs). I did not know that he was overweight for a reason, because I keep telling him, you know, cholesterol and the diabetes and try to eat healthy. And myself, it is hard when you are not slender to be a good example because if I was slender then he can see and I will be his example. We are struggling with that, but in that regard I was happy that the lady told him "you need to lose at least 30 pounds."

I told him, "You know what, in the army they are not going to let you sleep in. If you are hungry, and there is no, not enough food there, there is no seconds. And you will do your own laundry and you won't have hair"- like he has kind of curly hair. He likes to have long hair. I told him, "That is not going to happen. And they are going to- "You don't like to receive orders from me, well in the army you will be told what to do all day long." He was like "Oh, they are going to give me money for my college and then when I will come I will have this and this and this"- all the promises. And I told him, "what for do you want this scholarship for, or money for your college if you are going to come back in a wooden box, what that good for you" (laughs).

So, stuff like that I would like to have him diagnosed because if I will have any diagnostician paper then I know that the army won't be able to take him and right now I don't have that. And I don't have the prognosis- to know if he won't be successful in a Bachelors degree, then to help him to be happy and explore where he is good at. If he is good with his hands, he could be an electrician where he can make good money and it is

a good one. So, that is what I am struggling right now with and I will like to have help because like at this point in time I don't know-he could be autistic-and I don't know, because I was not aware that they can be-because I never thought that he could be autistic, because if you meet him and you talked to him, like, one, two days, he will hug you, he will be the most, the, like he doesn't have any problems or limit with them touching, hugging. And I know that, that is one thing about autistic kids cannot put up with. Like, if there is an unknown people they will put the barriers, they will not like to be hugged or touched. So, that is why it never crossed my mind that he could be in that low spectrum of autism. So, right now it will be very helpful for me finding information.

Venessa continued:

We don't have any support, and then you know I work, my husband work, we never qualify for anything like special price lunches or Medicaid. Also we do not have any psychological support-nobody can orient us, like every time we struggle with him, it is like we are repeating the same and I don't know how to overcome that. I don't know. So, first I would like to know the specific diagnostic-I don't know if learning disabilities tell somebody else something, but to me that doesn't tell me much. And then he has dyslexia but then he cannot qualify and that doesn't help. And, like all the sensory processing disorder, like all the things he could have, I knew them in an unofficial way. So, I don't have any paper that says yes, he is autistic. How to overcome that I don't know. We do whatever we can with struggle.

### **Support from Parent Support Group**

Right now I joined the group, but the point is the kids are so different. So, to me is- it will be nice if somebody will have a kid with the same thing with me. I mean, I don't even

know what is his disability (laughs). I know that he is disabled when they ask me-like learning disability-like he struggle to learn, yeah. But like, the moms with Down syndrome. If I will find a mom with a kid like mine, it will be awesome. It's a good group because you know, I feel I was on my own, fighting the system. And then when I see other mothers with younger kids and are doing the same things that I did I said, "Well, at least don't feel alone," I am thinking. That is the way, or that is the kind of support but the cases are so different and the kids are so different that they cannot teach me what to do. I just find it nice to have somebody else struggle-like I am not the only one.

Also, if they train us for Medicaid-if we receive training for Medicaid-well, I don't qualify so I will just be sitting. I can help the mothers that don't speak a lot of English to translate and to pass the information. I can help- I feel that I can help more others but I don't feel they can help me much this point in time. Getting information, yes, yes. Like I wanted to do the- when you go to the judge and you ask for full custody when he is 18- what is that? Full guardianship. To get full custody for your kid, but I didn't know that it is very expensive and then once you get it the court and the judge have the right to show up in your house and say, "Well, we are checking for his wellbeing." And that day, if he was mad at you he can say, "Oh, she is being mean to me, I don't want to do it anymore." Then we will end in a court battle with my own son. I wanted to do it because if he joins the army. I want to show he cannot decide on his own and I call the shots and say he is not going.

Plus, the same thing- when I will be dead then somebody will need to take over and what if nobody wants. He is going to be institutionalized or what? So, it is a lot of stuff that you need to think through. It is not an easy decision and I was thinking that I

just go to the judge and I will tell him I want to have full custody of him. And then he will say, "Oh, yeah, you can go." And it is not that easy. I cannot do it, I need to pay a lawyer-that will be pricey and I am thinking there is like pro bono lawyers but again they have a long waiting list and then once you are in the system, it is not easy. They will have the right to intervene and check with the immigration papers, again when you are resident, you need to tell them every time that you move.

### **Looking Back**

In Mexico it is different because down there nobody is afraid to talk, because we don't sue everybody for small stuff. And, if we sue each other, that won't go within the court. The judge will be-like, like you won't be able to get money like for civil suits like this- "Oh, she told me this but she was not the diagnostician so I am suing her." We don't have that. So, the communication is more direct. In his school, they told me, "We used to have a speech therapist, but budget wise we moved her to another school, so he won't get services here. So, I get it at the first time. And then they told me, if you want services go and look for a private speech therapist and that will be your best way. That's what I did. That's what I wanted from here. On that regard, my country is better because they talk directly. They don't do anything under the table or in secrecy. No. They will tell you right up front- he won't get services. That was more helpful. They don't rephrase like, "Oh, you know what, let us do the re-accommodations and check the SLP schedule and then we will let you know." And then months or weeks to the next meeting and the-again I will ask, "Teacher, I am noticing that he is not getting any speech therapy, why?" "Oh, because she wants some vacation and blah, blah, blah."

What else, the bad thing in Mexico is if you don't have the money, like, parents with special education kids and if they don't have the money, I don't know what they will do. Right now I don't know, but back in those days when I left Juarez, it was one special education school and they were all together, like, Down syndrome, all the disabilities. I am thinking if you don't have the money and that school won't have a spot for your kid then you will be on your own. Back on the days if I hadn't had the money to pay for the session-the speech therapy sessions, we would have struggled. I am thinking that is the bad part of my country. The good part is the communication. But the resources are so limited. Here, they have more, but they don't have the information available. For somebody that doesn't speak English, that is illegal, and are not computer savvy, they will have more disadvantage. That is the disadvantage of this country.

### **My Advice to First Generation Immigrant Families**

Fight and search from the very beginning. Don't let the time go by. That was my mistake. If somebody else, it could be a family member, it could be a teacher, if somebody else tells you there is something not right with your kid, you should check onto it because, as parents we don't want to see our kid is different. But once somebody else tells you, follow up and search for more information because sometimes the resources are there but you don't know to obtain them or how to ask for help. Like in my case my mistake is I didn't check both- private and public. You know, I bang my head against the wall because if only I had checked. If I just do more research and I just crossed the street and ask that school, maybe they will- if they don't have the information, they will tell me where to get the information. So, my advice will be to check all your choices. And the

sooner the better. Don't wait. If somebody else told you your kids is different, maybe it is because he or she is (laughs).

### **The End: Hope and Doubts for the Future**

#### **Information for Families**

Venessa noted there were a few changes she would like to make in her community starting with the availability of information. She said:

All the packages that welcome new comers to our city- they will give you a package-you name it; they will give it to you. But there is nothing about schools or if you have one kid with special needs. That will be very helpful if the information can be put in there. You receive in the mail-packets like the bunch of postcards, information about restaurants, all the fun stuff, but not the schools or real legal stuff like the DD Waiver.

You know what, the open houses, all schools do open houses- have a special education booth. Because maybe they may not tell you everything, but if they hand you the information on who to call, then it will be up to you. Because if you don't have the information you won't call. And the- not funny- the sad part is- like my mother-in-law, she has a Ph.D. on early childhood studies or something like that, they don't even know because a family that never have a special education kid is as misinformed as the immigrants, we who are here for the first time. That is the sad part. My father-in-law also, they are both retired from the University. What I am saying is they are not ignorant- they are smart people- my husband, he is also smart, but when you don't have a kid with special needs, you are in the same boat as us immigrants coming here for the first time.

There is no information for those- you learn more from other families having a special education kid than from anybody else. So, I am thinking maybe in those open

houses we can have, well that is my idea (laughs), a booth with information on services for families with children with disabilities- it could be parents, it could be teachers. It is just the information should be right there. And you know where else- the registration day. Because I don't know about the open house, but on the registration day all the parents are there. Why not put a booth or a table with special education information? If your kid does not have a disability, well, you skip that. But in my case I knew that my kid has a disability, so it will be helpful to have a booth there.

### **Unable to Let Go of My Past**

The sad part is I wrote a big letter to the Catholic school and I thought that they will reach out to me and tell me, "Oh no, keep your kid here, you will get the help." I got no answer. I was very mad. So, I told them, "From the day one I came here for the orientation I asked for the special education service and that my kid will get the speech therapy sessions. You told me yes. But he never got any." They didn't answer. So, I don't know (laughs) I got more mad because it is, like to me, being Catholic, it was hurtful. But, it is what it is. You live and learn. I wish for other parents, like I wish I can help other parents. Because I still don't have solutions, I still don't know what is the future for my kid. But, I really think that the most help that they get in the early years, the better that they can overcome their disabilities.

And I still regret those years that he get no help. I mean, like, right now, you can understand him. But it will be nice if you could understand him when he was in fourth or fifth. He is still so shy, like, to go and ask for another napkin or something. I know that he is shy because, he will go and ask and then the other people will say, "What did he say?" And I told him, "that is fine honey, that happen to me too. I speak with an accent

and some people cannot understand me.” The people that can understand me the most are those who come from bilingual homes, but the person who is not exposed to Spanish- he cannot understand what I am trying to say, so a lot of times I need to repeat myself. I have white clients but they don’t speak anything else of Spanish and my job is to make them learn the process of buying a house. Because it has two sides-when you go and ask for the service like we are at the doctor I feel like there is the obligation to understand me because I am the client, I am the patient. But, when I am providing the services, it is up to me that they will understand me. Maybe I will have my accent all my life and “that is cool sweetie- that is the same with you. You need to work, you need to-we, that the English is not our first language and if you have the speech impairment, then you need to think, “Oh, I need to enunciate make myself clear.” But that is okay.”

### **The Future**

With our new President, I am concerned because- just talking about special education- not all the other craziness he has. If they start making disappear the bilingual fliers, bilingual information in this region- it is common that you will have this information. But, how I see, his nationalism and English only policy kind of thing- I am afraid that it will disappear. Because you know that the website of the Presidents, they used to have everything in English and Spanish. And then as January 20, they disappear from the website-all the Spanish information. Right now is limited but at least they will try. And you know that you can talk-like if you don’t speak English enough, you will talk to those teachers and you will be understood and they will give you good information. But, if, they disappear that or they cut funds then it will be less and less information in Spanish.

## **Portrait of Negroni and her family**

### **Overview**

My fourth interview was with Negroni and her daughter Vero (pseudonym). They are natives of Puerto Rico and came to the United States in 1999-2000. Negroni and her husband have three children with ages of 21, 19, and 18. All her children were born in Puerto Rico and have been identified as having dyslexia. Negroni's primary language is Spanish. Negroni has a bachelor's in criminology. They do not have any extended family members living close by.

### **The Beginning: The Early Life**

When asked about Negroni's early life experience, she narrated:

Puerto Rico is beautiful, is nice, I am happy there. But the reason we moved is my husband is a policeman in Puerto Rico. During the time he worked as a policeman, I studied in the university. We are, you know, try always to improve. I tell him "Okay, Puerto Rico not pay more for the college." Move to the United States, because my father and others moved to Minnesota. From there we moved here. The move is for improve, not because I not happy in Puerto Rico, no, no, or you know, it is to improve. We have the three kids, I finished my university, I married, I graduate in criminology, and I never working in that because you know, my husband work always for provide. We are fine. For us it is more important. No Mom in the house, the kids are no, no. We have values-Christian ones, you know, going in the Bible. That is my guide. I don't care the population, what the people are doing. I have my- my husband and me- we are purpose in life.

He is policeman in Puerto Rico. When we moved to here, the Sheriff department. He like law. And he enjoyed the army. When in Minnesota and he fight in Afghanistan for one year. I was alone with the kids and Grand Ma. But, my son in Minnesota say, "When my Daddy back." I tell.... "He will be back soon." And after a while he will say, "You have been saying that for a while now." So, he realized time. He was at a young age, he always noticed that time was moving. So, he had that sense already.

The school in Minnesota are different. Put more attention to the disabilities. Here no, but there, they give us....

Negroni's older daughter Vero interjected:

You know, there you don't really need to ask for services. They provide. I remember there were multiple times when I was in school they would take me out of class and give me to the English second language learner classes to catch me up in math and to catch me up in reading- like they would just take me out of there and, but put me back so I could socialize with other kids. So, they always did that by themselves. No real input from the parents. It is more like, "Did you notice this kid is not acting well. Okay, let's start and see what we can do. So, there is- difference in the culture.

Negroni continued:

My husband thinking is too. There are more resources. I live in St. Paul the capital city- Minneapolis, the twin cities. You know, they are more friendly with the immigrants. Here yes, because the most population is Hispanic. But there Hispanics are minority. Somalis are lot. So many Somalis. In the school, how many Somalis? More than half of their class. It's different experience. When you come here the White people- I don't know, the whole district is White (laughs). The people in the positions. I think, there is

discrimination..... It is not clear, but when you say for service, they always say, “No, no, you can’t, no, no.” What? When you know the right. (Sighs) The experiences is different in the different parts of the United States. I go to Florida. I feel like home. Again different position. Here is more.....many Mexicans from here are acting like Black or White people. They say, “No,” you know. For me especially, because I speak Spanish, but I have different custom. I don’t like spicy food, I don’t like the music. Because I am from Puerto Rico. Different, different food, different everything. Different thinking. My status is different. Of course I born in Puerto Rico, I was born with US citizenship. Because in Puerto Rico, citizenship is of USA. We are American. But, I feel discrimination from Americans because Puerto Rican is like second class citizenship.

Vero added:

Because in Puerto Rico you can’t vote for President. Because we are not a State, we are a Colony. So, if you are born on the Island, you are a US citizen, but you are pretty much don’t have any control on what happens in the White House or what they do with you as a citizen, unless you move and start getting a job in the mainland in the US. Then you have full control as a US citizen, but then we don’t know any English. Because the whole system there is Spanish. And every once in a while they will just put in an English word like- we will just throw that in there. But that is not it. It is not real into English- the English we need to know as Americans to communicate with the rest. But we don’t. So, when we get here we are treated like second class because they see us like every other immigrant. But in reality we are Americans born for generations but we are classified as immigrants trying to get in. That is why we see both sides and know how both sides feel.

Negroni noted:

My Grand Pa is a veteran too, from the second world war, army US. He always stay in Puerto Rico, but he is a veteran. He always teach me, "Always buy stuff made in US." He is proud to be an American in Puerto Rico that is why. But I not learning good English. Because the school, only one period in English in the day and the rest in Spanish. But the rich people in Puerto Rico go to the private school-all in English. Parents are doctors. If parents have the money to afford the tuition. Many people say, "Puerto Ricans speak English." But that is if we can afford we can get the education. Academic, pay a lot. Two thousand or more. Too much. But, the status of us affect me because I have college degree in the university but no work because I feel like no secure to speak. But now I feel like I need to maintain my Spanish for my kids. That is why no, no, no speaking English in home. Because I am proud about Spanish. I like Spanish better. I am proud to be a Puerto Rican and proud to be American. But my family in Puerto Rico want independence from US. I say, "Are you crazy. See the Mexicans. No visa, nothing. You are crazy." Puerto Rico is just so small. What happens there. I feel more secure with the US. My God, why they want to leave US. No, I don't know. But they are persistent. But I like America. We have a lot of opportunities. That is why my kids are strong- I tell them you have a disability but you have the tools to improve and be success. You feel proud to be Puerto Rican US citizen.

### **The Middle: Present Challenges and Needs of the Family**

When asked about what supports her family needs, Negroni narrated:

I think, parent resources are not here. We have no resource- what happen with my kid, where I do get it. I think the parents here are not fighting. Maybe one or two parents are fighting for the kids' education. That is why the schools say "No" because we don't

have support. We do not have an office for disability rights here. Here I go to the office, but the lady working there tell me, "I help more the veterans, less schools." We are so desperate. She say's not here but in the big city- but it is far away. We need people here. But she gave me the name of the lawyers. I appreciate that. But the parents continue not to find the support. I'm working, we need more in my language. Many people say, "But study English." But in my case I'm US citizen, I am born speaking Spanish, it is not my fault they give me Spanish in all my years-in the University-twelve years, with my Bachelor's degree. My Bachelor degree is good here but I know my English is not. They no provide a good education in English to us.

My husband speak Spanish all the time. In Minnesota, when he go to the job fair, the table Sheriff, he told to the people there, he say, "You are a Puerto Rican police. Oh my God. It is good, because it is hard to be a police man in Puerto Rico, it is more dangerous. Because Puerto Rico is difficult. The guy in Minnesota "Oh my God, don't worry. I pay for you to learn English because you are policeman. It is more hard to teach to be a policeman." He worked for five, four years in the Sheriff department in the Detention Center in the County, St. Paul, but my husband not like the cold weather, you know with the zero degree. I like it but he not like it. He said "No" but that is why he joined the army. And the Sheriff teaching English. My husband has no problems; he is very smart. He learning English.

You see my situation affect our life. I have Bachelor's degree. I wanted to get a Master's degree but everything is in English. That is why I am happy we moved for our kids. They have English. That is why as parent I am happy. I am happy in Puerto Rico. I live big, good, I have everything there, my family, my culture. But I need the English.

That is why I moved. I feel sad, my mother just have her Happy Birthday, all my aunts are in Puerto Rico. Me, I can't touch my Mom. They come but it is expensive. I feel depressed in the beginning because.....I go to the church on Sunday- I go to the Pentecost type close to my house. That support is like family. Here there is not much family. Many Mexican women are shy. The culture is different. In the Mexican heritage men are very macho. You know macho? But in Puerto Rico women are stronger. I feel like different. And my husband has friends but he doesn't go there alone anywhere. My father-in-law, yes the macho kind in Puerto Rico. But my mom, she teach me- Daddy always home with her to help. You know when I met my husband I saw his father do this- he go out and play with the guys. I tell him "I am not your mother; you not do the same as your father. I don't care, it's my rules, you know. You wanted me." Twenty-one years of marriage, nothing happen. You know, I think the communication of the couples-very important. In my family, now my husband is my best friend. When we have some problem-you know, relationships always have problem, he thinking different to me, he is quiet (laughs). But, the love is strong.

In my home, my children they go to the church, participate, I don't push them. But I teach them to be a leader because important is to help people. Do something. Never something bad. And many occasions in the school is hard for the kid. A lot of drug, a lot of sex, you know, bad things. But that is why we need communication with the kid. And tell the truth always. If your kid-if you be an example, they saw that, they not take bad choice. In my daughter's life, she is 21, she works in the daycare for two years. She helps in the day care. It is a good job. She is responsible with that. Now she try the associate degree in Early Childhood. It is hard for her-for dyslexia. She is like "Ah, mama..." I

told her that I will help her. I help in the home. You have computer.” I tell her, “You need to improve and overcome your problems.”

Negrone continued narrating regarding their life here in the US. She said:

When I move to Minnesota my family there. Mommy, Pappi, my sister lives there, friends from Puerto Rico live there. We are, you know, when one move, everyone moves. We have no problem there. The kids are supported with cousins, grand pa, uncle, my grand ma. But, we move here I feel lost, most alone, or different. But, my husband work with lot of Puerto Ricans. Because, we go to the border patrol. You feel they maybe, seven families Puerto Rican work with him, you know. Sometimes we have reunions. But it taking more time. I prefer nobody, no others-my only priority is my kids. That is why, we are not-more also, they are not Christian, when they make a party, they drink a lot. I don't care about drink because I thinking they drunk. Drink is getting drunk for me. They eat food a lot, that is sin too. This control is the problem. But I thinking the example is more important. If you don't want your kid taking tattoos, don't do it. If you do not want your kid drinking it is important be happy with what you have. That is why no improve many people, no affect my kids. I am thinking I prefer alone to bad examples for my kids. But, it is okay. I am thinking I did the right decision. That is why I feel alone. Because for us it is important [was sad talking about this]. My husband and me, we work together for the benefit.

For us it is important vacations. They need to know the places. They go to the mountain-the President's faces. It is important Universal studio. We provide economic for that. I spend, but not loosely because we are going to the vacation, we support it. My husband is very strict that we stay on budget. We have houses in Puerto Rico. The first

one is for rental. We go back to Puerto Rico, the other house. My stuff is in Puerto Rico, most. We have a house here-we have three mortgages. My husband sometimes in Puerto Rico, the house not rent for one year. I pay \$700 from here to our house-both house. But we are satisfied because my husband thinking his retirement, rent and retirement, social security. You know, he is very strict. That is why we are- I not like spend for eat out. No, no, we are save money. I buy from Dollar Tree. That is good. It's one dollar. It is the same as \$3.

I don't care- we are like I don't care what the people tell us- "Your car is old." I am happy, no monthly pay. You know, that is not important. My friends decorate the nails, I don't care for them. We are more- I like only vacation, but in budget. The "save" is part of the life. Doesn't matter. Here, it is okay. The food is cheaper. The house.... depends what kind of house you have. Middle- not too much, not too less. In front of my house, they are Puerto Rican too. And the other side, they are Puerto Rican.....That I am feeling good. The head is the professor of the University. The other house, he is a police of border patrol too. That make us happy because they are my family. I am thinking God help me in that part, because they buy in different times and we have the support in my street. Two family. I know when they need help we are always there to support, you know. That is a good thing because that help with my ten years here. It is a good thing. But for the rest, I try to always support. I try always-my children go to the community to help. Like, the county has something for kid- I put my kids, like for study- Youth Initiative. The county has that program. Many parents no use it.

### **Challenges with Formal Support and Overcoming it**

Regarding the family's challenges with professionals and unmet needs, Negroni blurted out:

We need more help!!! Because my daughter had trouble with the academic stuff. And the school say “No,” they don’t want to do nothing. And, they make a test and they say, “No, she has only reading problem.” It is a long time fighting with them.

Negrone’s daughter explains what mom is relating:

We got another professional to take the dyslexia test because the school is law bound to give each student at a parent request. But, apparently the ones they kept giving me, they said, “No, you are fine, you are fine, you passed.” Well, the one, we went for a professional in the big City, away from the school system. So, there is no way they could interfere, no way into it. And it turned out, I had dyslexia. I had one for words mostly and phonics where I cannot read words correctly and the right phonics. Like sounds were not my strong point. And we gave it back to the school and they were like scared-like their faces and that showed they were messing with the test. So, just to cover themselves....

Negrone interjected:

Two years, 11<sup>th</sup> grade and 12<sup>th</sup>, you know they stop everything, not give service to them. It’s.....I am so.....crying, fighting, fighting, finding people to help me, my husband you know this is trouble, the family emotion.

Vero continued:

Because they like to isolate you. That is what they try to do. They try to isolate you to the point where you want to give up. And they try to make it seem like it is against the law to get help or to have people to help you. They go out of their way to make it sound like that.

Negrone stated:

And the school personal, always mean, you know. I am visiting their school many times, they, they, they, the people they scoff always, you know, look at you like, "Oh, she is over here." And, it is not only her. My two other sons have dyslexia. But, in her case it is too late. But with my second child I have more experience. I take less stress. Always I know what I do. More complains. And, they know me (laughs). I never stop. When I see my kids suffer, ha, ha, ha, no. Doesn't matter I no speak too much English. But my husband do it. My husband works a lot, that is why when I made the case it is me. All the time I tell him, but always he goes with me to the meetings- IEP. Because, he is part of the family and they saw the "unio"- unity in the family. My husband is policeman. Know all the laws. Me, I have a bachelor's degree in criminal justice from my university- we are studied, we know the rights. And they thinking "Oh, they are Hispanic.

But, now I, I help the district.....they know me more because I work in the program called "Parents Involved in the Education." It is a new program. I am facilitator for the Spanish speaker. I am working with them-superintendent. I am working with them because I know what happens there. They say "Okay." For me no more parents pass my experience. That is why I help in "Parents Involved in the Education." That is my passion. I am not working but I do this for the community. They say okay. And support emotionally. But, I do fight and it is working. I tell them the truth. Now I'm working with them. Because they have that good program to involve in the parents. We give everything to it. Because I know it is not personal, district is not personal. They try to do less for the kids, because, you know the budget. The budget, that is important. But, the law is appropriate education for everyone. Doesn't matter you are immigrant or no. Status

nothing. That is the law. Federal law help. And that is my passion, you know. I want to help people.

My grand pa in the town of Puerto Rico he is always in politics. I growing in family always involved in politics. He is - the Mayor and six people-city counselors- city council. My grand pa founded Lion Club in the town. He like, when he is in the politics, he helped old people to improve. I saw my grand pa always help. And always cleaning all around the house, the community he helps. I tell, "Why my grand pa going with machine to cut- the lawn mower grass." All the street. It is like military style. That values he show me. My mother and my father too.

### **The End: Justice and Hope for the Future**

Negrone continued her narrative without any prompting:

I love my grandpa, but sometimes he is racist. I tell, "You are racist." He is racist. Because you know our country-depends on what you study, your color, how you look- you are racist. I tell my grandma, "You are always racist." I fighting for the justice. When I was growing, many people, not talking to me, but I feel like it is bad. I feel my family thinking I'm different because I am here. I live with that. It is hard, because you need some people to get approval from others for life. Not me (laughs), because everyone needs to understand what you believe. You need to be strong (laughs). But, that is the way I feel to my family in Puerto Rico-not thinking like me, I say "Okay, I live here." Anyway- some people, but I don't understand their life. The purpose of the life is changed. God is good. He is the only One. I read yesterday, the, the trial movie of "God is not dead." I cry.....I saw the movie in the theatre. But I look every time, always, I feel like justice.

I think immigrants only thinking about work, you know. Mommy work, daddy work. In this city not have a lot but has something to do with a kid. Sports is good-taking turns. Many at the church has a good support for the kids. Find them. Because I go to the church, they have like boy scout- Royal Rangers. My kids always there. They like to go to camps. Now my kids are leaders in there-they Royal Rangers for other kids. But my church has maybe 1,500 people. But only 10 boys go to that class. Maybe less. Where are the parents. You need to provide time. Depend on the parents. What you want for your kids. But immigration status is hard-I know. They are.....emotional. Maybe they have stress now. But they need to make good decisions. Good decision. No bad decision because that affect your family. You are here-you are not a slave, you have too much rights, you know. I understand this because I am used to it. I speak up.

But I think the community-the Spanish ones are more.....the Mexicans, they don't have study over there. They are a little ignorant. It is too hard to provide- they thinking different. They always been thinking no education but money for them. In my family education more important. I don't want to be rich, I want like- good life. Rich is not happier. Rich people, you know. Education is your freedom for me. That is why I am thinking- that happen in Puerto Rico. You come to here when you are educated. That is why the education give you power to do something different. That is why I am here, it is different but I am power. You know, I have confidence here. That is why I don't need more support. I try to find the best for my family. But I thinking this community need education, they need rights, they need hope, and maybe the problem is with the- I can't imagine stay here without the paper. For me thinking it is hard-hard time.