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**Latino/a Adults with Down Syndrome Make Sense of Family
While Growing Up in a Bilingual Home**

A DISSERTATION

Submitted to the Faculty of
Montclair State University in partial fulfillment
of the requirements

for the degree of Doctor of Philosophy

by

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Montclair, NJ

January 2021

Dissertation Chair: Dr. Katia P. Goldfarb

MONTCLAIR STATE UNIVERSITY

THE GRADUATE SCHOOL

DISSERTATION APPROVAL

We hereby approve the Dissertation

Latino/a Adults with Down Syndrome Make Sense of Family While

Growing Up in a Bilingual Home

of

Linda M. Baron Cortes

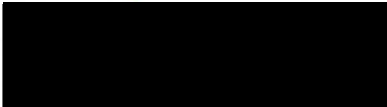
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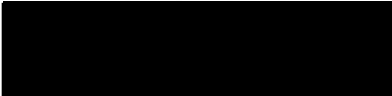
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ABSTRACTLATINO/A ADULTS WITH DOWN SYNDROME MAKE SENSE OF FAMILY WHILE
GROWING UP IN A BILINGUAL HOME

by Linda M. Baron Cortes

Previous research focuses on the linguistic capacities of individuals with DS and how dual language exposure can hinder or support their cognitive development (Chapman & Hesketh, 2001; Kay-Raining Bird, et al., 2005), yet research regarding how an adult with Down syndrome (ADS) makes meaning of family within Latino bilingual homes, where the ADS is the primary perspective taken into account, is missing in the research. This study aims to provide the perspective of adults with Down syndrome since conversations and research about their development should include their opinion and thoughts, especially when there continues to be a push for English-only, in regard to the person with disabilities development (Guiberson, 2013a; Paradis, 2016). The research question that guided the study was: *How does a Latino adult with Down syndrome make meaning of family, while growing up in a bilingual, Spanish-English speaking, home?* Five adults with Down syndrome between the ages of 21 to 40 were interviewed, through 3 waves of semi-structured interviews, where photographs were used to help with communication between the researcher and the participant. Through the lens of symbolic interactionism five main themes were derived: affection and love, companionship, being taken care of, cultural identity, and communication. Findings suggest that communication, verbal, non-verbal, and symbolic gestures, all built relationships, whereby making a strong familial connection was not contingent upon language usage, since a strong sense of family is embedded in the Latino Culture.

Keywords: Latino, family, language, meaning, bilingualism, symbolic interactionism, Down syndrome.

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And finally, this work was completed through the love and support of my friends, colleagues, doctoral peers, and family, especially my parents, children, and son's father who were a large part of this journey of becoming "Dra Mom", providing me with the confidence, encouragement, patience, and a listening ear as I processed this study, finding my way through the stories of the participants. They cared for each other through bath time, dinner, bedtime routines, and provided a shoulder to lean on when I was tired ready to give up and the laughter I needed to give me the confidence to push through the end.

DEDICATION

This work is dedicated to my parents who migrated to the United States, when I was 2 and half years old providing me with the opportunity to pursue an education and career. They stood by side and supported me was well as my educational career day by day, Maritza E. Baron and Alvaro Baron, never once complaining, rather always encouraging me and pushing me to be better. This work is also dedicated to my cousin with Down syndrome because his smile and unconditional love gave me the motivation to continue to gain knowledge and strive to provide the perspective of other adult's with Down syndrome. Finally, this work is dedicated to all immigrant children and adults who want to pursue an education, but are limited by their legal and/or financial situation. To all my DACA Dreamers. I want them to know:

“Si Se Puede”!

TABLE OF CONTENTS

CHAPTER 1. INTRODUCTION	13
Researchers Personal Experience	13
Childhood Experiences	14
Statement of the Problem.....	19
Importance of the Adults with Down syndromes’ Perspective	22
Research Question	23
Definition of Terms.....	24
Down syndrome	27
Understanding the Diagnosis	28
Co-morbidity	28
Communicative Profile	31
Learning Profile	32
Background and Significance	34
Parents and Family.....	36
Service Providers	41
Quantitative Scales and Academic Achievement	43
Purpose of the Study	46
Summary.....	46
CHAPTER 2. LITERATURE REVIEW	48
Theoretical Framework.....	49
Social Constructivism	49

Symbolic Interactionism	50
Symbolic Interactionism: A Tool for Understanding Individuals with Disabilities	51
Self as Dualistic	52
Mind as action toward Self	54
Symbolic Interactionism in the Current Study.....	56
Summary	59
Review of the Research	60
Bilingualism.....	60
Discrimination and Intelligence.....	63
Down Syndrome and Bilingual Capacity	65
Native Language-loss.....	66
Latino Family Connection.....	68
Familism	69
Summary	70
CHAPTER 3. METHODOLOGY	71
Justification for the Current Study	71
Process of Recruitment	72
Identification of Reasonable Participants for the Study	75
Criteria for Participants.....	76
Invitation for Participants with Approval of Legal Guardians	76
Pilot Study.....	78
Participant: John.....	78

Lessons Learned from Pilot Study	79
Barriers to Recruitment	80
Ensuring Confidentiality	82
Building Trust with Adults with Down syndrome.....	84
Building Trust with Legal Guardians	86
Rapport Building Capacity	89
Researchers Positionality	93
Participants.....	97
James.....	98
David.....	99
Betty.....	101
Olga.....	102
Interview Process	104
Understanding the process of Screening Protocol	106
Use of Photography to aid in in-depth Understanding.....	108
Researchers Reflexivity	110
Analysis of Interviews	112
Waves of Analysis	114
Thinking through the Process of Analysis: Olga	116
Trustworthiness.....	119
Credibility	119
Confirmability.....	120
Transferability.....	121

Dependability	122
Summary	123
CHAPTER 4. FINDINGS AND ETHICAL CONSIDERATIONS	124
Deriving the Themes.....	124
Table 1	125
Participants Expressions of Making Meaning of Family.....	131
Affection and Love	132
Companionship	136
Being Taken Care Of.....	140
Cultural Identity	143
Communication.....	146
Ethical Considerations	148
Separating Predispositions from Legal Guardians.....	149
Summary.....	151
CHAPTER 5. DISCUSSION.....	152
Meaning of Family and Language	152
Implications for Future Research.....	157
Implications for Practice.....	159
Implications for Policy.....	160
Limitations	161
Figure 1: Theoretical Framework	165
References.....	166
Appendix A: Information sheet for Consent Form.....	187

Appendix A1: Consent Form	191
Appendix B: Letter to Nonprofit Organization: Request for Permission	192
Appendix B1: Letter to Invite.....	194
Appendix B2: Information Sheet.....	195
Appendix B3: Screening Guide	196
Appendix B4: Non-disclosure.....	197
Appendix C: Tell Me About Yourself	199
Appendix D: Semi-structured Interview Protocol	201
Appendix D1: Semi-structured Interview Protocol - Spanish	204

LIST OF TABLES

Table	Page
1 Table 1.....	112

CHAPTER I: INTRODUCTION

Researchers Personal Experience

I am interested in researching the meaning that Latino adults with Down syndrome give to family when raised in bilingual, English-Spanish speaking homes. Reflecting upon my own experiences, having a cousin who is a bilingual Latino adult with Down syndrome (ADS) in his 30's, I have been able to see first-hand how he makes meaning of family within our English-Spanish speaking homes. Today, we still communicate daily through the use of technology, with video chats through Facetime and WhatsApp, or daily phone calls to check in on each other. It is not just me that he calls, it is multiple family members throughout the country, many of whom do not speak English very well. The predominant language spoken both in his home, with his parents, through daily videos or phone call chats to family members, and in-person at family gatherings is still Spanish. My cousin and I were raised in a family where the Colombian culture and language takes over almost immediately when entering any of our homes. Our houses reflect the culture through the smells of our foods that are made from a delicious sauce called sofrito, a combination of green, red bell peppers, onion, garlic, canola oil, Maggie bouillon cubes, and adobo, that gives flavor to the majority of our meals. The language that resonates is Spanish, through the daily conversations, the television shows, or the music playing the background.

It is inevitable, he was going to be exposed to the Spanish language since it is an integral part of our culture yet building a relationship with me and the rest of the family was not contingent on his ability to speak Spanish. This is not to say that Spanish is required or not required, it is simply a part of his and our world. The intent to teach Spanish is simply not needed since he will inadvertently pick up sounds, tones, words, and finally Spanish because of his constant emergence in the language. As a person who was not entrusted with the obligation to

raise my cousin, I just spoke to him, hung out with him, and continued to engage with him, not ever worrying about which language I was speaking. I never have, nor do so today. I just simply speak to him and enjoy his friendship, never worrying about his level of understanding, because of the language I have chosen to use while we communicate. As a family member, my main concern has always been and remains, his happiness and well-being. He has learned throughout his lifetime to simply communicate, whether that is verbal or nonverbal, or through of the use of gestures. He either speaks in Spanish, English, or a mixture of the two languages, commonly known as Spanglish. He also uses gestures, such as smiles or hand movements to communicate what he needs or wants, as well as objects, like grabbing a phone or iPad to use an image or symbol to explain what he is saying, all in accordance with our cultural teachings and his upbringing. He has learned to use the tools in his environment to express himself, which can be pictures, objects, words, music, or physical gestures, all which have been given meaning by the social interactions he has had with us, his family members, and all within our Latino Colombian culture.

Childhood Experiences

While growing up in a bilingual Latino family with a younger male cousin with Down syndrome (DS), I began to realize many of the struggles my aunt and uncle faced. They had to repeatedly attend appointments, with school staff, doctors, occupational therapists, and speech pathologists. My aunt and uncle had to shuffle around their schedules, ask my mom for help to babysit his older sister, since she also needed someone to care for her, while they maneuvered around his schedule of care. I remember seeing the frustration and anguish in my aunt and uncle's faces as they confronted the reality that my cousin had DS and would require care for the rest of his life. One of the major issues they were confronted with was the possibility of teaching

my cousin only English, since that was the constant advice from service providers who claimed it would be the best way to support their son's development.

The constant advice to teach my cousin only English created stress for my family, because as much as they would have wanted to stick to this advice when you have family members who speak little to no English, and are part of your primary support system, this just is not possible. When you have bilingual children being raised together, it is not possible to control the language(s) used to communicate amongst themselves, especially in the moments of play. Spanish is the most common non-English language spoke at home in the United States by Latinos and non-Hispanics (Gonzalez-Barrera, 2013). Over 73% of Latinos speak Spanish at home (Krogstad & Lopez, 2017), making exposure to the Spanish language almost inevitable amongst individuals with disabilities born into Latino families in the United States. My family was no exception. My cousin was exposed to Spanish since birth, because his reality was that he was part of a bilingual Latino family, where Spanish was, and continues to be a major piece of our culture and identity.

From personal first-hand experience individuals with Down syndrome raised in Latino bilingual, Spanish-English speaking homes, will be exposed to Spanish, regardless if the primary caretakers choose to speak to them in only the English language, because of the advice from others based on their own personal or professional beliefs, or on the caretakers own personal beliefs. The individual with DS will develop relationships and form familial bonds regardless of the language that is either directly used to speak to them, or the language(s) that are used within their environment. I believe because of my first-hand experience that individuals with Down syndrome can be bilingual and that it is important that they are taught the family's home-

language, preserving the native culture and allowing for the formation and maintenance of strong familial ties.

As a child, I was never told my cousin was different, that I should treat him differently, or that I should only speak to him in a particular language. I was never told that he had Down syndrome. I played with him, argued with him over toys, went outside to hang out, watched movies, sat and ate with him, in both Spanish and English, never once questioning whether he understood what I was saying. As a child, as a cousin, as peer, all I knew was everyone else in the family speaks Spanish, English, or a mixture of both at any given moment, and for us it was normal. As a child and teenager growing up interacting with my cousin frequently, I just spoke, never questioning what language to use. When in the comfort of family, I just spoke and continue to speak naturally, having a fluid transfer between both languages, a concept called translanguaging a concept discussed further in chapter 1 under the definition of terms ((García, 2009; García & Li Wei, 2014). It was no different when interacting with my cousin, even after I was told he was special, language use was never a topic of discussion. My aunt and uncle worried about how rough we were playing not the language we were using to communicate with him. We were family, we loved each other, regardless of our differences we spent time together, we supported each other, and were there for each other.

While growing up, I never realized that he had a disability that would one day impact our relationship. I never realized that my family's struggles as an immigrant, predominately Spanish speaking Latino family, raising a child with special needs in the United States, was going to impact my personal and professional life so much. Seeing how others looked at my cousin, the anguish on my aunt and uncles faces throughout the years and hearing the stories of how they were struggling to help him, caused me to feel the need to help them, and help him, but I was too

young and inexperienced to know how. It was not until I began college, through my psychology courses that I began to see the disconnect between research and practice; that there was a difference between what I was learning in my classes through readings, homework, and lectures, and what I had lived growing up in my own family all those years. My childhood, adolescent, and now adult experiences, personally, academically, and professionally showed me that although my aunt and uncle were advised to only teach my cousin English, and to treat him with special care, for my family, that would have not worked. Within a bilingual family where many of the family members within our support system spoke little to no English, leaving my cousin without the ability to communicate and understand Spanish would have cut him off from many people in the family like grandparents and foreign-born family members. Traveling to Colombia would have been very difficult because almost no one in our family speaks English, yet he travels and thrives, because he can communicate in Spanish, and understand the language. He has shown himself to have strong metalinguistics awareness (Cummins, 1978). I have seen how he switches between the two languages when addressing people, he is aware that, that person does not know English, well or all. In the familial level of cousins, most are born in the United States, so we revert to speaking English more than Spanish, or Spanglish, yet when he speaks to my Parents who are not American born, he is aware that they speak more Spanish. Many times, I have been sitting in a room talking to my cousin in English and my mom steps in the room and begins talking to him and he switches to Spanish to address her but then reverts back to English when addressing me, although I speak Spanish fluently.

We were and continue to be a predominately Spanish speaking Latino family, where our daily conversations, family gatherings, parties, festivals, traditions, and so many other cultural celebrations continue to be in the Spanish language. As of today, there are grandparents and

family from either, older generations, recent arrivals to the United States, or some that just come to visit, that speak little to no English, yet he communicates with them. For those who can speak English, the familial conversations, the music played at parties, gatherings, and celebrations are still predominately in Spanish, because that is our culture, our identity, or preference of music, games, and songs. As a family we integrate both American cultural activities, language, and music with our Latino culture, language, and music. My cousin as a child was able to and today as a bilingual adult with Down syndrome, is still able to join in those family cultural celebrations singing, dancing, and participating with all of us in both Spanish and English. Regardless of the disability he was born with, my cousin hangs out with all of us, takes selfies, uses social media, and jokes around. He is not limited in his interaction with us because he can speak and understand both the languages, which are utilized at any given moment during those interactions.

I personally have never had a conversation with my cousin asking him if he knows he is different, if he feels different, if he sees us as being different, if language is part of the difference? From all the conversations I have had with various family members, and the most important in my perspective, his parents, no one has ever had such a conversation. All we know is that he is family, so we must be able to communicate with him and him with us, so we can make sure he has the best quality of life that we can give him. All these experiences served to shape my beliefs on the subjects of bilingualism, preservation of the native language and culture, meaning making of family, and the linguistic and mental capacity of individuals with DS. I hold the belief that individuals with DS, raised within a Latino bilingual home, should be given the opportunity to learn both Spanish and English, since those are the languages of their family. I strongly believe that people with DS can build strong familial relationships regardless of the language they are spoken to since it is human nature to connect and socialize with one another,

but they should not be denied the opportunity to learn the native language of their family, since previous research has demonstrated that having a cognitive disability is not a deterrent for bilingual language learning (Kay-Raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kay-Raining Bird, Trudeau, & Sutton, 2016; Paradis, 2007).

It is important that I am clear about my personal beliefs and experiences, in order to conduct qualitative interviews with ADS that are bias free, although I am also aware that these beliefs can influence the way I will ask questions, interpret the data, and provide a final report of the data. This awareness and process is called positionality, where the researcher must reflect upon their own past experiences and predispositions since they could influence the way questions are asked, interpreted, and in the final write up of the data (Merriam & Tisdell, 2016). Positionality is accomplished through reflexivity, the researcher's personal stance on the topic of interest (Bourke, 2014), in this case, my personal beliefs on issues concerning bilingualism with Latino families, Down syndrome, and the importance of preserving the native language and culture regardless of the person's disability. My positionality and reflexivity will be further discussed in Chapter 3.

Statement of the Problem

Previous research focuses on the linguistic capacities of individuals with DS and how dual language exposure can hinder or support their cognitive development (Chapman & Hesketh, 2001; Kay-Raining Bird, et al., 2005), yet research regarding how an ADS makes meaning of family within Latino bilingual homes, where the ADS is the primary perspective taken in account, is missing in the research. In the current study, the term family is defined by the ADS, where they identify important people in their lives, whom they consider family. Meaning making is viewed as an internal mental process. It is understood in this study as the concept of mind

action, as defined in symbolic interactionism, as the ability for the individual to use symbols that have common social meaning created by the interactions with others (Charon, 2004), in this case family members. As people grow, words become symbolic, whereby social meanings get attached to words. A collection of words, i.e. language can then be interpreted by an individual to understand the meaning of family, through verbal communication. Non-verbal communication, such as gestures, tones, affect, and other objects in the environment are also used to understand how the ADS makes meaning of family, within Latino, English-Spanish speaking families (Charon, 2004).

Conversations and research about their development should include their opinion and thoughts, especially when there continues to be a push for English-only, in regard to the person with disabilities development (Guiberson, 2013a Paradis, 2016). It is estimated that the number of individuals (children, teens, and adults) with Down syndrome living in the United States is 1 out of every 1200 people (Presson et al., 2013). The estimated number of ADS currently living in the United States is unknown (Global Syndrome Foundation, 2018). There are 61 million adults with disabilities, 1 out of every 4, living in the United States, where less than 7% live independently (“Disability Impacts all of Us,” 2019). Meaning, that 93% of adults with disabilities, are over the age of 21, reside with family members, and have aged out of the public education system. Unless family members have enrolled the adult with a disability in local vocational training, the majority of the person’s time will be spent at home with the family. In the United States 21% of the population (Ryan, 2013), speaks a language other than English at home. Understanding, how individuals with disabilities, specifically ADS, make meaning of family while raised in bilingual homes, is important since the family members are the ones these individuals will spend most of their lifetime with.

For five years I have searched for a study that had interviewed individuals with Down syndrome and to date have been unsuccessful in finding one. Less than ten studies were found that directly addressed an adult with a disability and were published in the last 10 years. These studies investigated topics about employment needs, experiences, and access (Holwerda, et al, 2015; Patterson, 2013; Payne, 2010), lived experiences throughout the lifespan (Pointu, 2017), views towards physical education (Haegele & Sutherland, 2015), and living with anxiety, as well coping strategies (Marwood & Hewitt, 2012). Only one article was found where the person with a disability was the researcher, providing an in-depth perspective of his life (Hughes, 2016), which was also published in the last ten years. Hughes (2016) published a qualitative autoethnography research article, where he speaks about his life as an adult who lives with the diagnosis of Asperger's syndrome. He provided his perspective on the challenges he faces and others like him, when interacting with the world in social settings.

Worldwide, there are many people with DS that are doing great things, well beyond what is stereotypically expected for a person with a disability. Touchdown 21 (n.d.) is a research project made by people with DS about people with DS. This organization has gathered global information about people with DS highlighting their accomplishments, giving them a voice in regard to the topic of DS, their daily lives, creating awareness about the disability through eyes of those who live with it. They create exhibitions, seminars, forums for open dialogue, and a place to publish research about, for, or done by individuals with DS. This organization is based out of Germany but has pushing for global awareness for the capacity of individuals. As they state: "People with Down syndrome are found all around the work. They run food stalls, do powerlifting, and get their driver's license" (Touchdown 21, n.d.). Continuing the effort to create awareness and educate others on DS and individuals with DS, this study aims to highlight the

voice of the ADS, providing their perspective, as the singular voice in regard to their development in bilingual Latino homes in the United States. The current study can be seen as one of the first steps to providing the perspective of ADS, as it pertains to the area of making meaning of family when raised in bilingual, English-Spanish speaking, Latino homes.

Importance of the Adults with Down syndromes' Perspective

An ADS who is born into a Latino, English-Spanish speaking home, will be exposed to both languages since utero. Previous research has demonstrated children with DS, can become successful bilinguals, where they can learn more than one language without detrimental effects to their development (Kay-Raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kay-Raining Bird, Trudeau, & Sutton, 2016; Paradis, 2007), yet the myth persists, amongst service providers, parents, the educational system, and the overall system of care (Beauchamp & MacLeod, 2017; Guiberson, 2013; Kay-Raining Bird, et al., 2005; Peña, 2016; Thordardottir, 2002; Wong Fillmore, 2000) that bilingualism creates confusion and can delay the development of children with disabilities. When DS children have ample, consistent, and ongoing exposure to two languages, they are able to develop bilingual capacity, without hindering the development to the dominant language, as demonstrated by the comparison to children with DS who are developing in only the English language (Kay-Raining Bird, et al., 2005). On the contrary, the loss of the home-language, creates a disconnect between children, parents, and other family members, when they are limited English speakers (Thomas & Collier, 1997; Wong Fillmore, 2000), as in the case of Latino families in the United States (Cortes, 1995; Guardado, 2006; Farruggio, 2010; Worthy & Rodriguez-Galindo, 2006).

Within the United States, over 73% of Latinos speak Spanish at home Latino (Krogstad & Lopez, 2017), exposing children to the native language regardless of intent. If these families

have children with disabilities, such as DS, this places children within a predominately bilingual home, where exposure to Spanish is unavoidable. Latino families place importance on the ability to speak Spanish, have clear communication, and strong familial ties with each other, inclusive of all members, regardless of disability, creating a sense of familism (Cortes, 1995; Guardado, 2006; Wong Fillmore, 2000), which is a deep-rooted sense of family loyalty, obedience, and respect through the preservation of their culture, family characteristics, morals, values, and behaviors, grounded in the native language (Cortes, 1995; Stein et al., 2013). In a study conducted by the Pew Research, Hispanic Center, Latinos were asked, about language preservation, and 95% responded that Spanish should be passed down to future generations and preserved (Taylor, Lopez, Martinez, & Velasco, 2012). Spanish is viewed as an integral part of the culture. Parents of children with DS and other cognitive disabilities are still advised that they should teach their children only English (Kay-raining Bird, Genesee, & Verhoeven, 2016), yet this is a difficult task when children are born into a home where English is not the dominant spoken language, as in the case of 21% of the U.S. population (Ryan, 2013). When discussing the development of individuals with DS within bilingual families, findings come from the perspective, of either, the service providers and parents (Hughes, Valle-Riestra, Arguelles, 2008; Paradis, 2016), or quantitative scales and academic outcomes (Chapman & Hesketh, 2001; Kay-Raining Bird, et al., 2005), yet there is a gap, since no research was found that directly speaks to the individual with DS about their development.

Research Question

The aim of this study is to give Latino ADS a voice with a literature. Specifically, the purpose is to demonstrate how a Latino ADS makes meaning of family, when raised in a bilingual, English, Spanish speaking home. Previous research has documented the advantages of

bilingualism amongst both typically developing children and CWD (Cummins, 1981; Guiberson, 2013a; Kay-Raining Bird et al., 2005; Kay-Raining Bird, Lamond, & Holden, 2012; Paradis, 2001; Paradis, Schneider, & Duncan, 2013), yet there continues to be a disconnect between research and practice when working with people with cognitive disabilities, such as that with Down syndrome (Peña, 2016). Previous research in the field of Down syndrome has also demonstrated that they can become successful bilinguals, yet the “confusion myth” persists (Guiberson, 2013a; Kay-Raining Bird et al., 2005; Kay-Raining Bird, Lamond, & Holden, 2012; Paradis, 2001; Paradis, Schneider, & Duncan, 2013). The current study does not aim to provide further support for the topic of bilingual capacity amongst individuals with DS, rather it utilizes previous research in this area to demonstrate that people with DS that grow up in bilingual homes, will be exposed to more than one language in their development, regardless if the parent or service providers believe it is a benefit or disadvantage to the person with the disability. Exclusively, within Latino, Spanish-English speaking families, in the United States, who have ADS living within the home, the current research aims to providing the perspective, of Latino ADS as it pertains to their development on the concept of family. The research question that guides the study is as follows:

Research question: *How does a Latino adult with Down syndrome make meaning of family, while growing up in a bilingual, Spanish-English speaking, home?*

Definition of Terms

Through the lens of the ADS, the close relational interactions were examined to understand the process of meaning making as it pertains to the concept of family. Meaning is a fundamental part of life, where people act, react, and interpret their surroundings based on the meanings they place upon, person, events, situations or experiences (Carter & Fuller, 2016;

Chen, 2001; Krauss, 2005). Meanings are created, modified, and impacted by the day to day interactions with the others, as well as the cultural and linguistic context (Blumer, 1969; Carter & Fuller, 2016; Vygotsky, 1978). Through the lens of symbolic interactionism (further discussed in chapter 2), meanings are created in the Mind (Charon, 2004). Blumer provided insight on mind action, where the individual is constantly engaging in self talk, from the moment we awake until we fall asleep. As we encounter others, objects, and events throughout our day we engage in an on-going mental process to define these situations. As people interact with one another, meanings are attached to the symbols within the interaction of the given situation. In turn, symbols, can be verbal or nonverbal, such as words or gestures (Blumer, 1969; Charon, 2004). In this study meaning making refers to the individual's life experiences that created, changed, or enriched meanings that in-turn provided an explanation for the concept of family (Chen, 2001; Dewey, 1933).

Although the ADS identified those people who they consider to be family and provided the overall understanding of concept of family, from their perspective, for this study a definition of family is also given to serve as a guide. Family is defined as “including two or more people who regard themselves as a family and who carry out the functions that families perform.... who may or may not be related to by blood or marriage and may or may not usually live together” (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015, p. 6). This is all-inclusive definition that provided a foundation for the understanding that family is a term that is defined by each person making it organic, individualistic, for each Latino ADS interviewed.

Meaning of family for these individuals was created within a Latino bilingual context. Latino is understood as a group of people who live the United States, who can trace their roots back to Spanish-speaking countries (Taylor, Lopez, Martinez, Velasco, 2012). Language in this

study, refers to the means of communication by the ADS that is either verbal or non-verbal, whereby they use Spanish, English, gestures, tones, affect, or objects to express themselves. Language is viewed as an on-going process rather than static (i.e. *linguaging*), focusing on it as a tool for communication (Conteh, 2018). This study does not focus on the use of which language, either English or Spanish, rather it uses *linguaging* (Conteh, 2018), either verbal or non-verbal to provide access to the ADS voice. Bilingualism is defined as the use of two languages either jointly or separately for different reasons with different people in one's life, creating fluency between the use of two or more languages, rather than the use of two distinct languages with separate boundaries, such as speaking Spanish or English (Grosjean, 2010). In this study, bilingualism refers to prolonged, intense, ongoing exposure to two or more languages, whereby there is fluidity through either verbal usage or mental understanding (Garcia, 2009; Grosjean, 2010; Kay-raining Bird et al, 2005), further discussed in chapter 2.

Studies dealing with the of language practices amongst people who speak more than one language can also be understood through the concept of *translanguaging* (García, 2009; García & Li Wei, 2014; Otheguy, García, & Reid, 2015; Li Wei & García, 2017). With origins in bilingual education, translanguaging provides a beneficial understanding of multiple language usage within classroom settings (Conteh, 2018; Garcia, 2009) as well as familial settings (Mazzaferro, 2018). It builds upon the notion of Cummins (2001) *common underlying proficiency*, where multi-language usage is viewed as an integrated communicative process, where more than one language is used when communicating (Conteh, 2018). Although translanguaging is a an important paradigm shift in the understanding of multilingual communication profiles (Conteh, 2018), the current study more focused more on the meanings that ADS place upon the interaction with others to create an understanding of what they consider

family to be, rather than how language is used to communicate, excluding the topic of translanguaging (García, 2009; García & Li Wei, 2014).

Down Syndrome

In the United States 1 in 700 babies are born every day with the developmental disability, Down syndrome (Center for Disease Control and Prevention, 2017). According to the United States National Library of Medicine (2018), DS is defined as a chromosomal disorder where each cell in the individual's body has an extra chromosome 21 (Trisomy 21). In the majority of the cases, this means the person has three chromosomes 21, rather than the normal two. A small percentage, less than 4%, have just two of chromosomes 21, but a small piece of one the chromosomes attached to a different chromosome, called translocation which occurs during the formation of reproductive cells. Less than 1%, have some body cells with three chromosomes 21 and others with just two, called Mosaic DS (U.S. National Library of Medicine, 2018). DS is not considered a hereditary disorder when it is classified as Trisomy 21 or Mosaic, rather it is viewed as an abnormal random event that occurs in the formation of the reproductive cells of the parent, during cell division in the early stages of fetal development. An unaffected parent can pass down translocation DS where the child is born with condition, since the rearrangement of genetic material was balanced for the parent but became unbalanced when inherited by the child, during fetal development (U.S. National Library of Medicine, 2018).

When a child is born with a genetic disorder that is associated with a language delay, as is DS (National Down Syndrome Society, 2018), one of main concerns by both parents and professionals is exposure to more than one language and how that will impact the child's development (Kay-raining Bird, et al., 2005). All children with DS have language delays, cognitive delays, mild to moderate intellectual delays, physical and biological malformations

(National Down Syndrome Society, 2018; U.S. National Library of Medicine, 2018). Physical abnormalities include distinct facial features across all individuals affected by this disorder and weak muscle tone (U.S. National Library of Medicine, 2018). Biological conditions can include an array of gastrointestinal disorders (i.e. blockage and reflux), celiac disease, and Alzheimer's in older age. A small percentage develop a hypothyroidism, and a small percentage develop cancer (i.e. leukemia). Half of all children with DS are born with heart defects, that can range from mild to severe conditions, while other children also develop vision and hearing problems (Lockrow, Fortress, & Granholm, 2012; U.S. National Library of Medicine, 2018).

Understanding the Diagnosis

Individuals with DS can have an array of medical and mental conditions, which vary depending on the individual (Lockrow, Fortress, & Granholm, 2012; National Down Syndrome Society, 2018; U.S. National Library of Medicine, 2018). When working with this population the researcher must consider the following challenges individuals with DS can face throughout their development: co-morbidity (i.e. ADD/ADHD, Tourette syndrome, echolalia, Autism, and Alzheimer's) (Ekstein, Glick, Weill, Kay, & Berger, 2011; Oxelgren et al, 2017), communication (i.e. intelligibility, comprehension and expression (semantic vs. syntax)) (Chapman, Schwartz, & Kay-Raining Bird, 1991; Kent & Vorperian, 2013; Martin, Klusek, Estigarribia, & Roberts, 2009; Wild, Vorperian, Kent, Bolt, & Austin, 2018), and their general ability to learn (Mills & Black, 2014).

Co-morbidity. When working with individuals with disabilities it is important to understand the cognitive, physical, and psychological characteristic caused by the disability, yet it is as equally important to know that co-occurring mental disorders that can make this work more challenging. Individuals with DS can have co-existing disorders such as ADD/ADHD,

Tourette syndrome, Autism, and Alzheimer's (Ekstein, Glick, Weill, Kay, & Berger, 2011; Kerbeshian & Burd, 2000; McCarron, Gill, McCallion, & Begley, 2005; Oxelgren et al, 2017). These individuals can be considered a severely disabled group (Oxelgren et al, 2017).

Researcher has demonstrated that Attention deficit disorder/Attention deficit hyper disorder (ADD/ADHD) like behaviors and symptoms can occur in as high as 80% of individuals with developmental disability, such as DS (Frazier et al, 2001). In a study conducted by Edvardson et al (2014) over 30% of the participants with DS fit the criteria for dual diagnosis with ADHD. ADHD is a neurobehavioral disorder characterized by poor impulse control, inability to sustain attention, an increase in distractibility, motor activity, and a decrease in self-control behaviors. These symptoms become problematic interfering with the normal functioning of the individual. Edvardson et al (2014) concluded that the prevalence rate was high compared to the general population and that this co-existing disorder may be underdiagnosed amongst the population of individuals with DS. There are not adequate tools to distinguish between the phenotypic characteristics of ADHD and those that are typical of DS. This results from a lack research and treatments for individuals dually diagnosed with ADHD and DS (Edvardson et al, 2014)

Recent research has also demonstrated a high prevalence rate for a dual diagnosis of Autism and Down syndrome (Ekstein, Glick, Weill, Kay, & Berger, 2011; Oxelgren et al, 2017). A study conducted by Oxelgren et al. (2017) recruited 41 participants between the ages of 5 to 17 years old. With parental consent all DS children were then tested to see if they fit the diagnoses of Autism or ADHD. This resulted in 42% of participants meeting the criteria for ASD and DS and 34% meeting the dual diagnosis criteria for ADHD and DS. Common behaviors observed in this dually diagnosed population are as follows: food refusal, difficulty with changes in routines,

little to low meaningful communication, self-injurious behaviors, disruptive behaviors, unusual play or responses to sensations, hyperactivity, regression, and sleep disturbances (Capone, 2018). Specifically, DS and ASD are lifelong developmental disabilities that can range from low to severe symptoms that can cause disruptions in the daily interactions and functioning of the individual (Capone, 2018; Oxelgren et al, 2017). The incidence rate of this co-existing disorder is estimated to be between 5-7% (Capone, 2018).

Echolalia is also seen in children with down syndrome and autism, predominately those with a dual diagnosis, since it is predominately known as a sign for autism (Shield, Cooley, & Meier, 2017). Individuals with this diagnosis exhibit parrot like behavior, where the individual repeats words said to them either immediately or later. In order to fit the criteria for diagnosis the person must have repetitive involuntary motor tics and vocal tics for at least 1 year (Shield, Cooley, & Meier, 2017; Tourette disorder fact sheet, 2018). Another involuntary communicative disability is Tourette syndrome a disorder, which is less common to co-occur within the DS population, yet still note-worthy due to complications in communication that occur when an individual does suffer from this disorder. In a study conducted by Kerbeshian & Burd (2000), only 2% (i.e. 5 participants from a total of 258) of the individuals met the DSM-IV criteria for having both Tourette and DS. Tourette syndrome is characterized by repetitive and involuntary motor and vocal tics (Tourette disorder fact sheet, 2018). These movements can be sudden, simple, complex, last briefly or for an extended period of time. Communicating with individuals can become complex with the sudden onset of involuntary behaviors. Some individuals suffer from coprolalia, which is the sudden onset of shouting out inappropriate or crude words.

Research has also demonstrated up to 40% of individuals with DS over the age of 35 suffer from Alzheimer's and some form of dementia (Prasher & Krishnan, 1993). Individuals

with DS who also suffered from Alzheimer's and dementia had an array of medical and mental problems that worsened with age (McCarron, Gill, McCallion, and Begley, 2005). These individuals require special medical care at the end-stages of the disorders, as in the study conducted by McCarron, Gill, McCallion, and Begley (2005), where 36% of the participants were tube-fed and 88% were totally immobile. Almost 90% of the participants suffered from visual impairments and 38% suffered from depression. Lung disease and epilepsy were also heightened co-existing conditions amongst the participants, where 55.5% suffered from either lung disease or epilepsy.

Communicative profile. It is important to understand the communication profile of individuals with DS, in order to gain a better understanding of how individuals with DS developed a sense of family in Latino bilingual homes while growing up. In a study by Wild, Vorperian, Kent, Bolt, & Austin (2018) adults with DS were interviewed due to difficulties in intelligibility before the age of 16. Intelligibility refers to ability to be understood or comprehended (Intelligibility, 2018). There is reduced speech intelligibility in people with Down syndrome, resulting in frequent communication barriers and feelings of frustration amongst both the person with DS and the family member (Kent & Vorperian, 2013; Wild, Vorperian, Kent, Bolt, & Austin, 2018). For individuals with DS, there is a critical period of linguistic development between the ages of 4 to 16 years old. Although the individual can achieve high levels of intelligibility by age 16, progressing into adulthood, there continues to be difficulty in comprehension, sentence formation, and expression (Kumin, 1994; Wild, Vorperian, Kent, Bolt, & Austin, 2018). Speech intelligibility is considered a widespread problem amongst individuals with DS (Kumin, 1994).

Individuals with DS have stronger receptive language and vocabulary than expressive language and syntax (Martin, Klusek, Estigarribia, & Roberts, 2009). In other words, individuals with DS can understand more than they can speak. Non-verbal cognitive ability and vocabulary comprehension of adolescents and ADS either matches or exceeds the ability of their typically developing counterparts (Chapman, Schwartz, & Kay-Raining Bird, 1991; Glenn & Cunningham, 2005). Meaning, that when compared to individuals of that same age, without disabilities, teenagers with DS and ADS either match or surpass them in non-verbal cognitive abilities and linguistic comprehension. Before the age of 21 educational institutions provide support and constant services through the school day, providing the opportunity for linguistic development for students with DS. Previous research has examined children and adolescents with Down syndromes' linguistic development and bilingual capabilities (Chapman, 2006; Chapman & Hesketh, 2001; Cleave, Kay-Raining Bird, Czutrin, & Smith, 2012; Kay-Raining Bird et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016), yet there is limited research that examines their linguistic capability into adulthood (Wild, Vorperian, Kent, Bolt, & Austin, 2018).

Learning profile. Individuals with DS have a specific learning profile that consists of distinctive strengths and weakness, due to the cognitive impairment (Down syndrome Foundation of Orange County, 2015). The areas of strength are in social skills, visual short-term memory, and daily independent living skills (Mills & Black, 2014). People with DS are described as social-able individuals, with great social comprehension skills. Many are characterized as being empathetic, socially sensitive, with an understanding of social cues, facial expression, emotion, body language, and tones of the voice (Down syndrome Foundation of Orange County, 2015; Mills & Black, 2014). Others include visuospatial short-memory recall

and visual processing, identifying individuals with DS as visual learners (Down syndrome Foundation of Orange County, 2015; Lockrow, Fortress, & Granholm, 2012). They have strengths in reading, performing at rates equivalent to or better than their typically developing counterparts (Down syndrome Foundation of Orange County, 2015; Chapman, Schwartz, & Kay-Raining Bird, 1991). This is important to understand, since reading activities can help improve spoken language skills, cognition, grammar, and memory for children with DS, areas where they have weaknesses (Down syndrome Foundation of Orange County, 2015).

The areas of weakness for individuals with DS as outlined by the Down syndrome Foundation of Orange County (2015) are speech and language development, hearing and visual impairments, verbal short-term memory, motor skills, and information processing (Mills & Black, 2014, Ratz, 2013). Speech and language impairment yield low intelligibility (Wild, Vorperian, Kent, Bolt, & Austin, 2018), marked by a limitation in oral expression as compared to cognitive understanding (Down syndrome Foundation of Orange County, 2015). Deficits in vision, hearing, and verbal short-term memory can impact learning, especially language, if the child cannot see the object spoken about in the conversation, retain the information temporarily, nor hear clearly the instructions, commands, story, consonants, tones, and verbal cues given by the other. Information processing weaknesses are characterized by difficulty storing and processing information, resulting in deficits in language and working memory. Motor skills deficits are viewed as a near weakness, since most individuals with DS will generally reach the developmental milestones, although there may be a delay in acquiring these skills (Down syndrome Foundation of Orange County, 2015).

Individuals with DS already have frustrations when trying to communicate with family members, due to reduced intelligibility (Kumin, 1994). Preventing them from accessing the

families' native-home language by denying them the opportunity to acquire this tool for communication can serve to enhance this feeling. When the parents cannot communicate with their children because of a language barrier, then children are left to fend for themselves in a dominant culture they are unfamiliar with and a native culture they do not identify with. They are left without parents who can serve as a primary resource to guide them throughout their development in distinct environmental context. The parental and familial connections are limited and the ability to teach children how to socialize in the dominant and minority culture are then lost (Wong Fillmore, 2000). Language is a communicative tool, where the first language can serve as support for second language acquisition (Cummins, 1981; Guiberson, 2013; Paradis, 2007). Research has shown how a strong development in language 1 (L1) can serve to support the development in language 2 (L2) (Cummins, 2001, 1981; Guiberson, 2013, 2013a) As in parents whose home-language is not English in the United States, they teach their children strong foundation in L1 which will serve as an essential support for the acquisition of L2, the English language (Cummins, 1981; Thomas & Collier, 1997). As in the case of many families in the United States, since 1 out of 5 families the dominant home-language is not English (Ryan, 2013).

Background and significance

For many children born across the United States, bilingualism is not a choice, rather it is a reality. More than 20% of the U.S. population speaks a language other than English at home, where the most common non-English spoken language is Spanish, spoken at home by over 37 million Latinos (Gonzalez-Barrera & Lopez, 2013; Ryan, 2013). In this study Hispanic and Latino will be used interchangeably, as defined by the U.S. Census Bureau (2018), which pertains to those individuals with a shared ethnicity, outlined by similarities in language (i.e. Spanish), culture, or origin, regardless of race. The Latino population reached almost 57 million

in 2015 (Krogstad, 2016), where almost 30% of individuals in the United States, do not speak English “very well” or “at all” (Ryan, 2013). Many children are born into an environment where the native-home language differs from the larger society, requiring them to learn both languages in order to navigate within and between their environmental contexts. These children are then considered bilingual, where the use of their languages will increase or decrease over time, depending on the changes in their daily linguistic interactions (Bialystok, 2001), regardless of the limitations of the disability, dual language exposure cannot be prevented when the home environment is bilingual.

About 33% percent of U.S. families have at least one family member with a disability living within the home (Wang, 2005) and not all these homes are monolingual, English speaking. Many Latino families must confront their inability to speak English well, or at all, while raising a CWD in the United States, where the dominant cultural language is not their primary home language (Ryan, 2013). With the infinite number of medical and physical needs a child with a disability can have, concerns about communication (i.e. language usage) should not be an added stressor for Latino families, when research has demonstrated that children with DS can become successful bilinguals without harmful effects to their development (Kay-Raining Bird et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Guiberson, 2013a; Peña, 2016). Previous research has examined the topic of individuals with Down syndrome and bilingualism on a macro-level perspective, meaning the perspective of parents, family, (Guiberson, 2013b; Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008), and service providers (Kremer-Sadlik, 2004; Levey & Sola, 2013; Wharton, Levine, Miller, Breslau, & Greenspan, 2000), through the use of quantitative-scales or academic achievement (Feltmate & Kay-Raining Bird, 2008; Kay-

raining Bird et al, 2005; Paradis, Crago, Genesee, & Rice, 2003) to describe their linguistic ability.

Parents and Family

Raising a family is a difficult task. The birth of a child with a disability, can represent the loss of the ideal child for most parents, where parents can grieve this loss as they begin to adapt to their new reality and way of life (Ellis, 1989; Roll-Pettersson, 2001). Parents and caretakers worry about quality of education, safety, and providing the basic needs for their children, with added concerns when a CWD is born (Renty & Roeyers, 2006; Roper, Allred, Mandelco, Freeborn, & Dyches, 2014; Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008). This new reality comes with questions, fears, confusion, but can bring hope, unity, love, and compassion (Roll-Pettersson, 2001). Specifically, for families with children with DS, nearly 40% had at least one member stay home to provide fulltime care for the child and nearly 40% also suffered financial problems due to their child's condition (Schieve, Boulet, Kogan, Van Naarden-Braun, & Boyle, 2011). Latino families with children with DS, not only worry about medical and financial care, but they must confront concerns communicating with children's schools and service providers due to their own limited English proficiency (Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008), and apprehensions surrounding home-language use (Guiberson, 2013b).

Latinos families must learn to navigate, an English-dominated society, culture, and education system, but also a Special Education system, in order to ensure their children receive the necessary services for their overall physical, mental, and psychological care (Roper, Allred, Mandelco, Freeborn, & Dyches, 2014). In a study by Tejero Hughes, Martinez Valle-Risestra, & Arguelles (2008) 16 Latino bilingual families were interviewed in order have their voices heard

within the conversation of raising children with special needs. Latino parents said they treated the all children as if they were normal, they did not treat any child differently because of a disability, which included conversations around language since 37% of the primary care givers (the mothers) did not speak English well, where over 87% of the families ($n = 14$) conducted the semi-structured interviews in Spanish. Parents also stated that a child with special needs required extra care and more attention on a daily basis than their other typically developing children. They indicated that there was an increased level of involvement in the child with special needs' academic life, advocating, parent-teacher conferences, and meetings. Families detailed hopes, goals, and concerns about their children's future, talking about ability to self-sustain and gain independence. Parents described an overall feeling of grief, frustration, helplessness, and worry when dealing with their children. Although families express a satisfaction with children with special needs academic programming, they still indicated they would benefit from improved communication with professionals (Renty & Roeyers, 2006; Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008). Tejero Hughes, Martinez Valle-Risestra, & Arguelles (2008) concluded that there is a great need to understanding the Latino sub-culture, home-life, and experiences, since families continue to express there is a disconnect between themselves and the educational system, when raising children with special needs in the American-culture, as supported by similar findings (Harry, 1992; Kalyanpur et al., 2000; Rueda et al., 2005; Zetlin et al., 1996).

Coupled with various decisions surrounding the topics of education and long-term care, the other major concern for families is language confusion and possible delays (Guiberson, 2013a), if the family's home-language is not English. According to Guiberson (2013a) the common belief, still persists today, that children, with or without a disability, would become

confused and delayed in their development during the acquisition of more than one language, yet research has shown that this is not the case amongst typically developing children and CWD (Cummins 1981; Guiberson 2013a; Kay-Raining Bird et al., 2005; Paradis 2001; Peña, 2016; Wong Fillmore, 2000). Guiberson (2013b) conducted a study where (n = 71) Hispanic parents of children who are deaf or hard of hearing (DHH), whose home environment is bilingual, were asked to complete a survey anonymously. The survey design allowed for participating parents to communicate information about their personal familial experiences and aspects pertaining to decisions about bilingual language exposure and communication modality. It contained questions there were related to four specific topics: (1) family involvement and supportiveness, (2) professional involvement and supportiveness, (3) accessibility to information and services, and (4) bilingual variables (Guiberson, 2013b).

The participating families were from 13 of the 17 autonomous communities in Spain, where 40% were from Madrid, and 24% were from communities where they spoke an autonomous community Spanish dialect (e.g. Galicia, the Basque Country, Catalonia, or Valencia). The majority of participating children had severe-to-profound hearing loss, 69% had cochlear implants, and 32% had secondary implants. Of the 71 families in the study, 73% had children with DHH and 27% of families had children with other disabilities. Communication amongst parents and children varied, where 50% of families selected an oral only mode, 24% used oral and sign language, 20% selected only sign language, where 38% of these families were spoken language bilinguals. A one-way ANOVA was used to analyze the three groups (e.g. oral-only, oral and sign, and sign only). In regard to the family's decision-making factors when pertaining to language exposure the first area examined, family involvement and supportiveness, no significant differences were found amongst the groups. Across the groups, it was reported that

partners and grandparents were most supportive and other family members and friends were less supportive. Similarly, in the United States, Latino families also report partners and grandparents as the most supportive and involved in decision-making process when pertaining to the topic of bilingualism and home communication modality (Puig, 2012; Steinberg, et al., 2004).

Guiberson (2013b) concluded that there no significant differences were found amongst the groups in regard to professional involvement and supportiveness. All groups reported the most support came from speech and language pathologist, audiologists, and deaf educators. Meanwhile, somewhat support came from teachers, principals, Otolaryngologists, and less support came from General doctors, pediatricians, and counselors. There was a significant difference found amongst the groups in regard to accessibility to information and services, where the sign only group rated this more important than the other two groups. It is important to note that 71% of parents overall rated the type of services provided by the school-setting important-very important influential factor when they were making decision about home communication modality. In the final area of research, bilingual variables, Guiberson (2013b) sought to describe the factors that are related to parental decision-making in regard to spoken-language bilingualism for children who are DHH and if the bilingual variables are indicators for children's bilingual ability in a country where bilingualism is a common belief. Bilingual variables were examined in four specific areas: 1) family bilingual status and characteristics, 2) parental beliefs about bilingualism, 3) encouragement or discouragement related to raising their child spoken-language bilingual, and 4) aggregate variables (e.g. child's bilingual score, parents' bilingual score, parents' beliefs about raising children spoken-language bilingual, and parents' beliefs about raising children who are DHH spoken-language bilingual).

Guiberson (2013b) concluded that there was a positive and significant association between children's bilingual status and the first three bilingual variables, when compared individually (i.e. family bilingual status and characteristics/bilingual status; parental beliefs about bilingualism/bilingual status; and encouragement or discouragement related to raising their child spoken-language bilingual/bilingual status). Over 80% of families indicated a belief that bilingualism was a natural occurrence, that their children could be spoken-language bilinguals, and children would benefit from it, yet this belief was not significantly associated with the parent's decision to raise DHH children as spoken language bilinguals, where only 38% choose to raise children bilingually. Guiberson (2013b) did not find a definitive reason as to why parents did not choose to raise children as spoken-language bilinguals. There was a no significant association between discouragement of bilingualism and parent decision-making, where 36% of parents with children with DHH stated that they had been discouraged to raise children as spoken-language bilinguals, while 50% of families received encouragement.

Guiberson (2013b) also concluded that when combined, family bilingual status and characteristics, parental beliefs about bilingualism, and encouragement or discouragement related to raising their child spoken-language bilingual were a significant predictor for children's spoken-language bilingual status, a country where there is a general positive outlook on bilingualism. This indicates that parents in Spain will often make the choice to raise their children as spoken-language bilinguals when they are supported and encouraged in their decision, similar to Latino families with children with disabilities (Puig, 2012; Steinberg, Bain, Li, Delgado, & Ruperto, 2003) such as those with children with DS in the United (Kay-raining Bird, Lamond, & Holden, 2012). A strong support system through reassurance from family members is a strong indicator that bilingual families (Kay-raining Bird, Lamond, & Holden,

2012), specifically Latino families (Steinberg, Bain, Li, Delgado, & Ruperto, 2003), will raise children with disabilities bilingually.

Service Providers

Service providers continue to push for mono-linguistic development for children with disabilities (Kremer-Sadlik, 2004; Levey & Sola, 2013; Wharton, Levine, Miller, Breslau, & Greenspan, 2000), going against the vast research that indicates there are no harmful effects to their development when raised in bilingual environments (Guiberson, 2013a; Kay-raining Bird, et al, 2005; Paradis, 2007; Pena, 2016). In a study conducted by Wharton, Levine, Miller, Breslau, & Greenspan (2000) three sets of immigrant parents all stated that they were advised by professionals to speak only in English to their children with disabilities, regardless of their own limited English proficiency (, 2000), similar to other research (Kremer-Sadlik, 2004; Nayeb, Wallby, Westerlund, Salameh, & Sarkadi, 2015; Peña, 2016). Levey and Sola (2013) recruited one hundred and twenty-four English speaking students who were speech and language pathologist in-training, where 52 were graduate students and 72 were undergraduate students from the speech-language-hearing sciences department at a major urban college. They were given a questionnaire with 20 statements, 12 were experimental statements, and 8 were foils from a major textbook where there were clear grammatical errors in linguistic development. The 12 major statements were broken down into two categories, the first consisted of 4 general simple statements about bilingualism that would be taught in any general course in the program, and the other 8 were technical statements that were complex and reflective of essential evidence-based information taught in course when speaking about patients were either English language learners or speak African American English. The majority of undergraduate and graduate speech and language pathologist in-training, who lacked coursework in bilingualism, believed that

children with specific language impairments should be taught in only one language (i.e. English), regardless of the family's home-language (Levey & Sola, 2013). When presented with the general statement "Parents whose first language is not English should only speak English in the home if their child has a language disorder" over 70% of students answered yes demonstrating a belief that children with disabilities should be taught only the English language to prevent confusion, and aid in their successful development of language.

Levey and Sola (2013) concluded that the participants that had taken bilingual course work had a better understanding of the differences in language development amongst persons from English limited backgrounds and/or African American English, versus what was truly considered a disorder. Students who had not taken bilingual course work had a lower understanding of children's linguistic development when raised in homes where the primary and sole language used was not English. Those that had taken bilingual course work scored six times higher on the technical statements. Only 77% of participants had taken bilingual course work during their program of study, although this type of course-work is generally considered mandatory in this program of study (Levey & Sola, 2013).

The overall conclusion was that although the majority of students had prior knowledge, they may still lack the necessary information and experience to understand difference versus disorder, continuing to push forward the recommendation to bilingual families that English only is the best way to support children's development (Levey & Sola, 2013). Research has demonstrated that service providers and teachers have a general awareness and belief the children with language impairments can develop bilingual, with difficulty, (Marinova-Todd et al, 2016), yet there is still a disconnect between this belief and practice (Peña, 2016; Levey & Sola, 2013). Parents of children with cognitive disabilities such as Down syndrome and Autism from

homes, where the primary language spoken is not English, continue to be advised by professionals to switch to single language in put (Kay-raining Bird et al, 2005; Kay-raining Bird, Genesee, & Verhoeven, 2016; Levey & Sola, 2013; Marinova-Todd et al., 2016).

Quantitative Studies and Academic Achievement

The language capabilities of children with disabilities has also been discussed and demonstrated by research in the area of academic achievement and/or through the use of quantitative measurements scales. Kay-Raining Bird et al (2005) demonstrated that bilingual children with DS tested for language abilities, scored, at least as well as, on English tests, as in comparison to DS monolingual peers, demonstrating that bilingual language development does not have adverse effects on the children's linguistic development, similar to other research (Feltmate & Kay-Raining Bird, 2008; Paradis, Crago, Genesee, & Rice, 2003). In more recent research, Kay-raining Bird, Lamond, & Holden (2012) investigated bilingualism within families with children with Autism Spectrum Disorder (ASD). A survey was given to 49 parents or guardians of bilingual families with children with ASD. The survey was designed to address the following five main questions: 1) Are bilingual families raising their children with ASD to be bilingual?; 2) What factors influence their decision to raise or not raise their children with ASD bilingually?; 3) How successful are individuals with ASD in becoming bilingual?; 4) What advice do families receive from professionals about raising their child with ASD bilingually?; 5) What needs or supports do families have to help them make decisions regarding bilingualism? The final survey consisted of 48 close-ended questions and three open-ended questions, whose results are not all addressed and reported in this article due to the lack of interpretable results (Kay-raining Bird, Lamond, & Holden, 2012), specifically, severity and type of secondary diagnoses, rating of severity of various behaviors, and rating of various abilities, as well as those

that were considered beyond the scope of the current study (i.e., questions regarding details of exposure and use of each language).

The results were reported addressing each of the five main questions. The first, are bilingual families raising their children with ASD to be bilingual, provided insight around the topic of parental decision-making factors. Seventy-five percent of families exposed their children to more than one language either in or out of the home since birth, while the remaining twenty-five percent decided not to expose the child to more than one-language although the family was bilingual. Some parents continued to expose children to more than one language, although the child was experiencing difficulty learning language, providing the explanation, that the child is going to struggle regardless so why not allow them to learn more than one language, while others, stopped exposure when the child demonstrated difficulties in language learning. The second main question, about factors that influence parental decisions surrounding the choice to raise or not raise ASD children bilingually, provided insight on the things to consider and examine when investigating this topic. One important factor was parents feeling of importance towards the need for children with ASD to be bilingual. Those who exposed their children to more than one language scored higher on importance, than those who choose monolingualism. Parents explained that children with ASD need to communicate with family members, school, and neighbors, as well as it opens up doors in the future for life opportunities, making bilingualism essential to their development (Kay-raining Bird, Lamond, & Holden, 2012).

Parents also discussed barriers as to why children should only be taught one language. They discussed concerns surrounding available supports from professionals, access to services, and the level of children's cognitive functioning. Parents believed that children with low functioning should not be exposed to more than one language. The third main question discussed

the success of individuals with ASD to become bilingual. There was individual variability amongst the level of success of bilingualism amongst the participants which is expected of bilingual children, regardless of the disability, due to external and internal factors. Ten children had either adult-like and age appropriate capability, verbal or written. Twenty children could read in two languages. Then eight of the children were monolingual although they were exposed to more than one language, demonstrating that although a child is exposed to more than one language it does not mean they will be bilingual. The fourth main question speaks about professional advice when raising children with ASD bilingually. Similar to previous research (Wharton, Levine, Miller, Breslau, & Greenspan, 2000), 43% of families were advised to only teach their child one language, while only 16% were encouraged. Six parents received conflicting advice, and eleven parents received only negative advice, compared to five that received both negative and positive advice, and three who received consistent encouragement (Kay-raining Bird, Lamond, & Holden, 2012).

Another important main question to consider speaks about types of supports available to parents when making the decision of bilingual language exposure, when raising children with ASD, where three needs were identified. The first is the availability of information on the impact of bilingualism on language learning for children with ASD and intervention strategies. The second is access to public support program and services, such as dual language immersion for children with ASD. The third area of need identified was training for service providers. Professionals should have adequate training to work with such a population from distinct linguistic backgrounds. The research by Kay-raining Bird, Lamond, & Holden (2012), provided a comprehensive look at children with ASD' bilingual capacity, parental decisions, and the advice given by professionals to parents of children with ASD regarding the topic of

bilingualism through the use of quantitative measurements, results are similar to those of parents with children with Down syndrome and other specific language impairment disabilities (Guiberson, 2013a; Kay-raining Bird et al, 2005; Paradis, 2007; Paradis, Crago, Genesee, & Rice, 2003, Peña, 2016).

Purpose of the Study

The purpose of this study is to give Latino Adults with Down syndrome an opportunity to provide their perspective on how they make meaning of family, when raised in bilingual homes. Previous research has examined children with DS and their capabilities to become successful bilinguals demonstrating that there are little to no negative effects to their development (Kay-Raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kay-Raining Bird, Trudeau, & Sutton, 2016; Paradis, 2007), since they already have to face challenges due to their disability, yet these conclusions are drawn from neurological research (Chapman, 2006; Rondal, 2009), quantitative scales (Cleave, Kay-Raining Bird, Czutrin, & Smith, 2012; Guiberson, 2013a, Kay-raining Bird, Lamond, & Holden, (2012), and the perspective of others (Hughes, Valle-Riestra, Arguelles, 2008; Paradis, 2016; Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008), rather than the ADS or child with DS. Research has not been found that focuses on the individual with DS's familial development in a bilingual context, with their direct perspective as the voice guiding the research findings.

Summary

Research has provided the perspective of others, through the use of surveys, questionnaires, and academic achievement scales (Guiberson, 2013a; Kay-raining Bird et al, 2005; Kay-raining Bird, Lamond, & Holden, 2012; Paradis, 2007; Paradis, Crago, Genesee, & Rice, 2003, Peña, 2016), through parental and familial qualitative interviews (Tejero Hughes,

Martinez Valle-Risestra, & Arguelles, 2008), and questionnaires' directed at professionals, such as speech and language pathologist (Levey & Sola, 2013), regarding the topic of bilingual language development and children with disabilities. Parents and guardians have been interviewed and asked to complete surveys, about their children's quality of life, regardless if their children were over the age of 18 (Leonard, 2016; Richardson, et al., 2011), yet there were no articles found that questioned the individual with the disability, specifically adults with DS, regarding their life when raised in Latino bilingual environments.

Latino children, regardless of a disability, can be born into either monolingual Spanish environment or one where more than one language is spoken, such as a Spanish-English speaking environment. The Latino population represents one of the fastest growing minority subcultures in the United States (Brown, 2014), where the most common language spoken at home is Spanish (Gonzalez-Barrera & Lopez, 2013). The U.S. Census Bureau (2010) projected that 82% of the U.S. population will be born into immigrant families or into U.S. minority families. Professionals such as teachers, psychologists, counselors and others working with these families will encounter bilingual CWD from birth to age 3 and as old as age 5, through early intervention services (Puig, 2010, 2012). The U.S. Census Bureau (2008) concluded that 28% of pre-school age children are being raised in homes where the main language spoken, is not English. Children do not have a choice whether or not they become bilingual, when they are born into homes where the native home language differs from the dominant cultural language, yet parents with CWD are advised on single language input, English, to aid in the success of the development of their children, and prevent delays, regardless if the parents can speak English well or at all (Kay-Raining Bird et al., 2005; Peña, 2016; Thordardottir, 2002). The persistent disconnect between research and practice serves to support the importance of understanding the

perspective of how a Latino adult with Down syndrome makes meaning of family, while growing up in a bilingual home, since they are the ones directly impacted by this disconnect.

Through direct personal interviews from the developing adult, rather than others, researchers can start to create strategies that support and strengthen bilingual language development and more important the overall familial development for people with DS, since 25% of the U.S. families have at least one adult with a disability living within in the home (Wang, 2005) and their voice is absent from the research creating a gap. There is very limited research that asks the perspective of the adult with a disability as it pertains to matters concerning their overall quality of life nationally and internationally (Holwerda, et al, 2015; Marwood, & Hewitt, 2012; Patterson, 2013; Payne, 2010). There was no previous research found that interviews the adult with Down syndrome (ADS) about making meaning of family, as it relates to being raised in a bilingual, English-Spanish speaking, home environment. This research aimed to fill this gap by conducting semi-structured qualitative interviews aided by select photographs from the participants lives, which allowed the researcher to gain an insight about how ADS make sense of family while growing up, in Latino bilingual, English-Spanish speaking, home environments, see Figure 1.

CHAPTER 2: LITERATURE REVIEW

The purpose of the study is to give the perspective of Latino ADS in regard to how they make sense of family when being raised in a bilingual home. Dual language exposure is an integral part of life when a child is born into a family where the family's native language is other than English. In order to gain a better understanding, this chapter grounds the study in a social constructivist epistemological perspective (Cottone, 2007; Guba & Lincoln, 1994), where symbolic interactionism (Blumer, 1969; Charon, 2004; Mead, 1967) is used as the analytical and

theoretical framework for inquiry. Next, this chapters provides the research question that guides the study, with the conceptualization of the terms of bilingualism and meaning making. Then the chapter provides a review of the literature to demonstrate the rationale for the study, by including research about the discrimination placed upon children who were bilingual when testing for intelligence. Historically, bilingualism has been shown to support the development of children regardless of a disability (Beauchamp & MacLeod, 2017; Kay-Raining Bird, Lamond, & Holden, 2012), while native language loss has been demonstrated to have notable negative effects on children's development (Paradis, 2001; Thomas & Collier, 2003; Wong Fillmore, 1991, 2000), yet children were diagnosed as learning disabled due to their bilingual capacity. Specifically, a review of research is provided in the section labeled Down syndrome and bilingual capacity, which speaks to individuals with DS and their capacity to be bilingual, regardless of the constraints placed upon them by their cognitive disability (Kay-Raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kay-Raining Bird, Trudeau, & Sutton, 2016; Paradis, 2007). Finally, this chapter, provides a better understanding of the Latino family, through the concept of familism (Cortes, 1995; Stein, 2013), and how native language loss impacts the family.

Theoretical Framework

Social Constructivism

This study is grounded in the epistemological paradigm of social constructivism (Cottone, 2007; Guba & Lincoln, 1994). Social constructivism stems from constructivism, which posits the ontological reality as subjective. Reality is constructed by the individual, relative, rather than assumed to simply exist (naïve realism) (Guba & Lincoln, 1994). The epistemological question about knowledge, which refers to the nature of knowledge, and how the

individuals goes about knowing, is viewed through the constructivist paradigm where knowledge is created through the interaction between the individual and the investigator and is an interpretation of the dialectic (Cottone, 2007; Guba & Lincoln, 1994). The goal of inquiry is to gain an informed understanding and reconstruction of the constructions that the individuals initially hold to be true, which are organic, changing overtime as new knowledge is gained and interpretation accounts for these changes (Guba & Lincoln, 1994). Social constructivism explains that meanings are derived from the social interactions between the individual and their social world (Cottone, 2007). Meanings are constructed through the interactions in the social world, rather than through the individual's intellect, creating multiple meanings of the same experience, that can change as the constructor acquires knowledge (Cohen, Marion, & Morrison, 2007; Cottone, 2007; Guba & Lincoln, 1994).

Symbolic Interactionism

Following social constructivism, paradigm (Cottone, 2007; Guba & Lincoln, 1994) whereby the construction of reality is individualistic and contingent upon the individual's interpretation of the environment, symbolic interactionism (Charon, 2004) builds upon this notion, by providing an in-depth understanding of mental process that construct this reality. In this study symbolic interactionism is used as the theoretical and analytical framework. Symbolic interactionism (SI) is a theoretical perspective that views human beings as active in the environment. SI a term coined by Blumer (1969), a student of Herbert Mead, who is known as the father of SI, examines personal interactions amongst individuals and how these interactions create meaning. SI provides a theoretical framework for understanding communication on a small scale. It provides a real-world perspective and technique to interview and analyze data

produced from working with the experiences and perspectives of individuals with disabilities (Hughes, 2016; Rossetti, 2014).

Symbolic interactionism uses the *emergent-man point of view*, where human beings are seen as individuals who do not simply exist within their environment, rather they respond to it, interpret it, and make adjustments to their reality using *symbols* and the concept of the *self* to define their daily context and social interactions (Charon, 2004). People are organisms that engage with others and *self*, unique beings that define immediate situations in reference to their own perspectives which were developed or changed through on-going social interactions. Individuals define, act towards, and use the environment, rather than be responsive to it, through on-going definitions derived from dynamic perspectives that originate in the *mind* (Littlejohn, 1977). SI views human beings as dependent on the four unique interdependent and socially constructed qualities, 1) the use of *symbols*, 2) the possession of *self*, 3) as engaging in on-going *mind-actions*, and 4) as always *taking on the role of the other* in order to interpret, make adjustments to, and understand the world around us (Charon, 2004).

Symbolic Interactionism: A Tool for Understanding Individuals with Disabilities

As described by Mead (1967) and Blumer (1969) SI assumes that the individual behaves pragmatically interpreting and making sense of symbols in the situation, making judgements, adjusting their behavior according to the way they feel they should be acting and viewed by others. The individual reads the signs and interprets the symbols within the given situation, making changes in behavior and thoughts as needed. SI is concerned with the subjective meanings, created by repetitive meaningful interactions that shape individual's definition of self and society (Carter & Fuller, 2016). These meanings are used to describe and create internal beliefs about symbols in their environment, whether it be a person, objects, or events (Blumer,

1969; Carter & Fuller, 2016). Blumer (1969) believed that knowledge should be derived from first-hand participatory action conducted by the researcher, where the individual's autonomous contributions should be considered (Littlejohn, 1977). He summarized his beliefs in three basic tenets: (i) human beings' actions are dictated by the meanings they ascribe towards other people or things; (ii) meaning, arises from or comes out of, social interactions between the individual and others; (iii) and meanings are modified through an interpretive process by the person when dealing with people, events, or objects they encounter (Blumer, 1969; Shibutani, 1988). These three basic tenets outlined by Blumer (1969), provide a theoretical framework for interviewing and analyzing the experiences of individuals with disabilities.

Self as Dualistic. A core concept of SI, described by Mead (1967), is the *self* which is described as dualistic. Mead described the concept of self as consisting of the "I" and the "Me", where the "I" is the part of the human being that is uncontrolled, impulsive, spontaneous, and unpredictable (Charon, 2004). It is internal piece of a person that creates human action that originates from a place that is nonsocial, untouched, unaffected by the outside world. It is not considered as a positive or a negative, since the "I" can lead to creativity, destruction, actions, or places the individual did not think possible, leading to what Mead described as creating freedom if opens choices for the actor (Charon, 2004). The actions portrayed by the "I" are a surprise even to the individual. The "Me" differs in that it is a more reflective, controlled response, and socially constructed. It allows the individual to act in a deliberate way in social situations. Meaning it allows the person to act in the manner that they think others expect them to act (Charon, 2004; Hughes, 2016; Mead, 1967). The "Me" is the central point for understanding Mead's concept of the self since it is the part of the human being that is purely socially constructed. The role of human action begins the "I" yet ends and continues to exist in the "Me",

where the individual can be the actor who takes actions towards themselves or the outside environment (i.e. actor towards object or actor as the object) (Charon, 2004).

SI allowed for the reflective and interpretive understanding of the “Me” (Charon, 2004), in a study conducted by Hughes (2016). SI was used as a theoretical lens to understand the self in social interactions for individuals with Asperger’s syndrome, a disability categorized by an inability to understand social settings, symbols, and signs through verbal and non-verbal communication (Hughes, 2016). Through the theoretic lens of SI and autoethnography Hughes (2016) an individual with Asperger’s syndrome provided insight on the challenges individuals with Asperger’s face when interacting with the world. Through a reflective and interpretive process, Hughes (2016) was able to focus on his deliberate actions of the “Me” and provide insight through a person-centric outlook, that gives communication strategies and techniques that can be personalized for other individuals with Asperger’s syndrome when in social settings.

Through the lens of SI, Hughes (2016) was able to illustrate the pragmatic approach an individual with Asperger’s syndrome approaches on a day-to-day social situations, where he is able to engage in mind-action (Charon, 2004). He had a planned approach to his daily situations, such as those, that he would encounter while at work or in common areas at the University. He *planned communication scenarios* (linguistic symbols) to ease anxiety about spontaneous conversations, as well as, formal *standbys*, in case he became overwhelmed to allow him to temporarily leave a conversation, and if it became too stressful, he had organized and planned *exit strategies* (Hughes, 2016). He would constantly try to interpret others body language, words, and actions (social objects) in order to make meaning of social interactions. Having planned communication scenarios, that he would practice, gave him the ability to be aware of possible outcomes in given conversation’s scenarios, and purposeful actions, creating shared meaning,

and enjoyment within these conversations that would otherwise have been uncomfortable to a degree that would require him to leave. It allowed him to accomplish his goal of preventing and avoiding awkward and uncomfortable conversation's (Charon, 2004; Hughes, 2016).

Hughes (2016), demonstrated the overall premise of the SI, which is summarized in six basic propositions by Manis and Meltzer (1972). The first, that the theory of SI has three main structures, mind, self, and society, that are independent, whereby the connection is created by personal and interpersonal interactions. The second, both the mind and self are developed through language. The third, the mind is created by the individuals internalized social processes. The fourth, an individual's behavior is created through the course of action, instead of being purely reactive; followed by the fifth, where human behavior is contingent upon how the individual defines the given situation. The sixth proposition states that the self is derived from the individuals personal and societal definitions, rather than a reflection of others. As an individual with Asperger's syndrome, Hughes (2016), illustrates these propositions since he was aware of his own limitations placed upon him by his cognitive disability, and purposefully defined his social situations, make adjustment as he observed and encountered others on a daily basis. He would journal and create these conversation scenarios, standby, and exit strategies through a pure internal process of thinking through situations, while engaging in conversation with himself about the environment, that was contingent upon other behaviors, his internal emotions, thoughts, and external social interactions (Hughes, 2016).

Mind as action toward Self. Hughes (2016) process of internal conversations and thoughts demonstrates Mead's concept of the *mind* (Charon, 2004). SI describes the mind as symbolic interaction towards the self. The mind is an active on-going process the individual engages in constantly. It is thinking, talking to yourself without speaking a word, about their

environment and their actions within that environment, making changes in behavior, self, and the use of symbols. (Charon, 2004). SI views, the *mind*, the *self*, and *symbol* as interlinked qualities that are central to human beings. The mind and the self-work together to create *society* and human society in turn creates a unique human being through this reciprocal relationship (Charon, 2004). Symbols are anything that the individual or actor uses to intentionally communicate or represent something of value to them, which can be the self, body language, words, objects, or events. Mead explains that SI views the mind as action, while the self and symbols are objects, all existent within society that human beings create through social interactions (Charon, 2004).

A study conducted by Rossetti (2014) utilized the concepts of the mind and self to understand friendship dyads, where one individual was diagnosed with a disability. Three friendship dyads from a secondary school were identified through purposeful sampling and were observed and interviewed. One friend from each of the dyads was diagnosed with Autism or intellectually developmentally disabled (ASD or IDD). Rossetti (2014), observed the dyads through the understanding that SI views social reality as the interpretation by the individuals in the relationships they create and participate in during their daily lives (Blumer, 1969). Meaning, that the personal identities created, enacted, and the social meanings were derived from the interaction with the other person in the dyad, which allowed for an understanding of the experiences and perceptions of the dyad's social interactions (Rossetti, 2014). The study was guided by the following two research questions: 1) How do secondary students with and without ASD or IDD who identify as friends enact and make meaning of their daily interactions? 2) How do they perceive their overall friendships with each other? Through the use of semi-structured interviews and naturalistic observations five themes were identified. For the first research question the following themes were identified: (a) excitement and motivation, (b) shared humor,

and (c) normalized supports. For the second research question the following themes were identified: (a) mutual benefits from their friendships and (b) differing conceptions of friendship. Rossetti (2014) sought out to explain how friendship dyads, where one individual was diagnosed with Autism or an intellectual developmental disability, and concluded that dyad friendships were fun, reciprocal, and meaningful. Interactions between the dyads demonstrated reciprocity through shared activities and roles within their social context, while fun was demonstrated by shared humor and excitement. Meaningfulness was evident through excitement expressed when individuals encountered each other, behaviors that demonstrated ways to maximize time spent, internal motivation to regularly spend time together, the oral descriptors of fun and desire to want to spend more time together. Second, the friendships were created over several occasions where they had the opportunity to interact; then third the individual without the disability did not view themselves as special because they had a friend who was disabled. Lastly, each friendship looked differently where 2 dyads viewed the friendship like any other friendship and the third viewed it as a true friendship since it required more work but was easy to develop and maintain. SI allowed for Rossetti (2014) to gain an in-depth interpretation of the interactions between the dyads.

Symbolic Interactionism in the Current Study

There is value in the perspective of the individual with DS in adulthood in-order to examine how they interpreted situations, created relationships, assigned meaning to body language, objects, words, and events to making meaning of family, when raised in a bilingual context. It is important to understand how an ADS developed a sense of family within a bilingual context, because when raised in Latino bilingual homes, there is no way to prevent exposure to English and Spanish. It goes much further than just exposure, through the lens of SI, the ADS are

seen as individuals who do not simply exist within a context of their bilingual family, rather they define their situation through the meanings they attach to the symbolic actions of others towards them. The actions of others towards them directly or indirectly, intentionally or non-intentionally, are interpreted by the individual as social objects where they attached meanings, adjusted, and made changes to their internal understanding of family, regardless of which language was used at the moment.

In order to begin to understand the perspective of the ADS, the concept of the *mind* is used as the primary focus of this study (Charon, 2004). SI views the mind as a constant internal process, where the individual interacts with others, and through these social interactions, makes meaning, interprets, and draws conclusions about relationships (Charon, 2004). The lens of SI allows the researcher to focus on the subjective meaning of family as defined by the ADS. Meanings are constructed through the daily interactions that the Latino ADS had with family members, which could have occurred in either the English or the Spanish Language. Family is broadly defined as a set people that interact and connect with each other where each person plays a specific role within the group (Nunes & Dupas, 2011). By asking the initial question “*can you tell me who are the important people in your life?*”, the researcher can begin to understand who the ADS consider family members, essentially the important people in their lives. Through semi-structured interviews the researcher was then able to have in-depth conversations, in order to understand how day to day social interactions, dictated the that internal processes and expression of behavior by the ADS. Meaning, that SI allowed the researcher to understand, how the *mind* dictated, how they ADS acted towards others and how they interpreted how others acted towards them. The interpretation of the Latino family includes actions, symbols, and objects all created

with a bilingual context, whereby these repetitive social interactions with family members helped shaped the ADS's internal meaning of family.

Within the Latino culture, the language utilized during day to day interactions becomes important for interpretation, because language is considered a prime component of mind-action and meaning making (Charon, 2004). SI lens views the individual's familial interactions as fluid. A central concept of SI is that "individuals use language and significant symbols in their communication with others" (Carter & Fuller, 2016, p. 932). As in Latino families, where over 73% speak Spanish at home (Krogstad & Lopez, 2017), an individual who is not taught the home language and exposed is limited, is then left out of many conversations and interactions, such as family gatherings, traditional and cultural norms, and simple daily conversations over tv watching or dinner time, common pastimes where families have the opportunity to engage with one another. It is important to take into account the context where the ADS is being raised, when studying individuals, who come from homes where the primary language spoke is not English. Many families value bilingualism in their child with disabilities since it provides opportunities for inclusions, in community, social, and familial settings (Jegatheesan, 2011). Bilingualism allows the individual with a disability to communicate with and connect with family in order to develop a relationship, a sense of family, and attached meaning to those daily social interactions (Charon, 2004; Guiberson, 2013a; Jegatheesan, 2011; Wharton, Levine, Miller, Breslau, & Greenspan, 2000). When parents are limited English speakers, having conversations in the native language allows for more effective communication between the parent and the child with disability (Wharton, Levine, Miller, Breslau, & Greenspan, 2000), rather than the child struggling to communicate, shortened conversations, and limited social interactions (Kremer & Sadlik, 2004).

There are limited studies that have examined the daily face to face interactions between families with individuals with DS in the context of bilingual homes (Cleave, Kay-Raining Bird, Czutrin, & Smith, 2012). There was no research found that specifically looks at the daily repetitive interactions amongst Latino ADS and their family members through different stages of the lifespan, when raised in bilingual homes. There is value in the adult with Down syndromes' individual perspective when speaking about making meaning of family, within bilingual context, since it is them who lived the experience. It is important to note who are the individuals who make-up those daily interactions as described by the ADS. Allowing them to place the label of family upon those individuals in their life, regardless of a biological kinship. By incorporating individuals who have relational ties that are not necessarily bound by living in the same household nor biological ties, it becomes important to see who ADS label as family, creates their reality, and makes sense of their environment while building connections, within Latino bilingual homes. SI allowed for an in-depth understanding of the adult with DS' interpretation of family.

Summary

In this study ADS were interviewed to understand how they make meaning of family within a bilingual, English-Spanish speaking home. Previous research has demonstrated that children with DS can develop bilingually, without negative effects to their development (Kay-raining Bird, et al, 2005; Kay-raining Bird, Genesee, & Verhoeven, 2016; Paradis, 2007; Peña, 2016), despite the differences characterized by the disability (Down syndrome Foundation of Orange County, 2015). The research findings remained disconnected from the practical application in regard to working with these individuals within bilingual homes (Guiberson, 2013a), such that as Latino families, despite the growing number of Spanish speaking home environments present in the United States (Gonzalez-Barrera & Lopez, 2013), where 1 in every

700 babies is born with Down syndrome (Center for Disease Control and Prevention, 2017), a cognitive disability characterized by language delays (U.S. National Library of Medicine, 2018).

Review of Research

Bilingualism

Parental concerns and messages of single language input from practitioners persists (Levey & Sola; 2013; Yu, 2013), despite the research that has demonstrated that typically developing children and CWD can learn more than one language, without harmful effects to their overall development (Beauchamp & MacLeod, 2017; Kay-Raining Bird, Lamond, & Holden, 2012). Recommendations to parents to speak only English to their children goes against the American Speech-Language-Hearing Association (ASHA, 2004, 2011), which stresses that practitioners be culturally and linguistically competent and consider the strengths and preferences of the family. The message conveyed by service providers persists that dual language development can create confusion and delay the development of the child, especially children diagnosed with a cognitive disability, which impacts their language learning capacity (Beauchamp & MacLeod, 2017; Kay-Raining Bird, Lamond, & Holden, 2012; Paradis, 2016). Bilingual children's linguistic developmental capacity continues to be compared to monolingual children, when this comparison puts bilingual children at a disadvantage (Peal & Lambert, 1962, Wong Fillmore 2001). Bilingual children typically developing or CWD should not be compared to their monolingual counterparts (Thordardottir, 2006).

Guiberson (2013a) examined the beliefs and myths around bilingualism. He concluded that the commonly held belief, that bilingualism causes confusion and delays the linguistic development of typically developing children and CWD, has a strong influence on interventions, assessments, strategies, and decision-making processes (Guiberson, 2013a). Various studies have

challenged the “confusion” myth and have been able to demonstrate that as long as typically developing children and CWD are provided with sufficient exposure to both languages, they are capable of learning two or more languages (Beauchamp & MacLeod, 2017; Cummins, 1981; Guiberson, 2013a; Kay-Raining Bird, et al., 2005). The first language provides a basis for the second language acquisition (Cummins, 1981, Wong Fillmore, 2000, Paradis, 2007). Young bilingual children’s linguistic development differs from that of monolingual children, since they are developing two languages simultaneously or sequentially. Monolingual children and children who are learning more than one language at a young age should not be compared in assessments, such as IQ tests, since they can have a better understanding in one language versus the other (Blanchett, Klingner, & Harry, 2009; Grosjean, 2010; Paradis, Schneider, & Duncan, 2013). An assessment testing only the child’s English capacity can lead to wrongful conclusions placing labels such as disabled on children who are still developing English but might excel if tested in the other language (Blanchett, Klingner, & Harry, 2009).

Fraser Lauchlan (2014) sets the stage for this very topic. His research examines the advantages and disadvantages of being raised bilingual. As presented through his careful examination and through the research of Bialystok (1999 & 2001) and Bialystok & Martin (2004) they were able to conclude that bilingual children are able to filter and focus better than monolingual children. Since bilingual children are constantly filtering the relevance of information and are forced to choose the correct label depending on the given language the task that is being performed, they have an advantage over monolingual children (Lauchlan 2014). Bialystok and Martin (2004) examined this same concept and were able to conclude, that the difference in card sorting task, was not due to the fact that bilingual children had better mental representations, but that they had better cognitive control skills due to developing better

inhibitory cognition skills. These children had to learn at an early age to distinguish between two labels, and keep appropriate information, while filtering out the rest, giving them a cognitive control advantage according to Bialystok (1999 & 2001).

Similarly, Paradis (2007) concluded that although there can be confusion due to grammaticism and pronunciation; there is no significant difference between the errors committed by monolingual children versus bilingual children. The assumption is that children who suffer from specific language impairment (SLI) would be impaired and their development would be stunted if they were forced to learn two distinct languages simultaneously or sequentially in the early stages of life. Paradis (2007) was able to provide evidence that the first language (L1) actually assisted in learning the second language (L2), also demonstrated through Lauchlan's (2014) research namely "transfer" of information. Bilingual children can use the conceptual understanding in one language to aid in the understanding of concepts in another language (Lauchlan, 2014). Cummins (1978) described this ability as the linguistic interdependence hypothesis, where language learning is like a *dual iceberg*. The two tips of the iceberg that are seen over the surface of the water represent the first and second language. The surface features of language usage, in either L1 or L2 refers to the persons basic ability to listen and speak in order to communicate concepts, a structure he called basic interpersonal communication skills (BICS). Underneath the surface is the common underlying proficiency (CUP) allowing for this transfer of information and L1 supporting the development of L2 (Cummins, 1978). Additionally, it is not just concepts that aid in comprehension, but also the root of language such as morphemes the gives bilingual children an advantage. SLI bilingual children and monolingual children were both lagging in grammatical morphology compared to typically developing children,

demonstrating that the lag is not due to dual language, but to the impairment suffered by the children (Paradis, 2007).

The research conducted by Kay-Raining Bird and colleagues, demonstrates that the bilingual capabilities of children with DS as compared to monolingual and bilingual children typically developing, as well as bilingual children who are diagnosed with DS. Through their research they have been able to demonstrate that the challenges in development, such as shortened speech utterance's and difficulty in verbal expression are typical of the disability, and not a direct effect of dual language development. They were able to demonstrate that when compared to peers of the same mental age, the child with DS either performed as well or superseded their monolingual typically developing and bilingual CWD counterparts (Burgoyne, et al.,2016; Cleave, et al. 2012, Kay-Raining Bird, et al., 2005), yet historically and continues to hold true today, bilingualism is considered a hinderance rather than a support for children L1 and L2 development (Blanchett, Klingner, and Harry, 2009; Guiberson, Barret, Jancosek, & Itano, 2006; Thomas & Collier, 1997; Peal & Lambert, 1962).

Discrimination and Intelligence. Studies have shown that assessments that compare bilingual children to monolingual children, put bilingual children at a clear disadvantage. Since the level of performance in English proficiency is set at the standards of monolingual children, bilingual children are put at risk of becoming over identified as having a specific or primary language impairment (Paradis, Schneider, & Duncan, 2013). According to Blanchett, Klingner, and Harry (2009), children of color have been overrepresented in special education programs since the assumption was that people of color were inferior. Historically, Latino children were being tested in English when they only spoke Spanish, classifying a disproportionate number of

Hispanics as mentally retarded (MR), according to IQ scores (Blanchett, Klingner, and Harry, 2009).

IQ tests examine the knowledge children have, but reflects the knowledge around the dominant social, linguistic, and culture, which again puts minorities at a disadvantage and higher risk of MR classification, due to the cultural bias in testing. These children suffer institutional racism, and white privilege discrimination, since they are at risk for identification as developmentally disabled, due to poverty, inadequate prenatal care, and having limited access to early intervention services (Blanchett, Klingner, & Harry, 2009). In an academic setting the occurrence of native-language loss can put children at risk for misdiagnosis for a language impairment (Guiberson, Barret, Jancosek, & Itano, 2006; Thomas & Collier, 1997; Peal & Lambert, 1962). Spanish language loss is reflective in grammatical errors, rather than verbal communicative errors, when tested for proficiency can deem a child deficient, comparable to monolinguals diagnosed with specific language impairments (Anderson, 1999; Thomas & Collier, 1997, 2002, 2003).

Classifying a child as handicapped or deficient discriminates the bilingual child and supports the status quo (Blanchett, Klingner, & Harry, 2009). Children should not be labeled by their disability, nor described as less because of the challenges they may face because of their differences. Research has shown that bilingual children, typically developing children and CWD can surpass monolingual children in certain non-verbal and verbal measures, and exhibit greater “cognitive flexibility”, yet the education system and societal view still reflects an emphasis on bilingualism creating deficits in children, even classifying some children as disabled (Blanchett, Klingner, & Harry, 2009; Guiberson, 2013a; Hruska, 2006; Lauchlan, 2014; Paradis, 2007; Peña, 2016). Bilingual CWD should not be compared nor expected to develop at the same rate as

bilingual typically developing children, yet they are compared (Kay-raining Bird, et al., 2005). Variability in syntax, vocabulary, and language capability amongst children with DS, just as in typically developing children, is shown to be contingent upon the amount of time exposed to each language, lack of unbiased scales of measurement for bilingual children, practice time, and sibling/peer influence (Bialystok, 2001; Cargo & Westernoff, 1997; Kay-raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kibler, Palacios, & Simpson Baird, 2014; Peal & Lambert, 1962). Children with DS have demonstrated they have the capacity to develop successfully as bilinguals within the limitations set by their disability (Kay-raining Bird, et al., 2005; Kay-Raining Bird, Genesee, & Verhoeven, 2016; Kay-Raining Bird, Lamond, & Holden, 2012; Paradis, 2016).

Down syndrome and Bilingual Capacity. There are limited studies that document the linguistic capacity and development of bilingual people with DS, and even less that have documented their capacity over time (Cleave et al., 2012; Kay-Raining Bird, Trudeau, & Sutton, 2016). In a study conducted by Burgoyne, et al. (2016), the case of MB is presented. She is a child who was born with Down syndrome into a bilingual Russian and English home. The predominant language spoken at home was Russian (L1), where she had limited exposure to English (L2), until the age of four when she entered school. By school entry, she was verbally proficient at Russian and could speak about 20 words in English. By age 9 years and 6 months her language development had been compared multiple times to her peers. Her L1 Russian capacity was compared to 11 monolingual Russian-speaking children who were typically developing. Her L2 English capacity was compared to 15 monolingual English-speaking children who were also typically developing, as well as 6 monolingual English-speaking children with Down syndrome. All comparisons yielded the same result, that MB a bilingual child with

DS was at the same rate of word reading ability as her peers, monolingual typically developing and with DS. This study continues to demonstrate that children with DS can develop bilingually without harmful effects to their linguistic development, despite the challenges they face from the chromosomal disability (Burgoyne, et al., 2016).

Kay-Raining Bird, et al. (2005) reported similar results, when examining the bilingual capacity of eight bilingual children with DS. This study examined children who had L1 English and L2 as French. All children had on-going and intensive exposure to both languages since birth. In the study, these 8 children were compared to peers of the same mental age: 14 monolingual children with DS, 18 typically developing monolingual children, and 11 typically developing bilingual children. As expected, children with DS, from both the experimental and control groups, had delayed verbal development than their peers a challenge placed upon them by the disability. The eight children with DS yielded an equivalent capacity to receptive and expressive vocabulary as compared to the typically developing bilingual children although they demonstrated difficulties in the areas of word utterance and expressive language. When comparing all groups, the bilingual children DS did not show any delay in the development of L1, suggesting that bilingualism had no negative effect on language competence in the English language. Another study conducted by Cleave and Colleagues (2014), tested the L1 language capacity of children with DS, monolingual and bilingual through the use of fast mapping. They concluded that there was no difference in language development of these children, again demonstrating that L1 and L2 do not hinder each other's development in bilingual children with DS (Cleave, et al., 2014).

Native-language loss

Language is an essential tool of communication amongst family members, limited

communication negatively impacts children and families overall (NAEYC, 1995; Puig, 2010; Wong Fillmore, 1991, 2000). It is the main form of communication that they use to pass on stories, wisdom, idiosyncrasies, and especially values to younger generations (Kouritzin, 1999; Schechter & Bayley, 1997; Toppelberg & Collins, 2010; Wong Fillmore, 1991, 2000). There is concern when parents are limited English speakers and their children are limited Spanish speakers, since the ability to communicate needs, wants, desires, problems, and frustrations is constrained. A disconnect and separation begins to occur within the family due to a loss of common language ability (Paradis, 2001; Thomas & Collier, 2003; Wong Fillmore, 1991, 2000), which is reflected through academic achievement in school-aged children (Kouritzin, 1999; Schechter & Bayley, 1997; Thomas & Collier, 2002; Toppelberg & Collins, 2010). Research has shown that children's loss of the native language impedes upon parent and familial socialization hindering communication within the immediate and extended family members. Cultural identity can be lost, family relationships negatively affected, compromised school retention, graduation rates, and poor-self-image (Kouritzin, 1999; Schechter & Bayley, 1997; Toppelberg & Collins, 2010; Wong Fillmore, 1991).

Support of home-language amongst bilingual children becomes a critical issue when speaking about future impacts, due to globalization of jobs, economy, and the interaction with diverse societies (Toppelberg & Collins, 2010). Maintenance of the native language aids in strong familial ties, healthy adjustments amongst children and adolescents as they encounter society mainly, the school system and peers, providing them with a strong identification of self and internalization of family values and morals. In turn, as children age, bilingual, bicultural, and biliteracy serve as supports for future employment opportunities within their own immediate network and beyond, providing the individual with a strong set of life-related skills, since parents

are able to pass on life skills, job training and experience through practice, stories, and examples. As in, Latino children become disconnected from families and cultural roots affecting their identity, sense of self-worth, and overall sense of connection with family.

Latino family connection. Most Latino families have a deep-rooted sense of “familism” (Cortes, 1995), where importance is placed on the family, characteristics of the culture, which includes the preservation of the home-language (Cortes, 1995; Guardado, 2006; Krogstad & Gonzalez-Barrera, 2015; Zuniga, 1992). Latino families believe in the importance of maintaining strong familial connections with immediate and extended family, native and foreign to the United States (Guardado, 2006, Zuniga, 1992), who may or may not speak English. Language is a key component to maintaining the familial connection with Latino families, preserving the culture (Cortes, 1995; Guardado, 2006). Latino families believe that language is deeply rooted in the preservation of the native culture (Guardado, 2006). Opportunities to communicate with immediate and extended family members becomes a mode for supporting native-language preservation. There is limited research on the familial views and effects native-language loss and maintenance amongst Latino families within the context of the home, yet research has demonstrated that Latino parents, interviewed by Guardado (2006), cherish moments where they were able to sing songs, tell stories, and read books with their children in Spanish. Parents expressed that preservation of the Spanish language, not only ensured clear communication with family members, but that it strengthened family relationships and helped maintain it throughout the life span (Guardado, 2006). It is important this connection is sustained.

According to Farruggio (2010), Latino parents associate the loss of Spanish amongst their children as creating a potential decrease in parental authority and an inability to convey cultural norms and values. Children tend to disconnect themselves from their Latino cultural practices

(Farruggio, 2010; Guardado, 2006; Worthy & Rodriguez-Galindo, 2006). The loss of the native language creates separation amongst children, parents, and other extended family members. The family is essential for providing the necessary tools for the children's success. The loss of strong communication skills amongst parents and children deprives children of the opportunity to gain important knowledge: dealing with adverse situations and gain a sense of belonging to self, family, and community (Wong Fillmore, 1991, 2000).

Familism. In the Latino culture there is a strong sense of connection with one-another that stems from shared language, culture, values, morals, and norms (Cortes, 1995; Stein, 2013). Latino families hold a strong sense of familism, which is a central feature in Latino culture (Stein, 2013). Children and adolescents have a great sense of loyalty, obligation, obedience, and responsibility towards family. The needs of the family are placed above the need of the individual, as compared to non-Latino children and adolescents (Calzada, Fernandez, & Cortes, 2010; Guilamo-Ramos et al., 2007). In a study conducted by Stein (2013), 191 Latino teens were recruited for the study ranging from students in 7th grade up to 10th grade. The study was conducted in North Carolina amongst two middle schools and one high school. Stein hypothesized that Latino youth who experienced high levels of familism would have lowered experiences of stress and negative outcomes (Stein, 2013), since previous research has demonstrated that high levels of familism is associated with low levels of depressive symptoms in Latino youth (Smokowski & Bacallao, 2007). He wanted to examine if familism would serve as a buffer for different types of stress the teens would encounter. Specifically, he examined familism, racial/ethnic discrimination, economic stress, acculturative stress, depressive symptoms, school belonging, and perception of barriers. Consistent with previous research (Smokowski & Bacallao, 2007), Stein (2013) found that students who reported higher levels of familism, reported lower levels of depressive symptoms, higher levels of a sense of school belonging, demonstrating it does serve as a supportive tool for

Latino youth psychosocial development. On the contrary, familism can interfere with student's ability to attend college, due to the sense of solidarity and obligation with family, at the same time it can serve as a motivator, due to familial emotional support (Gonzalez et al., 2012), which was not examined in this study. Stein (2013) concluded that familism can have positive and negative factors in regard to perception of barriers. Familism was found to not have an effect on racial/ethnic discrimination, economic stress, and acculturative stress. Adolescents' psychosocial development is still impacted negatively when encountering situations of discrimination and peer bullying regardless of strong family values and sense of connectedness is felt.

Summary

Bilingualism does not come at the expense of cognitive and linguistic development, as demonstrated by previous research (Cummins, 1981; Paradis, 2007; Wong Fillmore, 2000). A strong basis in the first language serves as a communicative tool for the acquisition of subsequent languages (Cummins, 1981; Guiberson, 2013a; Paradis, 2007), regardless of the presence of a disability, as in the case of DS (Kay-raining Bird, et al, 2005; Kay-raining Bird, Genesee, & Verhoeven, 2016). On the contrary, the loss of the native-language comes at the expense of the child's successful linguistic and emotional development, where there is an increase in familial separation and a deterioration of the native-language capability over time, as demonstrated in Latino families (Farruggio, 2010; Guiberson, 2013a; Worthy & Rodriguez-Galindo, 2006; Wong Fillmore, 1991, 2000). Latino sense of familism serves to create a strong sense of connectedness with family and culture, which is centered around commonality, such as language, food, music, and values (Cortes, 1995, Stein, 2013). Familism is a core factor in the development of Latino children regardless if they are typically developing or with a disability, since it cannot be avoided when born into a Latin family. It is an integral part of Latino culture influencing the way parents think and how children develop.

CHAPTER 3: METHODOLOGY

Justification for the Current Study

The current study aims to provide the point of view of the Latino ADS, since it is their voice that is absent in the literature as it pertains the meaning of family. Consistent with qualitative research, the theoretical framework of symbolic interactionism is used as the guiding tool when interviewing, evaluating, and discussing results from the study. Qualitative design is often a preferred research methodology when there is a lack of theory and research to explain a particular phenomenon (Merriam & Tisdell, 2016). It allows for in-depth interviews where the participant is able to express their experiences, about a given topic. It is an inductive process where through the stories of the participants, the researcher is able to gain a profound understanding of how the individual has made sense of their world. It draws upon the viewpoints of constructivism, phenomenology, and symbolic interactionism in order to understand how people interpret, create, and give meaning to their worlds and experiences. The main purpose of qualitative research design is to understand a particular phenomenon of interest through the viewpoint of the participant, referred to as *emic* (Merriam & Tisdell, 2016), allowing for the personal perspective of the Latino ADS.

Qualitative research is participant lead, utilizing strategies that ensure that the participants experiences are being recorded and analyzed from an inductive, bias free stance (Merriam & Tisdell, 2016). The disadvantage lies in the researcher's ability to remove and withhold all their personal experiences and knowledge, as to not influence the participant's responses and truly interpret the data objectively (Creswell, 1994). This relates to the concept of positionality, where the researcher must consider their own personal experiences and beliefs that could impact the overall process: (a) interpretation of data; (b) analysis of the data; and (c) the final reporting

(Merriam & Tisdell, 2016). Reflecting upon the researchers own predispositions throughout the entire process of qualitative research and reporting, a process called reflexivity, helps to ensure positionality is accomplished (Bourke, 2014), in the case of the current study, I must reflect upon my own upbringing, bias, predispositions, and overall beliefs and how these can affect the way I conduct the interview, and ultimately interpret the data. Since the ADS who were interviewed were from Latino countries, where bilingualism is a natural occurrence within their homes, here in the United States, it is difficult to separate the idea that the native language should be preserved regardless of the messages conveyed by professionals, especially as it pertains to the development of individuals with special needs. As a Latina researcher with a bilingual family member who is an ADS, it was important that I constantly reflected upon my own stance and beliefs, while conducting the study to ensure I was providing their voice and not my own. I also had to make sure that I was clear that I was aware that I am providing their voice, but my voice would still be present since I am the one interpreting and presenting the results. Through this repetitive process of reelection, interpretation, clarification from participant, reelection and a final interpretation, I tried to ensure that I was providing their voice and not mine.

Process of Recruitment

When designing the study and conducting research on the topic of people with DS, I was already aware of some of their capabilities and lack of ability in areas such as speech because of my own personal experience. I also took into account the research and my knowledge about education and Special Needs, when deciding how I was going to find the specific participant I wanted to interview. Latino adults with Down syndrome were invited to take part in the research study through purposeful sample selection (Merriam & Tisdell, 2016). A non-profit organization that serves adults with Down syndrome in the state of Florida was initially contacted. It is a

501(c)3 non-profit resource center that serves and supports families with children and adults with DS for the past 40 years. They have programs that service all types of families and individuals with DS throughout the life span, regardless of cultural or financial background. Having a family member who is an adult with DS, who has been an active member of this organization for almost 30 years, provided me with accessibility to the Executive Director (ED) of the organization. My Aunt and Uncle, also active members of the organization made the formal introduction to the ED in order to gain the approval to contact families, who had ADS that fit the participant criteria. Communicating with families via referral from the ED helped me gain the credibility and trust needed for families to at least listen to what I had to say. Otherwise, contacting families with Special Needs can be a difficult task since they might have bad past experiences with researchers or other professionals.

The initial communication with the ED was via teleconference, which provided more information about the current study and to discuss if the organization had families who fit the criteria and would be open to talking to me. This conversation also opened up the ability for me to email her the letter of invitation so she could take a look at it and learn more about the study, before she sent it out to families. After our telephone conversations, and with her approval I emailed her the following: formal request letter, letter to invite, information sheet, and screening guide, see Appendix B, B1, B2 & B3. A non-disclosure was also provided for the ED in order to ensure the identification and information of the families emailed was kept confidential, and that the final selected participants were unknown to even the ED, see Appendix B4. In order to conduct the interviews families were contacted through a referral list that was compiled, with the contact information of the individuals who fit the criteria of the study, by the non-profit Executive Director in the state of Florida. Other families contacted the researcher through word

of mouth referral, where they were also told about the research study and the potential for their family member to be interviewed if they fit the criteria. All ADS either in person or via the telephone were asked to participate, whereby the conversation was made possible by the connection made through the primary caretaker.

Participating families from the state of New Jersey were also selected through purposeful sampling, by word of mouth and referral at the local Church. Families and ADS were given the letter of invitation that briefly explained the research study, then a subsequent follow-up meeting via the phone were set up to explain the study further, and the need for the ADS to select three photographs, before the first meeting, of those people that were most important to them, that they would identify as family. I explained to the family, specifically parents, that the Adult with Down syndrome must select photos of their choice. Parents were instructed to not interfere with this process, so the pictures used for the study were selected by them. From the experience in the Florida recruitment, I realized that asking families to text me the images before our first meeting was good practice, since it ensured that this task was completed before we met.

Then, I asked the ADS if they had a personal cellphone, and when they said yes, I explained the requirement of the three photos suggesting that they review their pictures on their and find three pictures. I made it clear that, that was not the only place they could look, suggesting other places, such as around the house, in their room, parents cell phones, other digital albums, or lastly printed photo albums if they had some at home. Lastly, parents were also told that the ADS must give consent and the meeting would be with only the individual in a private setting of their choice. No one else, but the ADS would be part of the interview process, after the initial introductory meeting. This was also explained to the ADS via the phone or in person in the

presence of the primary caretaker before the introductory meeting. The ADS subsequently agreed to be interviewed and to be part of the research study.

Identification of Possible Participants for the Study

Adults with DS had to be between the age range of 21 to 40 in order to ensure participants had completed at least 4 years of secondary school, had passed the critical language learning age of 16 (Wild, Vorperian, Kent, Bolt, & Austin, 2018), and were of legal age to participate freely and voluntarily, if they demonstrate the mental capacity to consent, as demonstrated by select questions in the informed consent, see Appendix A, A1. It is important to note that memory recall for ADS is affected by the 4th and 5th decade of life, where progressive memory loss and neurodegeneration begins, similar to adults with Alzheimer's disease (Lockrow, Fortress, & Granholm, 2012). Mutation in amyloid precursor protein (APP) is one of the familial factors that is responsible for Alzheimer's disease. Individuals with Down syndrome, have triple the amount of APP in their body, leading to increase in dementia and the risk of the early onset of Alzheimer's disease, after the age of forty (Lockrow, Fortress, & Granholm, 2012), making 21 the minimum and 40 the maximum age requirement.

Taking into account mental capacity, another very important factor to consider for recruitment was the ability for the ADS to verbally communicate. This was not just the ability to speak, but the ability to hold a conversation about the topic of family and any other story they cared to share. This was determined by the initial conversation I had with parents and the possible participant. I asked parents, but as well as ADS if they wanted to sit down and talk to me for about an hour. I have an advantage that my ear is used to listening to ADS speak, which made it easier for me to decide whether or not I could understand the participant enough to complete the 3 sets of interviews and transcribe them for analysis. This decision was made at the

after the introductory meeting rather than the going by the opinion of the parent, who would tend to say they were not sure of their child was able to communicate what I was asking. After the first interview, and more important discussing the informed consent and what that meant, I was able to determine that they would be able to tell me stories about their life and that I was able to understand what they were trying to say to me. I was able to successfully complete 5 sets of interviews with participants, with the exception of one due to her dual diagnosis of Echolalia (Tourette disorder fact sheet, 2018; Shield, Cooley, & Meier, 2017). I was then mindful of the Latino ADS, possible co-existing conditions, communicative, and learning profile (Down syndrome Foundation of Orange County, 2015; Wild, Vorperian, Kent, Bolt, & Austin, 2018).

Criteria for Participants. All participants who were subsequently interviewed had to meet the 5-item criteria in the screening guide which included the participant being: 1) an adult with Down syndrome, 2) between the ages of 21 and 40, 3) Latino or Hispanic, and 4) having been raised in a bilingual, English, Spanish speaking home, 5) agreeing to be part of the research, see Appendix B3. Participants not only had to meet the requirements, but they had to orally agree to them. I am aware that many of them could not read or in the case of Olga, she could not read English. I then read aloud the five items and had to reword the first three questions to make sure they understood what I was asking.

Invitation for Participants with Approval of Legal Guardians

I am aware that the individuals I was reaching out to are adults who have a Special Need, which meant that the initial contact with them would have to be through the legal Guardian, in this case the Mothers of the ADS. For the participants from the State of Florida, the Executive Director sent an email inviting them to participate (see, Appendix B1) and requesting their permission for me to contact them directly. Some families responded back to the email while

others did not, so she opted to call them directly and inform them of the research. She then obtained permission for me to contact them directly by exchanging phone numbers. I texted the Mothers before calling them since I thought it would be easier for them to read the message about who I was, and what I wanted briefly, then they could let me know what time it was best for me to call. I wanted to be respectful of their time and did not want to call first, when it could be an inconvenient time for them.

After coordinating a time to speak with the Mothers I proceeded to call and explain over the phone, who I was and what my intentions were. I used the rapport techniques of establishing common ground through self-disclosure. I told them that I was David's cousin, and my Uncle's niece, and proceeded to explain the study. I told them about the need for their ADS to select 3 photographs, which they asked if they could text me ahead of time or if they needed to be printed. I agreed and realized that texting me the images was a great and simple way for families to comply with this request, especially because all participants personal cellphones filled with pictures. I explained the importance of the ADS picking the pictures they wanted to tell me about, rather than the family picking them for them. I also explained that the meeting although initially would be with the parent so they could meet me in person, would then proceed to be alone, and would continue to be alone since my goal was to speak to the ADS without the influence of another person. I wanted the ADS to be as comfortable as possible in disclosing their life story.

The final, but most important part of our conversation was the oral consent from the ADS. Although I had already gotten the yes from the Mother, I wanted to be respectful and ask them if they wanted to meet with me so I could ask them some questions. I explained to both mom and all the participants that their commitment was 3 in-person interviews that could last

from 1 to 1.5 hours, where I would be audio recording our sessions. I requested the mom put the on the phone and I asked them directly if it was ok for me to meet them and talk to them about my work. They all agreed to at least meet with me. This was important to me because I did not want the parent to simply tell them you have an appointment with Linda on this day, at this time, and they had not even ever spoke to me. It would go against the current study to just have parents obligate the participants, rather than it be their choice.

Pilot Study

Although I have a family member with DS and have interacted with him as well as many others with this disability over my lifetime, I had never sat down and conducted formal interviews with these individuals. In order to gain experience, ensure that the protocol was truly guided by the research question, as well as test out to see if in-depth answers could be given and most importantly understood by me a Pilot was conducted. The process intended by the study was to interview each of the participants once, they transcribed and analyze first interviews individual and across each other, before the second interview. Then the same process would repeat at the second interview before the third, and at the final interviews all individual interviews and compared to each other would be examined to in order to reach a point of saturation. With the pilot study only one individual was interviewed so this process was not done, except the analysis of each interview to inform the second, and then the first and second to inform the third.

Participant: John

The first person interviewed, and part of the pilot study was John, a 31-year-old male, who identified as a person with Down syndrome and a man. He is Cuba-American and says that his mom and him are Spanish, but not his stepdad. He is one of four siblings and the only one

diagnosed with a disability. He currently lives with his mother and her boyfriend, who is Caucasian. At the time of interviewing, a “Tia” [*aunt*] had come to visit and stay with the family. Although the main language spoken between the three adults is English, mom and the aunt spoke Spanish since the aunt knew little English. When asked what language he spoke to “Tia” in, John said Spanish, because she did not speak English, something the mom was unaware of. It was interesting to hear that John spoke to non-English speaking family members in Spanish, when mom had told me that she did not teach him Spanish and that he only spoke English. When asked what language he spoke at home when growing up he said both Spanish and English, and when I asked him if he spoke both languages, he said “*yes, un poquito*”.

John graduated high school and was now working in a restaurant. He is a proud godfather of his niece and cousin in Cuba. He recalls those moments with pride and joy. He is independent enough to ride the bus or walk to work depending on the distance of his job. He said that mom had taught him how to ride the bus. He was also self-sufficient enough to stay home alone while both parents worked, if it was his day off. He had chores around the house, dressed himself, and cleaned his own room. He led a very independent life, where he even had a longtime girlfriend that he was planning on marrying. He traveled nationally and internationally, texted, used social media, and made plans with his friends and girlfriend just like his typically developing peers. He was aware of his work schedule, mindful of his girlfriend, and others schedule when making plans. He demonstrated through the interviews how much he was aware of his life, his age, and that he wanted to live an independent life with his girlfriend, “*like a married couple should*”.

Lessons Learned from the Pilot Study

The most important lesson gained from the pilot study was the confidence to conduct this study. It is scary and nerve racking wondering so many things. Such as, will the participant

understand what I am asking, will they be able to give an answer that is longer than a simple yes or no, will the prompts to try and get a more in-depth and detailed answer work? I was honestly not surprised when the first interview went so well. Once John and I passed all the preliminary paperwork and began our interview the conversation flowed very well. I was able to ask questions that led to stories, he was very detailed, and expressed emotions, such as shyness, embarrassment, and even anger and frustration. He responded well to prompts such as “why”, “how did that make you feel”, or “can you tell me more about that”. His stories about his girlfriend were filled with details of their relationship, how they met, what his intentions were with her, and what the future of their relationship would be like. When it came to his siblings, he told me stories of how they would tease each other and the pride he had to have been selected as the God father of his niece. He used facial expressions, pitch like lowering voice when he wanted to make sure what he said was not heard by his mom. He blushed as he spoke about his girlfriend and sat up straight as if puffing out his chest in pride when talking about his responsibility as God father. After analyzing and conducting all three interviews, I learned that individuals with DS have a lot to say, they are aware of their surroundings, and want to be involved and in control of their life. John expressed multiple times throughout the interviews that it was his life, he was a responsible adult, and would be moving out to live it like a married couple should.

Barriers to Recruitment

The pilot study also helped me understand the barriers to recruitment since this study only included the ADS, excluding parents, who are accustomed to being part of all processed that include their children with disabilities. Parental approval is required for recruitment since I cannot access the ADS without first speaking to the parent, making them the most important barrier to recruitment. When conducting a study with a Special Needs population it is important

to consider how will the researcher approach the family. Through my own experience families with Special needs have fears and anxiety of being criticized and misunderstood by others in the way they raised their children and the decisions they have made to support their development. It is difficult for people who do not have family members or children with disabilities to understand the day to day struggle, stress, and the amount of work it takes to care for a person with a disability. It is a lifetime responsibility. My Aunt and Uncles have spoken to me many times about the negative feedback and rude opinions of others when advocating for my cousin over the years. There is a common misconception that Latino parents with Children with Special needs do not want to be involved in children's education, critique about the choices they make whether to introduce Spanish to the child or not, and their own lack of English when speaking to service providers (Hughes, Valle-Risestra, & Arguelles, M. E. 2008). Even within our own Spanish culture we get criticized. Having insider access was a benefit in establishing rapport and building trust with the family, but the referral from a credible source was the best option for the current study, to allow me to overcome any parental fears, anxiety, or past negative experiences.

Another barrier to consider, is where to access the families whose Special Needs family member is no longer attending school. When children are of school-age, they are involved in a number to services through the state and the school. Having a solid research plan presented to the school principal and others required for recruitment can make it easy to find Latino families with children with Down Syndrome. This option was not available for the current study due to the age requirement. In the State of Florida, I had a personal connection the Non-profit organization. In New Jersey I did not have such a connection and many of the organizations service children and families, rather than the ADS. Another option for recruitment would be to go through NJ State agencies which could have gotten a bit complicated since I did not want to be considered as a

person who was soliciting. I was referred to the Arc of New Jersey and the Division of Vocational and Rehabilitation Services but was unable get a meeting with the Director. State agencies manage large caseloads and can be very hard to speak to someone without a connection. I was not able to network my way into a meeting with someone from the New Jersey agencies in order to invite families to participate. Since I am not personally connected to families with ADS in New Jersey, I had a difficult contacting and successfully meeting with multiple families in order to conduct this study with participants locally.

Ensuring Confidentiality

Confidentiality in the current study refers to keeping the identity of the participants private, safeguarding the data, and making sure that I had an isolated place for the interviews to take place. The executive director of the Non-Profit in Florida signed a non-disclosure agreement (see Appendix B4) to ensure that she would not talk to others in the organization the purpose of my presence, since I would be present at local events. Also, for her not to share with other employees or families the reason I was there. The organization has a tight-knit group of people where the Latino families are the minority and know most of each other. It was difficult to get families to stay silent about my studies, because it is natural for parents to talk and ask each other if their Son or Daughter had interviewed with me. When I had my initial meetings with the families, I explained confidentiality and that they should not inquire with other families, as a way to show respect for their own ADS privacy, as well as other ADS who agreed to participate. This was hard to accomplish since my presence at events like, Wine and Cheese night, drew families to me to ask me how things were going in my research. I did my best to change the subject and remind families that the study was confidential and all I could say was that it was going well and

thanked them again for their time. I made sure to avoid group chats where I could have been asked about the subject in front of other families.

In order to safeguard the data, I backed it up on two drives, one external, and the other a virtual cloud, that are both are password protected, where I am the only person who knows it. The original data is my personal computer where my fingerprint is the password to unlock it. The data and study are both inside multiple layers of internal folders where a person would to purposefully go digging for it to find them. Analysis and writing of the study are conducted at a home-office, so the computer is never let open for others to see, when I am actively working on the study. When interviewing the participants, I had to make sure that parents either left the space, I went into another room with a door closed, or I met with them with the permission of the parent when they were not home. Having trust was really important, because the best time to meet with the ADS was during the day when we were both available, but parents were at work. For example, when conducting the initial meeting with John, my first participant interviewed, mom said she had left us alone, but was attentively listening to our conversation. I was made aware when after our introductory meeting, she said that he did not speak Spanish, because she heard when I asked him if he did, that he said yes. She went on to explain how she was advised not to teach him Spanish, so she has spoken to him primarily in English. I asked her if she spoke Spanish at home and to her other children and she said “yes”. I then had to explain in a respectful manner, that it is his perspective that I am interested in, not what is factually correct in her eyes. Also, I had to reiterate and ask if meeting alone was going to be possible, since she could not listen in on our conversation because that was violating his privacy and the purpose of my study, especially if he was to find out that she was listening to the things he was telling in confidence. Moving forward I made sure to remind parents of two things: 1) the conversation was private and

that they needed to ensure that we could speak alone before confirming appointments, 2) I was interested in the ADS truth, reality, and perspective, since I was aware of the limitations that DS placed upon them. I thanked them for their efforts and made sure to double check we had privacy before starting the interview. It was important to the study that I made them feel as comfortable as possible so they would talk to me open and freely.

Building Trust with the Adults with Down syndrome

When I first met each of the ADS, I made sure to present myself with a smile using a pleasant tone of voice in order to show that I was amicable. People with Down syndrome are characterized as individuals who are highly sociable, making trust building with Adults with Down syndrome a relatively simple task. These individuals are described as being highly intuitive and sensitive to others' emotions, allowing them to demonstrate emotions such as empathy towards others' (Down syndrome Foundation of Orange County, 2015; Mills & Black, 2014). They are highly communicative and when I sat with them to speak, they were open to talking and were excited to participate. I could notice they were happy that I was interested in listening to them for as long as they needed to tell me their life experiences. My past experience, of having a cousin who is an ADS, allowed me to have an advantage on how to sit and patiently wait for them to speak. Making sure that I gave them eye contact, was sitting facing them attentively listening, encouraged them to speak more. Making sure I gave gestures like head nods and smiles throughout the conversation encouraged openness and trust. Saying phrases such as "yes I understand" and repeating things they had said for clarification allowed them to continue to trust that I was listening and would continue to speak with them for further interviews.

An important moment when trust was established was when four of the five participants asked me for my cell phone number so that they could directly communicate with me and set

up/confirm future appointments. The participants who had Facebook also made sure to have me open up my social media and connect with them. Agreeing to these requests demonstrated the importance it was for them to feel like they have a choice when to speak to me or not speak to me, and to have control over the way that we could communicate when the interview had ended. Establishing these means of communication was not something that I expected, especially the use of social media, yet it served as a great way to build a relationship with each of the members as time passed from one interview to the other. It was important that in the time in-between our interviews, that I responded back to each of their text, Facebook, or WhatsApp messages, such as “*how are you?, I’m doing ok*”, and “*when will I see you again?*”. I made sure that I responded back and giving them the attention, they deserved allowing us to continue to build our relationship outside of our regularly scheduled meetings.

These short conversations, that were outside of the designated interview time, served also as a support for trust building. As long as I showed each of them the respect they deserved as individuals through my actions, such responding back when they called, texted, or messaged, allowing them to be the dictator of our meetings, rather than their parents. I was able to reassure them that these meetings were about them, since I would always confirm with them when they would be available, allowing me to strengthen our relationship. It is important to note that as high functioning ADS they were aware of their day to day schedule and could tell me when they worked, had family engagements to attend, had plans with friends, or other events that would make them unavailable to meet with me. Although, before I left every interview I would confirm with the primary caretaker, in this case, Mom for all participants, I was confirming a date and time that had already been set with the ADS rather than having Mom tell them when we would see each other again. Building trust with the participants came relatively easy as long as I made

sure to treat them with respect, be genuinely nice, showing my authentic interest in what they had to say, make them feel how important they were to my research, and thank them for their participation. I made sure to remind them every time we met that my goal was to learn more about them, their life, and how most important how they make meaning of family. When speaking to them directly I would say “what family means to them”, listening to their stories allowing them to start and end when they were ready. I would ask at every interview where they would like to start off. My consistent responses to messages in between our scheduled meetings, my punctuality, and most important to them was keeping my meeting dates showed them I was interested and seriously committed to them. I know they looked forward to meeting with me every time, because when we had our last meeting, all participants asked if they could remain in contact with me and offered to give me more interviews if I needed to talk to them again.

Building Trust with Legal Guardians

Initial communication with ADS is always through the primary legal guardians, so building trust with them is crucial to building trust with the ADS. It is important to remember that I am speaking to parents from a special population. I made sure to be mindful of the words I used, such as refereeing to the participants by their names rather than their disability. I made sure to show them respect by explaining to them who I was, what my credentials were as a doctoral student, researcher and having a family member who is an ADS. Most important that I had the best interest of their children (i.e. ADS) in mind. Having an aunt and an uncle who went through this struggle, when they were limited English speakers, also gave me advantage since I have seen first-hand what they went through. I was able to quickly connect with these parents, explaining my families own struggles, such as my uncles fear, anxiety, and sadness when he was told at the birth of my cousin, that he had Down syndrome. It was hard for him to come to terms with the

fact that his child would now need care for the rest of his life, at a time where over 30 years there were limited services and not a lot known about DS. Many families at first are uneducated when it comes to their child's disability and struggle to support the child throughout their development and become overwhelmed and experience multiple negative impacts on their psychological well-being depending on the severity of the diagnosis. Parents must go through a period of acceptance, adaptation, and adjustments to lifestyle, and future expectations. As the child ages, there are concerns about financial well-being, health care, and education. Unfortunately, many Latino parents with children with special needs feel excluded from their children's education, by either overt or covert societal messages, that they are un-interested, when in fact many are and want to be part of the decision-making process (Hughes, Valle-Riestra, Arguelles, 2008; Kummerer, Lopez-Reyna, & Hughes, 2007; Salas, 2004; Valle-Riestra & Hughes, 2007). This is attributed to either limited English skills, parents' financial struggles or work schedules not permitting to be present at school as much as they would want, and for others the cultural norms, where teachers and services providers are seen as all-knowing and not to be questioned (Lalvani, 2012). I was able to witness all these struggles, since my own family went through them when raising a child with Special Needs. This gave me a lot of topics of conversation when sitting with the parents and discussing my own personal interest in this research. I explained to them the frustrations and fears felt by aunt and uncle as they raised my cousin. I told them how I watched as he grew up bilingual, where we as his peers were never told to speak to him in only English. We just spoke Spanglish as we played and interacted on a daily basis with him. I used my experiences to explain to them my personal connection to this research study and the reason why I wanted to give ADS a voice. I told them it was important to me that moving forward their experiences told directly by them, and not others, was just as important as professionals, parents

and other family members. I explained how I believed they were capable of telling me their stories, and from those stories, my goal was to find out how they made meaning of family in Latino bilingual homes. I also allowed parents to ask me questions about my research and me as a person so they could feel confident in allowing me to privately speak to the participants. Parents wanted to make sure that I was not going to ask their child anything that might upset them or harm them. I assured them that I was going to ask questions about family, using an approved protocol by the IRB and a dissertation committee who was overseeing my work. All these people and entities were set in place to ensure that I was being ethical and making sure that the risks were low and that I would not bring harm to any of the participants.

The biggest challenge in trust building came when I had to have the conversation asking them to give me permission to sit and talk alone with the ADS alone. Initially none of the parents understood why they could not be present. They explained things like, their *“my child has a heavy tongue”*, *“will you understand them”* and *“they tell a lot of stories that might not be correct”*, *“they do not have a good sense of time, when things happened or will happen”*. I had to reiterate the important point in my study, that it was about being factual according to their standards, but to be as accurate as possible according to the words of the ADS. The approval to speak to the ADS was only given after I sat and explained thoroughly that my goal was to understand the world through their eyes and that I was aware of the limitations placed upon them by DS. I was fortunate enough that I had the backing of the Non-Profit organization that had helped with recruitment. Through the assistance and recommendation of the director I was able to meet with the families. Telling them that I also had a family member who had been part of the same organization for about 30 years helped in trust building. I explained how I was closely raised with my cousin who is a now a Latino ADS, which was a great way to segue into a

conversation with the parents. It allowed me to explain the purpose of my study, as well as the fact that my interest extended beyond research to include my own personal connection to the topic.

Sharing my educational background and personal background with families helped me paint a clear picture of who I was and what my intention was. Parents asked me if they would be able to know the results of my research. I told them yes, which was also a favoring point since they too were interested in my study and what other Latino ADS had to say. I informed them that at the conclusion of my work I would be sending a summary statement of my findings to the director. She would then make sure to disseminate it amongst all families so my work could serve as a tool that allowed parents to gain some insight on the point of view of ADS when it comes to making meaning of family. Another great advantage that I had in building trust was that I am a native Spanish speaker. I was able to connect with the families in Spanish, use Latino terminology, additionally, as a native of the Latino culture, I could understand jokes and sarcasm. Conducting these initial family meetings in that language that the parents were most comfortable in, allowed me to gain a deeper connection with the families (Tejero Hughes, Martinez Valle-Risestra, Arguelles, 2008).

Rapport Building Capacity

Rapport building is important in gaining the trust of both the Legal Guardian and the Adult with Down syndrome. Many of the strategies used to build trust with Legal guardians are used when approaching the ADS. These strategies also overlap with the capacity to build rapport with both Legal Guardians (i.e. parents) and ADS. For this study rapport defined as “a smooth, and positive interpersonal interaction with individuals”, which allows for an increase the amount of information shared by participants, with an increase in trust and cooperation overall (Abbe &

Brandon, 2014; Collins, Lincoln, & Frank, 2002). Abbe and Brandon (2014) outline seven strategies for building and maintaining rapport with a research study: immediacy behaviors, active listening, mimicry, contrast, self-disclosure, common ground, and contact and persistence. These strategies make the researcher a responsive and active participant in the interviewing process, which is the central point of building rapport. Immediacy behaviors refers to the interviewer using physical space and body language to convey the message that they are an active member of the conversation (Abbe & Brandon, 2014). When speaking to the ADS I would make sure to engage in constant eye contact, even when they were not looking at me, leaning forward and facing them, nodding my head all to show them I was in the moment, listening to them. The same tactics were used when engaging with the parents, following the Latino culture norms, of saying “Hola, mucho gusto”, a kiss on the cheek or a hug. Eye contact was also maintained with a smile and head nod to indicate understanding and empathy for concerns parents may have.

Active listening with mimicry (Abbe & Brandon, 2014), were an important of the conversation when addressing the ADS since they have a slowed speech pattern that can be repetitive with, more to do with the difficulties in expressive language (Kumin, 1994; Wild, Vorperian, Kent, Bolt, & Austin, 2018). By using verbal speech cues to demonstrate understanding and listening such as, *yes, si, ok, or uh-uh*, I was able to demonstrate active listening skills, coupled with nonverbal cues. I am aware that I am a fast talker, so by monitoring the rate of my speech I was able to partake in mimicry by slowing the way that I spoke and using easy common language to explain my research study. I was able to learn what phrases made the ADS most comfortable, such as “*that’s really cool*” or “*wow that’s great*”, or “*you are strong*” or “*you are smart*”, which served as words of encouragement to aid in rapport and trust building. I

was also able to use mimicry when working with the ADS, by making sure that I had a bottle of water to drink so we were both comfortable as we spoke. In the case of James, in our first interview I had water, but he did not. At the beginning of our interview he immediately stopped to make sure I had water. He asked, “*do you have water?*”, and I said yes, but noticed through his body language that he needed a drink. So I asked, “*did you need water?*”, and he responded “Yeah, yeah I do”. Moving forward I always made sure he had water and that all my participants had a drink present just in case they felt thirsty throughout our conversations since they were about an hour each time. I was able to mirror not only nonverbal behavior but actions and the needs of the participants which served me well in all interviews. On the contrary, contrast was not used. Abbe and Brandon (2014) describe it as when the interviewer needs to demonstrate hierarchy, power differentials, or opposite of emotions with the conversations, which can be beneficial in rapport building in cases like interrogation of suspects by law enforcement. The goal was to show empathy, excitement, and respect by speaking slowly, using the same language (i.e. English or Spanish), rather than establish myself as an authority figure with either parents or ADS, which is why I chose not to use the strategy of contrast.

Self-disclosure helped establish common ground, which was the most powerful technique used when building rapport with parents and the ADS. Knowing that I was a family member of an ADS that they also knew personally, gave me instant credibility. Abbe and Brandon (2014) make sure to stress the important of self-disclosure to be appropriately used, since it can work against me. I made sure to provide information about who I was, who my family was, but also made sure to do my research to know that none of these families had a negative past experience with my Uncle, Aunt, or Cousins. Not knowing could have led to having families be closed off to me and possibly telling other families to not work with me if there were contacted. I was lucky

enough to have a family that had nothing but positive experiences with the organization and other Latino families, aiding in my credibility and ability to quickly gain the families trust. The parents opened up to me and shared childhood stories of the ADS and told me the struggles they had over the years. I was able to relate and give similar stories since I also lived the experience. It made my educational knowledge that much richer since I could back up my stories with research and stories of other families who had similar experiences.

Finally, contact and persistence was a key element to rapport building (Abbe & Brandon, 2014), since I was able to interact with families in multiple settings outside the designated interview times. As a family member of an active member of the Non-profit I receive the invitation to annual fundraising and creating awareness events. While conducting the interviews in Florida, I attended with my Uncle the annual Wine and Cheese event where parents get to network with previous members, current, and new members of the organization. All the families I interviewed attended this event, including John, one of the ADS with his parents. It was great to be able to see him again and ask how he was doing. Parents were also excited to see me at the event and ask further questions about my study, me personally, and my children. I also make an effort to attend the Buddy Walk a national walk for individuals with DS. Where families gather for a 3k walk to fundraise and join in a collective voice to create awareness for DS. I have attended this event multiple times with my family and son. Families enjoyed and respected that fact that I traveled with my youngest son to support the cause and show my dedication the field of DS and persons with DS. It is also exciting since all of my participants along with my cousin perform every year at the Buddy Walk so it is a way for me to show my support and enthusiasm, which made interviewing ability stronger, since we had something to talk about, giving us common ground (Abbe & Brandon, 2014).

Researchers Positionality

It is important as the researcher, to be clear about my insider access, meaning that conducting a study about ADS when I have a personal relationship with an ADS gave me a natural advantage to building trust and rapport with the families purposively selected for the study (Merriam & Tisdell, 2016). I must bring to the front of my research the fact that I am a Latina who was raised with individuals with many different cognitive disabilities, specifically Autism, Down syndrome, ADD, ADHD, Depression, Anxiety, and Bipolar Type II disorder. I am well versed in the world of mental health because that is a norm for me and my family. My older sister who is now a woman of 38 years old, suffers from and has suffered from Depression, Anxiety, and Bipolar Type II disorder since she was a teenager. My younger male cousins, who are brothers and about 10 years younger than I, were diagnosed in elementary school with ADD and ADHD. I helped raise and tutored both of throughout elementary school. I was part of child study team meetings with the teachers, parents, and school psychologist. I was commended on how I was able to support both of their development and education through after school tutoring and mentorship, when I was still an undergraduate college student. My younger female third cousin was diagnosed with Autism 6 years ago and is currently in the third grade. Her mom and I have a close relationship and have assisted in investigating the best school districts and supports for their daughter. Currently, through my previous studies in Psychology, Behavioral Modification, Parent Coaching and in Family Science and Human Development, I have been able to give them strategies so as a family they can support the development of my little cousin. Finally, as evident through this research my younger male cousin was born with Down syndrome and is only 3 years younger than I.

I must also state my cultural connection and position within this research. As a Latina who was raised in a bilingual, English, Spanish speaking home I strongly believe in the importance teaching children, regardless of a disability, Spanish, when it is the dominant home language. I am aware that this is a bias that I must always make an effort to keep in check when approaching my research study. Encountering homes where families made conscious or unconscious choices to teach children more than one language, is a family's personal choice and I must make sure I respect it. My job as a researcher is to engage families and individuals without judgement, without imposing my beliefs on them, and most importantly ensuring that the wording in my interview questions, as well as the interpretation of what I am observing is also judgement free. It is difficult to not have an opinion, if families whose predominant language, and the one they are most effectively communicating in is Spanish, and when encountering their children who may or may not be children at that moment, have limited to no ability to speak Spanish. I cannot help but wonder, how these family members communicated, engaged each other and built relationships when they could barely speak the same language throughout the years. My inner thoughts can cloud my ability to see families and individuals' stories through a lens of openness, since all the while the question, why wouldn't you teach your child Spanish when that is a huge part of our culture, lingers in the back of my head.

In my own family and in all the families interviewed, children with special needs were raised in bilingual homes, and many were told that they should not teach nor expose their child to more than one language. Many were explicitly told that they should only teach their child English. My own mother was told once she arrived in the United States with me and my siblings, that she should only speak to us in English and should stop speaking Spanish, so we would not get confused, could learn English quickly, and assimilate the American culture. The importance

of English and the American culture was made so clear through the education system when my older brother and sister were placed in ESL courses and were almost held back because of their lack of English skills. She was faced with this dilemma when she had just arrived in the United States with a 6-year-old (my sister), 3-year-old (my brother), and a me a 2-year-old from Mexico, where no one in the home spoke more than one or two simple words in English in 1987, yet fast forward 30 years later my cousin with her daughter who has Autism is still told the same thing, English only is best.

I believe that there continues to be a lack of consideration for the parent's ability to speak English, since the advice given does not take into consideration the parents and primary care takers ability to speak English. My aunt and uncle as stated in the introduction of this study, were also given the same advice in regard to my cousin with Down syndrome, and again no one ever asked if the parents spoke English well. There seems to be little thought given to the idea of how the child will develop, build relationships, making meaning of their surroundings, interpret symbols, events, and objects (Charon, 2004), to create a strong sense of family without Spanish, the dominant language spoken and used in every day social interactions such as the labeling of meals, times of the day, rituals, customs, music, television shows, and terms of endearment and encouragement. I strongly believe that there is a disconnect between the day to day lives of these families, such as mine, current research, and the advice given by professionals.

I am aware that I stand in a position where I believe that all parents should teach their children their native language, especially when two factors hold true within a family, 1) the parents speak little English, 2) the child has a disability, because it is important that they can communicate effectively to support the development of the child. Through research, I have learned the benefits of bilingualism (Cummins, 1981; Espinosa, 2013; Guiberson, 2013a; Wong

Fillmore, 1991, 2000) for children and the detrimental effects of native language loss for children within these bilingual and multilingual families (Paradis, 2001; Thomas & Collier, 2003; Toppelberg & Collins, 2010; Wong Fillmore, 1991, 2000). Coupled with my own personal experiences in the world of Latino families and children with special needs, I am also aware of how research has demonstrated and continues to demonstrate how individuals with cognitive disabilities such as Autism and Down syndrome can become successful bilinguals without negatively affecting their development. I have first-hand witness how exposure to and being taught Spanish has benefited them. It has allowed them to communicate with foreign family members, older generations, participate in family parties, rituals, traditions, and in the day to day social interactions because they are not excluded due to language ability. They are able to make sense of their world, build a confident sense of self, and voice their needs, wants, and desires to those that matter most, their main caretakers, and in the case of and the participants in this study, their parents.

I cannot negate that I stand in advantageous position because I am part of a family where we have individuals with disabilities who are bilingual, rather than being part of a family who does not. I also cannot deny the fact that my cousin is one of the participants in the study, giving me an insider perspective when it comes to his meaning making. I try to always keep that at the forefront when I am interviewing him, and even more when I am reviewing the transcripts. I have made a great effort to focus on his words rather than the things that I know about his relationship with his family and friends. I am aware that I can influence him since we are related and that he could hold things back because of fear that his parents or sister will find out. I must also be aware at all times the influence that I can have on other ADS that I encounter, since they are individuals with Special Needs who can easily be taken advantage of. I am clear and have

made a great effort throughout the process to stay focused on my job of staying objective and listening to them rather. That my position as the researcher is to be as objective, respectful, and open-minded as possible, knowing that the only voice that the most important voice in the research is that of the ADS.

Participants

The current study identified 7 adults with DS, but 5 were selected as the final sample for the current study. Five were located in the State of Florida contacted through the Non-profit organization and the other two were recruited through word of mouth at the Local Church in New Jersey. One female who fit the 5-item criteria checklist, was not able to sustain a conversation although she had high verbal expression capabilities. She had a dual diagnosis of Down syndrome and Echolalia (Oxelgren et al., 2017). Unfortunately, Echolalia made it impossible to include her in the study since she would only mimic my words, and after 2 different attempts, even with the use of photographs, I was unable to have a conversation in private, where I was certain that she was understanding the questions I was asking, and could give me answer rather than just repeat my words. The family was welcoming and also attempted to help by explaining to her what we were going to do, but her Echolalia was so pronounced that it did not allow us to talk. Also, the family had not developed an alternate means of communication with her, just oral, so I was unable to try other communicative device, since she had no prior training using anything.

Another participant was a male, who I was unable to coordinate a meeting with since moms schedule and mine clashed. Also, when speaking to mom over the phone about my study, the need for 3 images selected by the ADS, she informed me that his speech was very limited and that talking to him would be very difficult. Although I attempted to meet with the mom and

ADS, despite her warning about his speech limitations, I was unable to coordinate a meeting where we were all available. The final group of 5 participants that met the criteria for the research were 3 males and 2 females, all 5 were bilingual, although their level of proficiency varied significantly. The first participant John was part of the pilot study, the other 4 participants were James, David, Betty, and Olga.

James

James is a Cuban-Puerto-Rican-American. He was a 27 years old male, who also identified as having Down syndrome and said he was a man. He was the only participant that was a balanced-bilingual, a person who has both a balanced use of the L1 and L2, alongside a balanced level of proficiency (Yow & Li, 2015). Meaning, he could fluently switch between languages speaking in either one, depending on the story he was telling and who he was talking to. At the beginning of the interview process, I make sure to ask participants which language they would like to speak in, and he was the only participant who told me both languages, "*let's do English first and then Spanish*". When asked if he spoke Spanish, he answered in Spanish, saying "*Yo hablo mucho Español*".

James has two sister and a cousin/sister as he called her. One sister is younger and the other is his twin sister. He held a special relationship with his twin and shared videos with me that they would make, where they would make up choreography to their favorite songs and dance while recording it. He would binge Netflix shows with his other sister and expressed how much he loved them. He had a job at a fast food-restaurant which at the time he was on vacation from, so he said his manager knew that he was on vacation. He made clear that both dad and the manager knew when he was returning which was soon, but he was still on vacation. He had a girlfriend of many years, who he complained about since he felt she was moving too fast and

asking too much of him. He said that “*she wants to have four babies, this is too much for me... she keeps on rushing her age... like to propose with me... she texted me and that’s why she said that to me... she wants to get engaged with me... but I said no*”. He said he wanted to just end the relationship and move to another state. Through the course of our interviews he ended up staying with his girlfriend and continuing his relationship since he no longer wanted to move, but this happened over a course of a few weeks.

His story was a unique in the sense that he belonged to another national organization and would travel alone to the annual conferences, meaning without family members, but with typically developing peers who worked for or volunteered for the organization. When I first met him, he was passionate about and consumed by the idea of moving to another state where could work for and permanently be part of this national organization. Many parts of the interview led us back to this organization and his desire to move but was upset that his parents did not approve. He was very vocal about his goals, dreams, and what he wanted out of life. He showed excitement and was the first participant to ask me for my Facebook account so we could connect. Just like John he also made sure to get my phone number so he could confirm our appointments and is mobile using the bus to get around.

David

David is my cousin. He is 31-year-olds and identified as being Colombian and a man. He is bilingual and can speak both languages fluently. He speaks to the older generations, such as my parent, aunts and his grandparents in Spanish. It is like he is aware that they speak predominately Spanish. When he speaks to me, his sister, and cousin peers he speaks to all of us in English. Unless we speak to him in Spanish, he automatically speaks to all of us in English. When speaking to his parents I see him mix switch between both Spanish and English. It seems

to depend on his mood and the topic of conversation. My Aunt and Uncle are now fluent in both languages, so they also speak what is commonly known as Spanglish to my cousin, a mix between English and Spanish as if it was one language.

Interviewing him was difficult since he knew I knew many things that were going on at home because of my close relationship with my Aunt and Uncle. At the time of our interviews, my Aunt had relocated to Texas since my cousin, his older sister had just had a baby, who was born little in size and needed extra care. Although she left for a good cause, he was very upset by her absence, since my Aunt had established a very rigid routine with him since was young. As long as I can remember she has gotten up between 4am and 5am to work out, cook, and get ready for work. She worked a 9am-5pm job but would make sure to cook enough food for my Uncle, herself, and David to eat. David and my uncle would have lunch together every day Monday through Friday since my uncle owns his own business.

When she left, there was no one to cook. My uncle was limited in his kitchen skills, so they were forced to eat out almost every day. When I arrived in at their home for the summer I took over some of those roles, such as cooking daily meals and cleaning so my uncle wouldn't have to. David is also semi-independent where he picks out his own clothes, showers, dresses himself, cleans his room, helps with chores around the house, talks on the phone, facetimes family, and makes his own breakfast every day. He is able to make plans with friends, plays sports, loves dancing and music, and socializes very well with the family. He does not hold a job, but occasionally works with my uncle at his shop. He does not know how to take the bus and get around since my Aunt and Uncle never taught him. They do not find the need to teach him. He can also stay home alone while they work and had been doing so since he was 21. On the contrary to John and James, David cannot write beyond a few words and phrases, making his

ability to text very limited. He also does not identify as having Down syndrome and when I asked him if he was an adult with Down syndrome he seemed not to be sure. I have never until that moment ever asked him if he had Down syndrome and I do not think that anyone in the family ever has. I know that my Aunt and Uncle had never asked him nor told him, nor explained to him what it was to have DS.

Betty

Betty is a 33-year-old Colombian woman who identifies as having Down syndrome. She has one younger male sibling who had just recently had triplets. She was a proud Aunt and explained how she helped feed, bathe, and dress her niece and nephews at least 2 to 3 times a week. She explained that her brother lives at home, but when his wife got pregnant with the babies, he spends a lot of time over there. The triplets were a surprise to the whole family since no one expected it to happen. She spoke about her brother and his family with a lot affection. She refers to his wife as her sister. She also speaks about her Grandma, her mother's mom, who used to live them but passed away a few years ago. She expressed that she loved her family very much and that they love her. She was aware that she was the first born and said "Because I her daughter... I her first baby" when referring to why her mom loves her. She then went on to tell a story where she was two and a half years old and had to have heart surgery. She said that her "Mommy and Daddy" took care of her and when she gets sick, "Mommy" makes her "chicken noodle soup".

Betty is very active; she is in a professional bowling league where she plays for the Special Olympics and competes. She has won various trophies. She has been bowling since she was little. I asked her how she learned, and she said "My Daddy. He teach me how when I was little". Bowling is bond that she has with her dad. Although she says that mom along with Dad

attend her bowling matches, it is still something that she constantly talks about doing with dad. When speaking about Mom she talks about home life, family life, or shopping. She also attends an annual Gala through another organization she is involved in, she volunteers three days a week, and has a boyfriend that she loves very much. She had a busy schedule but a fixed schedule making it easy to setup a time to speak to me. She was the only participant that did not ask to have my number or to connect via Facebook. I asked when we could meet again, and she told me her schedule, then said we could confirm with her mom. She does not move around through public transportation but is also semi-independent because just like all other participants she stayed home alone while her family worked. She stayed in her room watching tv or listening to music. If she was hungry, she knew how to heat up food to eat or find a snack while her mom arrived back home.

Olga

Olga a unique case, as compared to the other participants because our interviews were all in Spanish. She demonstrated the highest ability to communicate orally, showed in depth understanding of what I was asking, and was the only participant that was able to tell things in chronological order. She was aware of time, her age, the age when things occurred, and how she felt, as well as how her parents felt at the time of events. She is 30 years old and was born in Ecuador. Her parents brought her to the United States when she was 15 years old. She entered high school and was able to learn some English. She attended high school until her graduation at the age of 21 when things became very hard for her. She was the only participant where I was sure that when she identified as having Down syndrome that she knew it meant that she was different. That having DS limited her life. She began telling me about her life after she graduated high school. She openly shared that she fell into a depression since she was now home alone all

the time, rather than have something to do every day like go to school. She said that because of this depression she forgot almost all of the English language that she had learned at school:

“Cuando yo me enfermé. Tenia, tenia depresión y se me olvida todo el inglés. Por que me quede sola en casa. Mi papa estaba trabajando... ya no estudiaba mas por que ya terminaba la escuela”.

[“When I got sick. I had, had depression and I forgot all the English. Because I stayed at home all alone. My dad was working... I did go to school anymore because I had finished school”.]

She then went on to talk about how she did horrible things at home by watching television all day, being disrespectful to parents, and drinking all the liquor she could find in the house, stating

“Veía televisión. Yo hacia horrores por que me tomaba todo lo que era licores en la casa. Con mis papás. Pues. Yo respondiò groseramente con a mi mamá es una cosa tan difícil para mí esto”.

[I watched television. I did horrors because I drank all the alcohol in the house. With my parents. Well. I responded disrespectfully with my mom this is something difficult for me”.]

She recognizes how these were difficult moments for her. She is able to explain in detail what she did and more important that what she did was morally wrong.

Olga has an older brother who still resides in their native country. She lives in the United States with her parents, but they do not have any relatives here on the mother’s side, and only one sister on the dad’s side but they do not have any contact with her. She and her parents socialize with friends that they have made here in the United States over the past 15 years. They do not belong to any group or organization that supports adults with DS, so they have limited contact with other families like themselves. Every so often I see them at church, and it is always the three of them. She had a job at a law firm where she files papers and cleans. She also had a job at the local grocery store, but she struggles to get hours. She is aware that the previous manager was more helpful and gave her more hours, but the newest manager had cut her hours. She is very active on social media; she texts and messages me. She also asked for my number

and to be able to connect with me through Facebook. The majority of the time I get messages through Facebook or WhatsApp, two applications she uses very well since she has great writing skills in Spanish. She said that her parents are also limited English speakers, so they prefer to talk in Spanish as does she.

Interview Process

The data collection process was emergent and flexible, where the final product was produced from the semi-structured interviews rich descriptive narratives (Merriam & Tisdell, 2016). During recruitment and initial contact with the families via phone all families were advised that the participants must select three favorites photographs to bring to the first meeting, and all subsequent meetings of individuals whom they considered to be family and important people in their lives. At the initial family meeting, parents were briefly explained the purpose of the research and advised that the further conversations would be with the participant in a private setting. Then in the private one-to-one first interview the ADS was again explained the purpose of the research study and the research question. No further explanation was given in order to prevent influence from me and my personal point of view, unless I was otherwise asked to explain things that they may not have understood, answering specifically what I was asked. All forms were read aloud to participants since research has demonstrated that individuals with disabilities benefit from this method, since it aids in comprehension (Hurtado, Jones, & Burniston, 2014). Once, informed consent was reviewed, read aloud, agreed upon by the participant, and subsequently signed the interview process began. Using an adapted questionnaire from Davies & Burke (2016), labeled “Tell Me About Yourself, a 5-item graphically visual demographic survey, was selected in order to aid comprehension and to reduce frustrations that can come from limited expressive communication (Wild, Vorperian, Kent, Bolt,

& Austin, 2018) between the participant and the researcher, see Appendix C. This form was the beginning of our conversations since it allowed me to know one very important fact, did they identify as an ADS. All participants said yes, but by the facial expression and the certainty in the tone of their voice, Olga, Betty, John, and James gave me the impression that they had heard the term before and that they were individuals with DS. I am not sure if David knows that DS is and what it means to be a person with DS.

Then, following the semi-structured interview protocol, see Appendix D, D1, one to one audio recorded interviews were conducted. The protocol contained 4 open-ended questions, and set to last between an hour and an hour and half, see Appendix D. Each participant was interviewed a total of 3 times, to allow for member checking, validation, and to gain a better understanding of the ADS story, since comprehension was difficult at times and hard to understand in audio tapes for transcription. The second and third interview allowed for re-confirmation of details (i.e. member checking) that could have otherwise been missed or misunderstood on the first interview. At the third interview, the final questionnaire is utilized which is visually aesthetic and simplified to get and confirm the persons background and homelife, labeled the background questionnaire, designed to collect the demographic information of each participant, see Appendix C.

All scheduling was done through the primary care takers, since the ADS did not have the ability to set up a meeting alone, nor are they allowed to make such decisions, without the primary caretaker being notified. After our first in person interview dates and locations were selected, the primary caretaker was aware that the conversations would be moving to a private one-to-one meeting with the ADS. I made sure to set the date first with the ADS, since I wanted to make sure they knew that it was our private meetings, giving them a sense of control and

importance. Then, I would confirm with primary care takers that the date and time we set was ok. I would also tell the participants that I would be confirming the date and time with them, making sure that I was transparent in this process. I wanted to make sure during our interview process that I did not lose that trust and confidence that the participants were placing in me. Making sure I was authentic, honest, and transparent during the entire process was one of my main goals during data collection.

Understanding the Process of Screening Protocol

Taking into account the strengths in visual- short term memory and the ability to read the documents out loud to the participants, this helped guide the creation of the all consent forms, protocol questionnaires, and method of data collection. The use of recognizable and simplified visual images helped to illustrate the meaning of each question asked, helping ensure understanding (Hurtado, Jones, & Burniston, 2014; Pointu, 2017). The first forms used when contacting families and ADS were the letter to invite, information sheet, and screening guide, see Appendix B1, B2, and B3. All were adapted from Pointu (2017) a qualitative study conducted with older women with learning disabilities in the UK. She used images next to every question to help illustrate and support meaning. Following her model, all questionnaires that were going to have direct contact with each ADS, were created in the same format. They were successful because they allowed me to explain further, anything that might have seem too complex for the participant, since ethically I had to explain to them risks, benefits, and the most important, the fact that they could stop or withdrawal from the study at any time.

The first three forms were a shortened version of the informed consent and consent form (see Appendix A and A1), which were going to be used after the introductory meeting, at the first one-to-one private interview with the ADS. They also served as a way to explain to parents

what the study was about, the University I was studying at, and to provide a formalized invitation. Further, the screening guide (see Appendix B3) helped to ensure that the participant met the initial criteria before moving forward. Once participants accepted and we met to begin the first interview, I would present them with the information sheet for the informed consent and the consent form where they would be signing in agreement to partake in the study. Noting that it is them that I wanted to sign form, given their mental capacity and legal capacity to understand it and sign it, I created a modified version of questions from Pointu (2017) and in accordance with Florida confidentiality law, see Appendix A, & A1. The information sheet to the consent form and the consent are respectful towards the community of ADS seeking a signature that is independent and of free-will, without the pressure or influence of parents or others. I am aware that although I am asking them to sign if they agree, meaning if they choose all the smile faces and yes boxes, they are inclined to sign because it can be interpreted as me telling them to do so. The images and simple language were my attempt to overcome this possible misinterpretation.

The final form presented to the participants was the demographic questionnaire, called *Tell Me About Your Self*, which was an adaptation from Davies and Burke (2016). They also used imagery in their questionnaires when interviewing people with intellectual disabilities about the topic of workforce development (Davies & Burke, 2016). The decision was made to present this form last because I did not want to taint the person's idea of family. I am not sure what definition they had in mind or if family members had ever told them this person the person is not your family referring to blood relationships or family turmoil. The questionnaire asked questions about who lives with you now (i.e. do you live alone, with others, with family) and then who lives in your home now. These were meant to be pure biographical, so I did not want to put the idea that family is only who live in the same home as the ADS.

Use of Photography to aid in In-Depth Understanding

Photographs are subjective views of the individual's reality. They are created and set for a particular audience or to remember a particular moment or event (Holm, 2014). Photographs are used as research methods in various fields (Holm, 2014) and more recently through the method photovoice, as a tool is grounded in empowerment, focusing on individual's strengths and has been utilized with the population of individuals with special needs demonstrating successful results (Agarwal, Moya, Yasui, & Seymour, 2015; Bullard, 2015; Booth & Booth, 2003; Jurkowski & Paul-Ward, 2007; Holm, 2014). Photographs are a tool that is characterized as enabling, since it provides supports for the participant to reflect on, open up about, and communicate thoughts, concerns, and coping strategies (Hermanns, Greer, & Cooper, 2015). Photographs allow for the conversation to be participant led, where prompts are utilized to aid in the narrative behind the image, relying on the strengths of ADS's responsive language, vocabulary, and visuospatial memory recall (Holm, 2014; Lockrow, Fortress, & Granholm, 2012; Wild, Vorperian, Kent, Bolt, & Austin, 2018). ADS were asked previous to the first interview to select a maximum of 3 photographs to bring with them for the second session of interviews. They were asked to provide photographs where they were interacting with family or in a family related event, that may or may not have occurred within the immediate home.

Participants and care-takers were explained that they can bring any photograph that they deem important from a moment in their past, such as graduations, family parties, gatherings, celebrations, birthdays, homecoming, prom, as well as Latino rite of passages such as a quinceañera (i.e. sweet 15) for females and adulthood celebrations for males at 18. Any photograph of importance, such as those from significant moments in their lives or noteworthy milestones aid in visuospatial long-term memory recall (Lockrow, Fortress, & Granholm, 2012)

and help ADS to lead the conversation in a way that is empowering and respectful. Participants were asked to share the reasons why they selected the pictures and tell the story behind the image, as a way to initiate conversation and gain an in-depth understanding of how they make sense of family within their Latino bilingual contexts. The images are symbolic and helped the researcher understand the ADS perspective but also allowed the researcher to see how the ADS engages in on-going mind actions, taking the role of others, as well as how they may have a sense of self since they are reflecting up on moments from their perspective (Charon, 2004).

The inductive approach of qualitative research (Merriam & Tisdell, 2016) coupled the theoretical perspective of SI (Charon, 2004) allowed for a clearer understanding of how Latino ADS make meaning of family while growing up in a bilingual, English Spanish, speaking home, through the use of photographs. Research has demonstrated that native language loss can be problematic for individuals raised in multilingual contexts, creating a disconnect amongst family members (Guardado, 2006; Farruggio, 2010; Wong Fillmore, 2000), yet the perspective of Latino ADS is unknown, when they are such persons. In-depth interviews could lead to surprising conclusions. Latino families are naturally closed off from outsiders, and keep familial topics they consider private to themselves, rarely joining or seeking communal support and/or chat groups, especially families in lower socio-economic classes (Lalvani, 2012). The Hispanic community continues to grow (Brown, 2014), but the dominant spoken language continues to be English in the United States (Ryan, 2013).

The inability to speak English well, or at all, and raising children with a disability in the United States, where the dominant language is not the family's primary language, is a reality that many Latino families must face, hence there is value knowing and understanding the perspective of the person with a disability when it comes to decisions about language usage, exposure, and

purposefully being taught their native language. Being disabled should not be a barrier to freedom of choice and most important the right to be part of a conversation that will directly affect the life of the individual. Giving ADS the ability to select photographs to be presented as part of the conversation, supported the stories told by the individual, giving clarity in moments where the person was not able to clearly speak due the limitations imposed on them by the disability.

Researchers Reflexivity

Reflexivity is an ongoing process throughout data collection and the analysis of the results, whereas the researcher, I must be aware and make a conscious effort to continuously think and re-think my position, biases, and ensure that I am being objective (Bourke, 2014). It is an awareness of the influence I have on the current study, such as selecting participants, creating interview protocols, when saturation is reached, and the interpretation of the data. It also includes the impact the study has on me, which again can influence the study, especially in regard to the findings (Merriam & Tisdell, 2016). Through the course of the interviews, the participant, and I co-created in a shared space. It is important to note that this co-created space of shared identities, can have an impact on the research process (Bourke, 2014; England 1994). Being mindful of the influence created, I used qualitative methods to ensure an objective truth (reliability) was obtained and credibility (validity) of the results (Lincoln & Guba 1985; Merriam & Tisdell, 2016; Wolcott, 2005).

To help me with this reflexive process, detailed field notes were taken immediately following the session as audio recordings, that were later transcribed. They provided a highly descriptive account of the interview process, conversation, with reflective notes for the final write up, helping me better understand my positionality and through the reflexivity process (Merriam & Tisdell, 2016). Triangulation an important concept was used to ensure internal

validity was accomplished, evident through the use of multiple methods of data collection (i.e. semi-structured interviews, photographs, and member checking) and a strong theoretical understanding of symbolic interactionism in order to confirm findings (Merriam & Tisdell, 2016). Through the semi-structured interviews, I also ensured that I was building trust, comfort, and allowing for an open-engaging conversation. I was able to demonstrate respect for the ADS and parents, their cultural background and, the experiences they shared with me throughout the process (Merriam & Tisdell, 2016).

Throughout the entire process of designing the study, gaining IRB approval, writing the literature review, conducting the interviews, transcribing, and the final write which included the interpretation of the data, I must stop and reflect about my influence on this study. I questioned, if my own beliefs about ADS bilingual capacity, pushed me to see things that were not there. I pondered about my strong belief that ADS should be heard and that their voice matters. Although this is not a negative thought, it has made me wonder why they have not been interviewed before. Did I do enough to ensure that I brought them no harm, that me stepping in these family's lives had a positive effect rather than a negative influence. I evaluated and re-evaluated since the beginning of the study all the aspects that involved direct communication with the participant and family, listening to my notes again and again before meeting with families for second and third interviews to ensure that what I remember hearing or understanding was what they truly said, in accordance with the recordings, and the through the process of member-checking (Merriam & Tisdell, 2016). I constantly questioned myself, reviewed my notes, and had conversations with colleagues and family members about my work. I made sure to keep all identifying information confidential but talking through some of my own assumptions and hearing other assumptions about ADS helped me gain clarity. I also read and re-read my notes,

the transcripts, and more importantly listened to the audio-recordings listening to the pauses, tones, moments of silence, and other possible cues that allowed me to gain a better understanding of what they were saying to me.

Analysis of Interviews

Qualitative research is an on-going process where data collection is done almost simultaneously with analysis (Merriam & Tisdell, 2016). In the current study data collection and the subsequent analysis began almost immediately. As previously explained, following the initial contact with the Executive Director and then the introductory meetings with the families, notes and audio recordings were taken to assist me in the reflexivity as well as positionality, ensuring I was being ethical every step of the way. Each interview produced an audio recording for transcription field notes, and pictures for analysis. This data was transcribed, read, and re-read for patterns that were coded and linked together for possible emergent themes (Creswell, 1994; Merriam & Tisdell, 2016). This allowed for clarification in the follow-up interviews, preventing me from feeling overwhelmed, and unorganized with the amount of data collected and at the same time assisting me in the analysis of the data. The Nvivo 12 for Mac was utilized as the main device for coding the transcribed interviews and photo narratives. The following are ten suggestions made by Bogdan and Biklen (2007) for data analysis: 1) to narrow down the research and make sure, to make decisions early, 2) make sure to decide which type of study you want to accomplish, 3) review questions to ensure they are analytical, 4) let previous sessions guide data collection in the following sessions, 5) take many field notes and observer comments as you go, 6) write notes to yourself about what is learned and observed, 7) try out the emergent codes, ideas, and themes as part of the on-going interview process, 8) read, re-read, and explore data and literature throughout the process, 9) explore new concepts, metaphors, or themes, and 10) visualize and

use devices or hand written imagery to explore and organize data. These suggestions served as guideline in the current study.

Three waves of analysis were utilized as suggested by Miles and Huberman (1994). The first wave consisted of open-coding, line by line analysis, where the researcher read and re-read the transcriptions and field notes at the end of each interview session, pulling relevant information as it pertains to the research questions. The second wave consisted of further analysis of the data by making connections between relevant codes and units of information for the development of related or major themes. The exhaustive on-going process of repetitive reviewing of data allowed for consistency of codes, themes, and for saturation to occur naturally (Lincoln & Guba, 1985). The third wave of analysis consisted of drawing conclusions and verification of findings for the final write up of results, a shortened thematic analysis (Miles & Huberman, 1994; Nowell, Norris, White, & Moules, 2017).

Using Bogdan and Biklen (2007) and Miles and Huberman (1994) guides on how to conduct a basic analysis allowed me to have a better in-depth thematic analysis of the data (Nowell, Norris, White, & Moules, 2017). Thematic analysis begins with familiarization of the collected data, then generate of initial codes, a search for themes, review of the themes, definition and naming of themes, in order to finalize the analysis and produce a report (Nowell, Norris, White, & Moules, 2017). I combined these guidelines and process to help me organize my data as I went through the interview process and transcribed and analyzed as part of an ongoing organic process. Referencing and keeping in mind Bogdan and Biklen's (2007) ten suggestions, Miles and Huberman (1994) three wave strategy was the main technique I used was to conduct the three waves of analysis. It gave me a simple but very useful way to organize data,

in a way that I could understand that interviews, better especially since it is my first time conducting a formal qualitative study.

Waves of Analysis

The first wave was conducted by re-reading John's first interview to help me learn how to better ask questions, when to prompt, when not to too, and to remember that I should not use loaded questions nor closed-ended questions. I was able to see how I was as an interviewer as well as how my prompts either aided in the interview or could have possibly caused confusion. For example, in my eagerness to jump right into the interview process I could have overwhelmed and confused John. After going through informed consent and asking if he had selected his three pictures to help us during our interview, I began by asking,

Linda: Okay. So the first thing I want to ask you about is, can you tell me about your family? Who Do you consider your family? Who are your closest people in your life that you consider family?

John: Ummm, My mom.

I was fortunate enough that he gave me an answer, but I could tell at first, he had to really think about what I was asking since I asked three questions. Reviewing his interview helped me catch myself when I conducted James' first interview. I initially made the same mistake after completing the informed consent process I asked three questions again,

Linda: Okay. So the first thing I want to let you know is I kind of want to talk to you about what family is like for you, what life was like for you growing up in a Spanish, English, bilingual home, Latino home. I want to know how you made meaning of family.

James: Oh, to me, my family.

Except this time, I realized and slowed down. I am aware that I speak quickly and think quickly, when get can faster when I am nervous. Conducting these interviews as a Qualitative researcher with little experience, I tend to be nervous at the first interview, but am able to get comfortable,

push through, and conduct subsequent interviews becoming more relaxed in the process. I went on to say,

Linda: Yes. I want to talk to do with you, with your family. Okay. So I want to first start by asking you a first question. Can you tell me about your family?

James: Yes I do. Okay.

Linda: So tell me about your family. Who's in your family?

James: So my family, [pause] I love my family so much and um, so you saying my family. Uh, let's see. [pause]

Linda: Can you describe to me your family?

James: Yeah, I, yeah, I was grabbing, thinking like, [pause] ummm Christmas. Thanksgiving... Christmas or thanksgiving. Man, It's like, it's like my mom, uh, it's like, it's like my mom and um.

Then with Betty's first interview I was shorter sticking more to my protocol and realizing that I should be clear with my questions allowing them to process what I am asking. I still asked two questions, but it was more to clarify and to be consistent with my study where I had decided that family in those who are important to the participant not just people who are blood-related or identified by others as family.

Linda: So can you please tell me about your family and the people who are important to you?

Betty: Uh Huh, I have a lot of family.

Linda: Yeah, that's great. Can you tell me about them?

Betty: I have my uncle. I have daddy, baby, my brother, my sister in law, my mom and my daddy.

I then prompted her and asked her who she wanted to tell me about first. She went on to describe her cousins and other family in Colombia as well as those in the United States. I realize that by the time I got to my third first interview, reviewing the first interview of John and James, helped me grow into a better interviewer, especially at the start of the interviews which is critical in building rapport and gaining their trust.

The second wave of analysis then consisted of reviewing all the 5 first interviews first individually, yet I could not help noticing similarities between the interviews. So, I thought I was

going to first transcribe and go through the entire first interview of each person before I compared them, but I quickly realized that as I was reading and highlighting, I would take note of something that sounded familiar in another person's interview and did not want to forget it, so I would stop and pull up that interview. What ended up happening was at one point I had all 5 first interviews open across my computer screen and through Microsoft word then NVIVO 12 comparing the words and stories of the participants. The same occurred when I was reviewing the second interviews. As words become codes, the main themes in my data began to emerge.

For example, David, Betty, James, and John all included their significant others as part of their family and spoke about the relationships. They talked about intimacy, love, and happiness. Both Betty and John mentioned the kiss they had with their partners but did not want parents to know about it. The four of them also mentioned about parents interfering in the relationship. Then, all five participants, David, Betty, James, John, and Olga mentioned aspects of their relationship with their mom. The things they did with mom such as shop or the chores they had been assigned by her, such as clean and set the table. They were expected to help out around the house. All of these common stories were seen and examined further by the third interview. I was able to use the tools of member checking, triangulation, and my own audit trail (Merriam & Tisdell, 2016) to get a better understanding of their world through their eyes. The main themes of affection and love, companionship, being cared for, cultural identity, and communication all emerged, which are individually discussed in chapter 4.

Thinking through the Process of Analysis: Olga

As the first wave of analysis was completed, I was faced with the first problem in regard to participants ability to continue to be part of the overall study. The last participant interviewed was a Latina ADS who is very different than the rest of the participants. The other 3 males and 1

female were born and raised in the United States making their primary language English, or a mix of both Spanish and English, having had special needs services their entire lives in the United States. Olga, the pseudo name used to protect her identity, came to the United States when she was fifteen years old. She received some services in Ecuador but had to transition to the United States where she only received services while in school. Her predominant language is Spanish, today she barely speaks English, and speaks very little English at home with parents. After speaking to the Chair of my dissertation committee we decided that Olga should be interviewed, that she did meet the criteria, see Appendix, B3, and was a unique addition to the current study.

Through the second interview and the second wave of thematic analysis, the decision to continue with Olga was still not clear. Her story is one that definitely needs to be told but, her life is very different than the others in regard to upbringing, home-life, lack of being raised with siblings or others in home who were English speakers when brought to the United States, making her home a bilingual home. Also, Olga has a complex story, that involves being arrested since she was not aware that she was drinking underage, when she was 20 and entered a bar while being left home alone, as well as suffering from severe depression after graduating high school, which was briefly mentioned in her description. Her complete account of that situation is stated below:

Cuando yo me enferme. Tenia, tenia depresión y se me olvido todo el ingles. Por que me quede sola en casa. Por que mis papas tenia que trabajar. Yo ya había terminado la escuela. Ya me había graduado. Hacia horrores porque me tomaba todo lo que era licores. Le respondí grosera a mi mama. Yo me fui de la casa a un bar que no era y conocí un hombre que me invito a tomar una cerveza, comer una tortilla con cebolla y algo así y pasarla bien. Pero después de pronto llego la policia y me pusieron una cosa en la mano. Y justo fue ese día un milagro de, de Dios porque me, me, tu que reaccionara porque estaba mal lo que hice, entonces por eso me rescataron y me salvó la vida.
[When I get sick. I had, I had depression and I forgot all English. Because I stayed home alone. Because my parents had to work. I had already finished school. I had already

graduated. I made horrors because I took everything that was liquor. I replied rudely to my mother. I went from the house to a bar that was not, and I met a man who invited me to have a beer, eat a tortilla with onions and something like that and have a good time. But soon the police arrived, and they put a thing on my hand. And that day was just a miracle of, of God because me, me, you who reacted because what I did was wrong, so that's why they rescued me and saved my life.]

Olga can be the focal point of research, by conducting a case study on her narrative and lived experience, a study to consider for future work. She is unique in that she is the person who was the most well-spoken. When I initially met her and heard her speak, I doubted if she was really a person with Down syndrome. She is aware of her disability, aware that she is different, and is capable to truly taking on the perspective of others going into deep thoughts and explanations, a challenge I found with all other participants. There was no doubt that Olga was understanding my questions and that she knew that the purpose of my study was to allow her to share her story about what family means to her and how she builds a sense of family. All other participants would give shorter answers and through coding the two words used most often stated by participants when asked how they felt was “*I feel good or I feel great*” yet there is a value in all perspectives collectively, no matter the length of the responses.

Through the theoretical lens of symbolic interactionism (Charon, 2004), the actions of others and the social interactions with others allowed me to interpret the words of the ADS, by keeping remembering that my goal was to listen to them and allow their voice to be heard. As the interviews progressed, I was able to repeat conversations about special family moments, such as vacations and gatherings where I could compare and understand their stories clearly. I was able to see how different interactions were interpreted by them and internalized regardless of the language that was being spoken at the moment, to build relationships with the loved ones, and ultimately making meaning of family. By the time I arrived at the second wave of analysis of interviews I was able to see that although Olga gave very in-depth stories in our first interview

and thereafter, so did the other participants at a slower pace, but just as detailed within their capacity. Keeping Olga as part of this group gave me a great comparison between the different abilities each participant had, but at the same time how all their stories were valuable, unique, but quite similar. They each had their own individual experiences to tell me about, but I still found the commonality.

Trustworthiness

In order to conduct studies with a high-risk population, as is individuals with cognitive disabilities, it is important to ensure that the researcher establishes a strong sense of trust. Trustworthiness was established by using the four techniques outlined by Lincoln and Guba (1985): credibility, transferability, dependability, and confirmability. Through pro-longed conversations, more than one interview for member checking, the use of triangulation, positionality, reflexivity, and an audit trail, credibility and confirmability were established, until saturation occurred (Lincoln & Guba, 1985; Merriam & Tisdell, 2016). Thick rich in-depth description obtained from interviews and the narratives behind selected photographs helped ensure, transferability. Finally, through inquiry, and evaluation from colleagues, and the dissertation committee, dependability was established (Lincoln & Guba, 1985).

Credibility

The most important part of this study for me was to allow the participant to share their stories. Listening to each of the participants over and over through their audio recordings allowed to truly understand what they were trying to say. I would listen to the specific words they used when describing family, events, or emotions. Then I would further listen to what I said, my reaction or words. In order to make sure that I heard or understood correctly I would sometimes repeat what they said and ask them if I was correct. I would also listen for those

moments where I missed an important time where I could have prompted and pushed to get more detail, but rather stayed quite or changed the subject. For example, when talking to Betty, she began talking about Grandma but then the conversation quickly changed to food and her parents.

Betty: My Grandma, she died earlier this April.

Linda: Oh, she passed away?

Betty: Yes. She passed away

Linda: Did she live with you for a very long time?

Betty: Yes still yes.

Linda: Yes.

Betty: Yes.

Linda: Okay. And what you do with your grandma?

Betty: I'm I do in my grandma's room, to fix, make a bed and a clothes. She would always cook every day. Yeah, yeah. He-here in this kitchen.

Linda: Oh. What kinds of things did she cook?

Betty: She like soup and pancakes, hotdog, hamburger and I make it a cheese.

Linda: You make the cheese?

Betty: Yeah. And my mom cooks fish and salad. And uh, she always make juice for me. Apple Juice.

Linda: And how does that make you feel?

Betty: I feel good. And my daddy, he likes hamburger with me, and my, my brother and uh chicken and rice, he's, my dad is still Colombia.

When reviewing Betty I realized moments like these where, I could have learned more about her relationship with her grandma, yet when I asked about her cooking that led me to her parents and the conversation quickly ended in in Colombia where I learned about her first communion.

Regardless of where of the conversations led, reviewing each interview and cross checking them allowed me to take better notes and member check as well as using data triangulation to ensure that I was interpreting was as accurate and truthful as possible staying true to their stories and not my own biases or assumptions (Guion, 2002, Merriam & Tisdell, 2016).

Confirmability

In order to establish confirmability an audit trail was kept. As stated previously through the use of the Miles and Huberman (1994) three waves of analysis I was able to keep detailed notes about my data analysis and collection process. I used two white boards in my office to

write codes, tally words, define concepts, draw lines, and circles detailing a visual illustration of the connections I was discovering. I coded and categorized themes through the use of the NVivo 12 program. I was able to cross examine tally of words, codes, and formulate the overall themes that emerged from the study. This helped me understand that decisions I was making around themes and if I was truly keeping my own biases in check. I would constantly question myself, asking if this was my understanding or their words. When I arrived at a theme such as companionship, I would look back at my white board and see what codes I used to arrive at that theme and how participants supported each code and then subsequent themes. This in-depth analysis and cross examination helped me keep an audit trail that consisted to handwritten notes, printed out transcripts with high lights, and side notes, NVivo codes and categories, as well as the whiteboard drawings (Lincoln & Guba, 1985; Merriam & Tisdell, 2016).

Transferability

Transferability was accomplished by providing a thick description of the entire process of this study from start to finish (Lincoln & Guba, 1985). With the support and approval of the Dissertation committee and the IRB at Montclair State University the study was designed and implemented. As the researcher, I made a great effort to provide a detailed account of how participants were founded, selected, and contacted. Providing a detailed account as to how I gained the families trust and some of the barriers I had when recruited families serves as a tool for other researchers who might not have the insider advantage (i.e. coming from a family with special needs) when conducting a study with families with participants with Special Needs. Adding photographs also ensured the I was able to better understand what the participants were telling me. I encourage other researchers to use photographs and other artifacts, since as explained, the DS population has limited verbal capacity (Intelligibility, 2018), so these tools

also help the researcher gain a better understanding of what they are saying. It is also accomplished by demonstrating that research is also applicable in other settings and with other individuals with disabilities, supporting the concept of dependability (Lincoln & Guba, 1985; Merriam & Tisdell, 2016).

Dependability

Although this study was conducted with ADS, it is important to note that there are similarities amongst other individuals with cognitive disabilities, such as limited verbal skills, but their voices should also be part of research. In the current study I used Pointu (2017) and Davies and Burke (2016) studies as a model to design and create the questionnaires. Both studies are based out of the United Kingdom and as adults with learning disabilities and intellectual disabilities about their lived experiences. Pointu (2017) interviewed older women with learning disabilities, over the age of 55 to participant in interviews to gain a better understanding of their lived experiences as they aged, and how those experiences could help improve policies and practices in regard to services provided for these women. Similarly, Davies and Burke (2016) spoke to 70 participants across multiple counties to gain knowledge about their experiences in the work force and provide a voice for them. Asking them what they wanted the workforce to know about individuals with disabilities, helping they gain a better quality of life, more opportunities, and promoting the rights of individuals with disabilities. Just as these studies conducted in United Kingdom provide adults with disabilities as voice in their field of research, the current study used them as guides to do the same, when creating tools needed to conduct the interviews as well as the protocols. By providing the guides used, a detailed account as to how these findings were derived, and the findings themselves discussed in chapter 4, another research can replicate this study with either individual with DS, or do I did using Pointu (2017) and

Davies and Burke (2016) as guides, and branch out to different individuals in the field of research that is conducted with adults with disabilities.

Summary

Participants were recruited from Florida and New Jersey, were the final group was 5 ADS. In order to test if the study would be successful in gaining access to, interviewing, and being able to get think rich data from the ADS, a pilot study with John, the first male participant was first interviewed, and the data was transcribed. This was presented to the Dissertation committee as preliminary work and with their approval the current study was then fully conducted between the two states. Participants were interviewed in private one-to-one conversations, where photographs that were pre-selected were used to help with understanding, and as communication tools in the semi-structured format. Then, serving as a guiding tool, Bogdan and Biklen's (2007) ten steps to data analysis were carefully implement. Transcripts were reviewed through NVivo12, coded, and compared, yet step 10 was very helpful. Handwritten line by line coding aided in finding the similarities and differences amongst the participants interviews. Multiple transcripts were printed out, laid side by side and organized visualizing the stories presented before me. Then, utilizing the procedure suggested by Miles and Huberman (1994), I proceeded to do three waves of coding and allowing for the natural emergence of themes. By listening to and subsequently reading their stories and listening for the moments of social interaction, five themes were identified: *affection and love, companionship, being cared for, cultural identity, and communication*, which are further discussed in chapter 4. All the while I made sure to continue to reevaluate my own bias and keep in mind the 4 methods that helped me accomplish trustworthiness throughout the study (Lincoln & Guba, 1985; Merriam & Tisdell, 2016).

CHAPTER 4: FINDINGS AND ETHICAL CONSIDERATIONS

Deriving the Themes

Following the concept of the *mind*, as defined through Symbolic Interactionism (Charon, 2004), I was interested in examining the subjective meaning of family through the lens of each of the participants. As I questioned and prompted each participant, I was able to gain insight on the ADS internal mental processes, whereby the repetitive social interactions they encountered with each of those they considered family, helped shape their meaning of family. *Meaning* for the ADS is created, shaped, modified, and impacted by the day to day cultural and linguistic interactions (Blumer, 1969; Carter & Fuller, 2016), in this study specifically it is the Latino Spanish-English bilingual context. As I carefully read through and listened to the interviews with all of the participants guided by the theoretical framework, I began to notice the similarities within their stories. For example, James spoke about the times that he watched his favorite shows on Netflix with his sister, while John spoke about the Chicken Dance that he shared with his moms' friend. The subcodes Netflix and music fell under the code shared interest. John spoke about joking around with his cousins and siblings and all participants spoke about fun times with family members. These moments fell under the subcode family jokes and fun, leading to the code shared humor, which combed with shared interest led to the theme *companionship*. As I examined the data, I began to notice moments that sounded that same between participants creating subcodes such as labels, words, places, and moments of fun. These subcodes were then combined to make larger more concrete codes. A total of 12 codes began to take shape from over 60 subcodes. After finalizing the three waves of coding, this led to the emergence of the 5 major themes in this study: *affection and love*, *companionship*, *being taken care of*, *cultural identity*, and *communication*, see Table 1.

Table 1

Theoretical Framework	Sub-Codes	Codes	Themes	Description of Themes
<i>Mind</i> as defined through Symbolic Interactionism helps define how the ADS Makes Meaning of Family (Charon, 2004)	Love, Miss, Support,	Expressions of Love	Affection and Love	The specific instances where the ADS talked about their feelings towards family members and the moments, were they received acts of love such as hugs or support and are made to feel as important members of the family.
	Godfather, Aunt, Tio, Smart, Great, Amazing	Expressions of being Important family members		
	Being Capable, Working, Cleaning, Chores, Success	Independence		
	Music, Movies, Netflix	Shared Interest	Companionship	The instances where the ADS talked about time spent with parents, siblings, cousins, aunts, and other family members engaging in family events, where they seemed to internalize these moments and interpret them as emotions of happiness and joy brought upon by the social interaction with others.
	Family Jokes, Respect, Fun	Shared Humor		
	Emotional, Physical	Closeness		
	Buy Clothes, Shopping, Cook Meals, Help, Loyalty, Valued, Important, Smart, Feel Useful, Needed, Wanted	Trust	Being Taken Care of	The instances where the ADS talked about the primary caretaker, the parents and grandparents, actions towards them whereby they felt cared for helping build trust towards them.
	Egypt, Cartagena, Cuba, Colombia, Puerto Rico, Ecuador, Beach, Farm	Travel	Cultural Identity	The instances where the ADS spoke about their Latino origins, referring to moments when they traveled back to their native countries and told stories about the things they did while there, as well as when they went on vacation with family other places.
	Colombia, Cuba, Puerto Rico, Ecuador	County of Birth		
	Salsa, Chicken Dance, Kiki do you love me, Songs	Music		
Hamburger, Sandwich, Soup, French Fries, Cook food, Pan con Queso, Pollo, Chicken, Burger King, Buy Food,	Food			
Language chosen to speak: English, Spanish	Verbal	Communication	The instances where the ADS would switch between Spanish or English when either speaking about family or referring to times when they spoke to family in Spanish. It also refers to the body language expressed when speaking, showing anger or frustration in their faces, using hand movements, or lowering their voice during the course of the interviews.	
Tone, Affect, Gestures	Non-Verbal			

It was great to hear that all participants use the word love, when referring to the affection felt towards the family and the family's feeling toward them. When I asked how do you feel about your parents, or siblings, or friends in moments of our conversations all participants would say that they loved them. I asked how does your family feel towards and the response was the same, they love me. For example, Betty used the word love over multiple times, when referring to her daddy. It was evident that she deeply cared for her father. She talked about the times they would go bowling and the times they spent together. She expressed how she missed him since at the time of our interviews he was in Colombia. She also spoke about the love she had towards her grandmother and how she missed her since she had passed away. Similarly, James first interview began with his grandmother and how he deeply missed her, even whimpering, putting his down, rubbing his forehead as he told about their last thanksgiving together. These subcodes of the feelings of love, missing, nice, and help led to the code of expression of love.

There were also labels that the participants were proud to wear and given to them by family. John spoke proudly about being a Godfather to two nieces. Betty spoke about being an Aunt to her triplet nephews and one niece. James spoke about becoming a Tio [Uncle] since his sister was pregnant, while David mentioned being an Uncle to his niece, and even Olga talked about being an Aunt to her brothers children who were located in Ecuador but who had come to visit her the year before. They also labeled themselves as being great as in the case of John, and smart, as in the case of Betty and James. These labels were all subcoded as expressions of being important members of the family. Feeling as a valued member of the family also came through when the third code of independence arose. It originated from the subcodes of being capable, working, cleaning, doing chores, and having success. James spoke about his job at Popeyes Chicken and the trip to Indiana. He talked about wanted to have a job with the organization Best

Buddies, a leadership conference he attended every year without parental supervision. He said how it made him feel. “I just feel like to be a Rockstar” when he talked about being backstage. Although he said his mom did not want him to move, he said that his dad supported his decision to move to Indiana. His dad would take him to the airport and on their drive, they were “just chilling like a villain”, enjoying the ride together. He said he was capable of taking care of himself since he already had a job and was saving money. John expressed the same when he spoke about marriage to his girlfriend and that it was the man’s job to work and take care of the house and pay the bills. Both John, James, Betty, and Olga all spoke about being capable of working, taking care of themselves, taking public transportation or walking to get around. All participants spoke about their successes, whether it was helping out around the house and completing chores, or in sports getting trophies as in the case of Betty in bowling, David in soccer and basketball, Olga with her job at the law firm. All of the participants felt supported by their family in one form or another. When combined, expressions of love, expressions of being important members of the family, and independence led to the emergence of the first theme *affection and love*.

As previously mentioned, the second theme *companionship* emerged from the two of the three codes shared interest and shared humor which were derived from the subcodes movies, music, Netflix, and family jokes, respect, and fun. These codes were then combined with the third code of closeness. This code originated from moments where the participants talked about physical and emotional closeness. Physical closeness referred to the moments of close proximity. For David this was really hard to speak about since at the time of our interviews his mother had recently relocated to Texas and he was angry about this situation. He spoke about the family being split into two where his sister and mom were one team and his dad and himself were

another team. He clearly expressed how he cared for and needed his dad but did not need his mom. David said that he “didn’t want to come here anymore”, referring to mom and not wanting her to return, but then went on to express how he was sad. When I asked him why he was sad, he said, “because dad was at work” and wanted “dad to come home” from work since he missed him. He also spoke about how Dad missed mom. He was clearly aware of her absence and that it was affecting dad. Having family members there close to them where they could have personal interactions with them was important to David, as well as Betty when referring to dad and her brother, as well as James when talking about his sister who had moved out and grandmother who had passed. Physical closeness was tied to emotional closeness since proximity for many of the participants was made possible by being able to spend quality time with the ones they loved, where that was significant others, cousins, siblings, parents, and friends, all whom they considered family.

The third theme emerged from 12 subcodes. As the participants spoke about their family and the times they spent together I was able to learn about the things that their family did for them. Although they were self-sufficient, when I asked about the things that mom did for them since they all talked about their moms, they began to all say the same thing. Mom cooked them making them their favorite foods such as sandwiches, hamburgers and French fries as in the case of John and Betty. David and James would talk about Latino dishes like arroz and frijoles [rice and beans], or chicken and rice. Betty spoke about being a great aunt since she “helped feed the babies and bathe them”. I noticed how proud she was to feel needed and useful by the smile on her face and the way she sat up straight when she talked about those moments. David spoke about working with his dad and hammering away at chairs three days a week. He talked about going to eat with Dad and him giving him money to get pizza and chicken when he would finish

his weekly classes at the Nonprofit center in Florida. Olga talked about accompanying her parents to church and being part of a prayer group. All these subcodes led to the overarching code of trust. It was evident that the participants trusted that their family would there for them and that they were also there for their family when they needed them, leading the third theme of *being taken care of*.

All the participants identified as being Latino. David and Betty said they were from Colombia, while James and John spoke about their Cuban side, and Olga spoke about Ecuador. Travel became a common code that I began to notice as well as Country of birth, food, and music, which related to the overarching theme of *Cultural Identity*. Both Betty and David choose a picture where they were abroad with family. Betty choose pictures of her most recent trip to Egypt with her parents. She went on to tell me about her vacation and that she travels every year with her parents. This also branched out into conversations about Colombia, the country her family is from, and the time where she had done her first communion in Colombia. I got to hear how she bonded with family and enjoyed spending time with them. David also choose a picture where he was with cousins on the beach in Cartagena, Colombia spending time with dad as well. He said he loved to travel with dad and missed expressed how fun he had. James similarly spoke about the food he would eat in Cuban and Puerto Rico. He told he about traveling to each of the countries and began speaking Spanish when referring to the food and time spent abroad. John told he stories about playing soccer with cousins on Cuba, while Olga spoke about growing up in Ecuador and that her brother stills there. All participants had a strong sense of cultural identity smiling and showing excitement when they spoke about their Latino countries and the times, they spent there with family. All participants stated that they spoke Spanish with family abroad and did not show any negative emotion when speaking about their experiences there.

The Spanish language became symbolic. It became a tool rather than just the language they were speaking. Symbolic Interactionism describes a symbol as anything that the person is using to intentionally communicate (Charon, 2004). The theme of communication stemmed from verbal and nonverbal forms of communication. Under verbal, the language the ADS choose to use became a symbol. For example, in the case of James, John, and David, they are made a choice to use Spanish to communicate with family members they knew did not speak English well or at all. Betty spoke about speaking Spanish to her grandma, while John did the same with a visiting Aunt and cousins he would visit in Cuba, while David would speak to Aunts and Uncles in Spanish, but to me and his peer cousins he would switch to English. As I coded for language usage. I became to realize the intent behind using English or Spanish, regardless of familial choice. All families had told me that they had been advised to raise their child using English only, and John's mother as well as David's made the effort to do so. Although David's mom inevitably spoke to him in Spanish as well as other family members, John's mom and siblings spoke to him and continue to speak to him in English, yet he still speaks some Spanish, and uses the language as a tool to communicate to family that he is consciously aware does not speak English.

Coding for the intent of language usage (i.e. English or Spanish), I began to realize this was part of a bigger code, verbal communication, because there was also non-verbal communication that was derived from three codes: *tone, gestures, and affect*. As I reviewed the transcripts and audio recordings, I realized that when the participants were talking about things, they considered to be private, they would lower their voice. For example, John and Betty would lower their voice when speaking about their significant others. David would raise his voice when speaking about his mom and girlfriend, as well as, when speaking about his emotions towards

mom having temporarily relocated to Houston, Texas, to his sister house. At the same time the expression on their faces and the gestures they would make like putting their hands to their face as if they were shy, in the case of John and Betty, or balling his hands up in a fist to show anger in the case of David. All participants had very expressive body language that allowed to understand not just the words they were saying, but how they felt the situation or events they were describing. My memory, the giggles, laughs lowering or raising of voices, the sound of their voice muffled, all came through in the audio recordings when I was coding, as well as in my notes after the interviews. Verbal and non-verbal communication were eventually combined to create the theme *communication*, which is discussed further, along the other four themes, in the following section.

Participants Expressions of Making Meaning of Family

After the three waves of the coding, the final themes occurred naturally, keeping at the forefront of analysis the theoretical framework of symbolic interactionism (Charon, 2004): *affection and love, companionship, being taken care of, cultural identity, and communication*. All the themes were evident across all participants interviews where *affection and love*, refers to the conclusion that the ADS have drawn from the interaction with loved ones, referring to the specific instances where the participants talk about their feelings towards family members and the moments they were received acts of love such as hugs or support. It also included those moments where they spoke about being capable of taking care of themselves and helping take care of the family. The second theme, *companionship* refers to the times spent with parents, siblings, cousins, aunts, and other family members engaging in family events, where they seemed to internalize these acts and interpret them as emotions of happiness and joy brought upon by the interactions with others, including physical and emotional closeness to the family.

The third theme, *being taken care of* refers to the primary caretaker, as in the parents and grandparents, actions towards them whereby they felt cared for, needed, and valued. The acts of cooking, doing their laundry, buying them clothes, and driving them to events and activities they enjoyed doing, showed them they were loved and important. The fourth theme *cultural identity* referred to the instances where the ADS spoke about their Latino origins, referring to moments when they traveled back to their native countries and told stories about the things they did while there, as well as when they went on vacation with family to other places. It also encompassed other aspects of their culture such as food and music. The final and fifth theme that emerged was *communication* where the ADS would switch between Spanish or English when either speaking about family or referring to times when they spoke to family in Spanish. It also refers to the body language expressed when speaking, showing anger or frustration in their faces, using hand movements, or lowering their voice during the course of the interviews, which refers to the tones, gestures, and affect all exhibited by the participants during the course of our interviews.

Affection and Love

The first theme that emerged was affection and love because it was so evident throughout all conversations that there were deep emotions felt by the ADS towards those, they considered family. For example, John like the rest of the participants felt loved and saw love through others action, which they freely expressed allowing me to see and understand their internal thought processes and how interactions with family gave them a sense of an intense feeling of affection, commonly recognized as love. As they interacted with others, they drew conclusions, made adjustments, and internalized what family was to them. John said it very clearly when telling me about a conversation he had with his best friends, who are also ADS,

They said family, no I mean friends first and then family second. And I said for me, I'm different. Family first. Friends second. That's for me.

He regarded to family as, “they are number one”, even above the opinions of his two best friends.

Similarly, when talking to Betty she expressed how much she loved her family, and when asked why she said, “Because we are Family. They make me so happy”. All participants had similar interpretations of family, which centered around the idea of being moment where they were shown affection. They internalized these moments, making them meaningful parts of the construct family. Olga talks about her best friend showing her affection for her birthday, which happened to be the day prior to our second interview.

Ella me dio tarjeta de cumpleaños. A veces me da una tarjeta de iHop de 40. Entonces ella es mi mjeor amiga. Por que ella es buena connmigo. Ella me da cosas. Ella es muy divertida. Por que ella siempre me hace reir, me haces, las bromas todas. Nos llevamos muy bien. [She gave me a card for my birthday. Sometimes she gives me a card from iHop of 40. Therefore, she is my best friend. Because she is good with me. She give me things. She is a lot of fun. Because she always makes me laugh, she makes, does jokes many. We get along well.]

These words served to demonstrate how she felt supported and cared for. She also talked about the brotherly love that she had with her brother. She said,

Me escribe, me dice cosas bonitas. Me quiere mucho y nos queremos como hermanos. [He writes me, tells me nice things. He loves me very much, and we love each other like siblings].

James also received words of affection and support by his grandmother which he loved very much. She was the first person who spoke about when I asked him about his family at our first interview. His demeanor showed that of a person who was sadden by her passing. He shared a moment where she provided words of encouragement, which he made clear was something she did often.

Okay. I just remember, um, [Sighs]. James boy, James boy, James boy, don't worry, if you want to move to California that's fine, but you still my James boy and I suppose to make my own choice, but James boy, you always be responsible. Now is your own

choice and no one is stepping in right now? No one is controlling you. No one is controlling your past. No one is controlling your life right now. James. Boy, I love you. I know everyone will look out for you now. But I still love you. Still Miss you.

Guided by symbolic interactionism, I listened and observed James, as his voice went low, his eyes teared, and at the end of his paragraph he could barely speak demonstrates to me the power of these words for him. The confidence he had gained in me allowed him to express such hard moments, that demonstrated the in-depth meaning of these words.

Expressions from Betty also painted the picture of such beautiful and heartfelt moments of interactions that made her feel loved. As we spoke, I could see her smile get bigger and bigger when speaking about very important people in her life, mainly mom, dad, the triplets, and her boyfriend. When talking about her feeling towards her mom and her mom towards her she said,

Yes I do. I love my mom so much. Because I his daughter. I her first baby. I--I fff-feel good. She always make me happy. Be--because he, he loves me and I her.

The same was true of her daddy, “my dad always happy for me. H--he was happy for me on bowling”. When I asked her about the pictures of her triplet niece and nephews, she sweetly called them “my angles”, saying they loved her because she was their aunt, that changed their diapers, gave them a bottle, and helped her mom bathe them. She said, “I a good aunt”. I could tell that she took pride in the title Aunt and her ability to help with the triplets. Similarly, David, proudly labeled himself the “Uncle, Tio”, when speaking about his niece, since he had recently become an uncle.

Another symbolic action by the parents, was evident when both Betty and John spoke about moments when the parents accompanied them and showed them support during a sporting event. John was swimmer and spoke with excitement about the moment his mom and biological dad cheered him on, “they just uhh see me and... they cheering me”. He stated the purpose of

them being there that day was to “to support for me.. because I am the best swimmer ever”. Betty is a champion bowler who was taught by her dad at an early age,

My daddy always happy for me. He was happy for me on bowling, I won. When I went to bowling, I had a strike seven times. He said great job.

Mom who, as Betty said, “And my mom don’t like bowling at all”, still attended her games. It is important to note that Betty is aware that mom does like the sport that she is playing, but still attends the games and accompanies her in her victories and loses, a great insight on the way her mind is processing her mother’s support of her as a daughter regardless if she enjoys the sport or not

Then, John and David she also spoke about affectionate moments with their significant others. For John, his girlfriend was the woman he was going to propose to and marry. He affectionally told me the story of special kiss.

Um I think uh, she was at my house and um, We were, Un I mean, she fixing my macs, my, my, my, my breather Mac should want to fix it? And then after that she on her kiss her because someday I’m going to be husband and her husband and wife.

For David, his girlfriend was the one person he loved very much, she was the most important woman in his life and would get angry if anyone said anything that he considered negative about her or his relationship.

She has a problem with Jessica. She said no, to come here to my house. That is rude. My mom is rude to Jessica. That was hurting me.

David expressed how he loved his parents but both of them, especially mom did like accept the relationship, which he clearly did not like, since he said, “I love Jessica so much”. Our conversations kept circling back to his girlfriend since it was evident that she was a very important person in his life, regardless of his parent’s approval. These parts of our conversation were categorized under the code independence, since he was speaking about, he was clearly

capable of having a relationship with Jessica. Similar to Johns conversations where he was capable of marrying his girlfriend and eventually moving out since he was able to already sustain 2 jobs and make money. He recognized how this would be hard but it as his responsibility. Betty also talked about how her boyfriend and how he fell in love with her over a dance.

He fall in love with me and ddd-dancing. I fff-feel good. I said love you b--back.
He love me so m-much (point to lips). Hugs. And he gave me flowers.

She described this moment and her relationship as any other adult would, regardless of her disability, she was aware of the what expression of love and courtship were. She talked about the flowers he gave her, the hug, and the kiss they gave each other as a demonstration of his love for her. These moments of expressions of affection from family members and significant others allowed me to visualize the social interactions that led to the feelings of and the interpretations of love between the ADS and others.

Companionship

Through moments spent together (i.e. social interactions), the theme of companionship emerged providing another view on how ADS made meaning of family. There were various times spoken about that demonstrated how the actions of loved ones were symbolic of family. These are moments where she gets to spend quality time with parents continuing to build upon their relationship and solidify the meaning of family through the concept of companionship.

David, Olga, and James spoke about moments where they get to spend time at home with family. James makes reference to times where he watched movies with his mom, tv shows and Netflix with his sisters, and making music videos with his twin sister. For example, when talking about his sister Nancy he expressed some of the things they had in common and did together. He stated:

We both started watching it [Teen Wolf]. Like its too many seasons going on. It's on MTV...we watch together and um, Fuller House. It's on Netflix. Yes. Yeah. We watch movies together.

Then he went on to tell me more of the things that he did with his sister Nancy. He expressed that they were both dancers and enjoyed dancing together.

She is a ballerina. We do ballerina and we do hip hop. We do ballerina, but she teach me hip hop, that's from the movie. Step Up.

He spoke about how he enjoyed Netflix and common shows with both his sister Nancy and Jane. He also expressed how he missed his sisters since they no longer lived with him. With his twin sister Mandy, they shared a love for music and dancing as well, except they would make music videos together.

Uh, she like to make more videos. Un, more videos, more videos, more videos. Yeah, yeah for real. Its, mu--yeah, it's music videos. Now we're talking I'll show you. So like you see I had it with me... its google drive... so that is the video.

He showed me one of the music videos where she would create choreography to the song, then they would dance it and record the videos together. He talked about a special handshake they had and expressed how much he missed her, since she did not live with him. It was clear that these moments where very special to James, they were symbolic of what it meant to be siblings, and in their case twins. He then confided a secret that was about to be shortly known by the family, but he was lucky enough to know first, told to him by his sister Mandy.

My mom knows already, but only you. ...Okay, you promise to keep secret. ...Oh no no no no like it's a handshake. ...Um. I love her so much and she's pregnant. ...So yeah, she's pregnant she's having a baby... Like I just miss her. ...No she's um, what's it called again. Um Palmetto Pines.

He showed excitement for her pregnancy but at the same time showed sadness because she was no longer physically close to him. For him physical closeness with his sister was important because it gave him those moments where he got to spend time with her. They were able to do

the things they enjoyed together and have special secret moments which he seemed to enjoy very much.

Olga, who lives in New Jersey, also gave examples of moments where she would go to out with loved ones, out to eat, the mall, movies or watch tv at home, go to church, and spend quality time. For example, both her and her mom enjoy church and listening to the gospel. She shared with me that they go on YouTube together and watch the sermons together, because they both like it a lot. She also spoke about enjoying her summers with her family, especially her brother who currently lives in Ecuador, but comes almost every summer to visit them:

Para el verano. Creo que vamos a la playa or vamos a Orlando. Estoy muy feliz cuando el viene. Me siento feliz porque hay una foto familiar. Hablamos del amor. Pasamos bien, el me invita a comer. Nos vamos de paseo.

[For the summer. I think we go to the beach or Orlando. I am very happy when he comes. I feel happy because there is a family photo. We talk about love. We have a great time; he invites me to eat. We go to places.]

She is very close to brother despite them living in two different countries. She expressed how happy she was when he came to visit since she would get to spend time with him, but also expressed how they were able to communicate through WhatsApp or Facebook. Olga is not just skilled orally, but she is also able to write very well. Although I did not ask parents what her grade level of writing was, through her Facebook posts I was able to observe that she has the capacity of at least a high schooler, demonstrating that she was able to sustain long and detailed conversations with her brother via messaging, as described in our interviews.

David spoke about his aunt who he also spent quality time with and going to his basketball games,

Tia its nice, uhhh, she come, house, cook, clean, put table. She wanted to, to go out to Movies. She want ball, wants to go basketball. She wants her. No, no, no, no. Come here. Come here. Look at it in the game. Every day, all Sunday, my game.

He described how she helps them around the house since mom was not there. That she liked going out to the Movies and enjoyed going to his Basketball games. He talked about how he liked going out bowling, movies, and out to eat, things that he would get to do with her, dad, and his cousins. He spoke how he would hang out with cousins, who were his peers. When referring to his parents, the conversation was dominated by his negative feelings towards mom and his need for his father, and the fights they were constantly having due to her absence. On the contrary to Olga, where emotional closeness was not affected by proximity, for David it was. He was not happy that mom had left and that she had gone for an indefinite amount of time. Although he expressed anger when talking about her being gone, he expressed happiness when she was going to return for his birthday.

David: Because uh, there's problem because she wants here, here, come here for birthday.

Linda: Okay. So your saying that dad wants mom to come here for your birthday.

David: Yeah, he did.

Linda: Oh so is mom coming for your birthday.

David: Oh yeah.

Linda: You excited?

David: Yeah, yeah, yeah.

Linda: Is that why you have a smile.

David: Yeah I did. (giggles)

He then unfortunately when on to explain how they are constantly fighting and that makes him feel bad. Through our conversations he mentioned their fighting and how he knew it was about her being gone and dad wanting her to come home. Our conversations demonstrated to me that physical closeness was intensely tied to emotional closeness, when it came to the concept of companionship when making meaning of family. For him family lived together, when referring to parents, he did not seem affected that his sister was in Houston, since she had been gone for years at the time of our interviews. If I would have had this conversation when she first moved out, I am not sure if her physical closeness would have also been tied to their emotional

closeness. At the time of our interviews his anger was more geared towards mom since she was recently gone. He expressed rather that he wanted his sister to have another baby and that he was going to help her since she helped him when he had problems.

Have another kid. I I I I have toys, I I got to bed, I and clean and do that. That's it. Yeah I like help her. I did it a little bit because she she did, long time about help me, she dddd' did in my head, she wanted to, shhh'e know a problem she, she want to help. Yeah, me.

These examples of companionship described by the ADS can be interpreted as symbolic moments where they were able to interact with loved ones. It demonstrated instances where they laughed together, had fun, and got to frequently engage with loved ones. It showed hard moments for David and James how missed family members that no longer lived with them, but at that the same time fun moments where they got to spend quality time with those loved cared for. They expressed with smiles on their faces how they were proud of the places they went out to, the sports they played, and the joy of spending time together. For example, as mentioned previously, James confiding in me and showing his secret handshake and music videos with his twin were an in-depth illustration of how he internalizes those moments and processed them. It is evident through his expression and those of the other participants that spending time with family, especially those moments outside the home is symbolic of what family does and what family means, people who you go out with to have fun and engage in the things you like to do.

Being Taken Care Of

Having loved ones take care of the ADS basic needs such as food, clothing and task like homework are examples of how meaningful this support can be to help create the meaning of family. For example, Olga talks about her arrival in the United States at the age of 14. When she arrived, she studied in both the English and Spanish language. She talks about how her mother supported her education,

Mi mama, mi mama me ayudaba en todo. Eso creo yo creo en Ingles para eso mi mama me explica todo. Yo esta en escuela donde tenia maetro de Ingles. Ella me eseño verbos, sumas, matematica en Español. [My mom, my mom helped me in everything. That I believe I believe in English that's why she is my mom she explained it all. I was in school where I had a teacher in English. She taught me the verbs, addition, mathematics in Spanish.]

She and all participants express the how meaningful moments like these were for them. Betty demonstrated this through expressions such as “she would always cook every day”, referring to grandma who she loved dearly and passed away some time ago. She went on to speak about mom, who also cooked and cared for her, “my mom cooks fish and salad, and uh, she always make juice for me. apple juice”. Similarly, David, talked about how dad was a “good guy” who “cook good food” and “give me money”. He also spoke about mom how when he had problem, she would help him and care for him,

A long time. In my head, if shhh-she problem, all the time. Weeeelll, she share, eat, cook with me all the time.

His mother and father's presence during meals was really important to David. To know that they would be coming home from work and lived with him was important. David's mom's recent relocation to Texas, because his older sister had her first baby and needed special care. When talking about, he would get upset and say that he was “sad”, referring to her absence. This was the first time she had ever left him for a prolonged indefinite amount of time, disrupting a routine that he had established with both his parents for 30 years.

Olga spoke about an interesting aspect of being taken care of when referring to the use of social media. She spoke about her bother helped her create a Facebook page and that way she could post pictures, see the news feed, and communicate others.

Tengo mis primos en Ecuador. Me escriben ahi, a ver que puse. Como puse la foto de mi cumpleaños y todos me escribieron. Hay quien yo pusa la foto. Yo la iba y poner por mi perfil. Yo soy, quien pongo. Yo me entretengo asi. Yo eligo la foto, el titulo, and ahi comparto con la población. [I have cousin in Ecuador. They write me there, to see what I

put. How I put the picture of my birthday and everyone wrote me. I did put the picture. I was going to put it as my profile. I am, who puts my pictures. I entertain myself like this. I pick the picture, the title, and I share it on the news feed]

This account of her social media usage helped give another unique account of how acts by family members allowed Olga to feel cared for, since it gave her a way to communicate with not just her brother who is also abroad, but with other family members she would not otherwise communicated with as frequently. Her bother gave her a way to stay connected and feel cared for. It was an interaction that occurred over the phone, but none the less significant in Olga's life.

She also spoke about the new clothing that her mother bought her for her birthday, which was similar to Betty who loved shopping with her mom,

Olga: Me compro ropa, una camisa armilla. Ella me escogio la ropa. Era un sorpresa. Me senti muy feliz. [She bought me clothes, a yellow shirt. She chose the clothes. It was a surprise for me. I felt very happy.]

Betty: Sometimes I'm going out on my new new clothes. My pe my, pe my, other pants. And then, we have we have jacket, my new jacket, purple, black and pink. And I feel good.

Similarly, the buying of clothes can symbolize being sheltered (i.e. clothed), another meaningful internalization by our participants. It is not just about the clothes, it is the gesture, buying them something that they clearly like. Taking the time to know someone well enough to know their likes and dislikes is an important action, they symbolize a deep affection felt for the other person. Although the words of Olga and Betty are not as complex as my interpretation their words and smiles serves as a great support for this interpretation. I am able to see how these simple acts are symbolic of family as internalized and expressed by them.

The this third theme also had instances where it overlapped with *affection and love*, the first theme. As in the case of Betty when talking about her title of Aunt, she was proud to assist with the triplets. This also demonstrated the building of their relationship because despite her disability she was trusted by her sister-in-law, brother, and mother to feed the babies and help

bathe them. This was all done under their supervision, but she was made to feel needed, valued, and a contributing member of the family. Similarly, when David spoke about working with dad at the shop helping him out 3 days a week, as well as James when speaking about Grandma and the advice she would give him, making him feel capable when he wanted to move to Indiana. All these examples and the care given to the participants by their loved ones help build mutual trust between them, which lead to the overarching theme of *being taken care of*.

Cultural Identity

The fourth theme, cultural identity, consisted of a large part of the sub-coding and coding. There were over 20 subcodes which made up the 4 codes, that demonstrated this theme. This is significant since this study is based on the meaning of family in a Latino bilingual, English Spanish context. All participants spoke about their family's native Latino countries, whether they born in the USA or not. They had all traveled to or traveled from these countries and many parts of our conversations mentioned these countries, Colombia, Ecuador, Cuba, and Puerto Rico. For James, Betty, David, and John traveling was noted with terms of excitement, endearment, and as opportunities for them to see other family members and engage. James says, "I love Puerto Rico and Cuba". It is a place where he was able to eat some of the food he loves and play soccer with cousins,

Si y uh me gusta pan con queso, um ah, pan con queso. Um, con uh, cafe con leche.
[Yes and uh I like bread with cheese, uh ah, bread with cheese. Um, with uh, coffee with milk] Yeah, because he is like me, him so close and uh, we'll play stop soccer, and um, so I just tell him like, okay, go and this and try to tell him you're supposed to go on that side and then I say, but I try to say, but I try to say protect the ball.

Similarly, John spoke about playing with cousins, or as he referred to them, "I got my two boys with me". They also enjoyed soccer, video games, and hanging out together.

Hooooorrrrrsseeback ride. Umm... they diff un different countries and... huh uh at my cousins house they have a farm there. My, my cousins. Sports. Soccer. I kicked the ball. And say Loco Loco Loco. That means crazy (laughing).

They played until the evening, where he made two goals, screaming out “Gooooaaall”! One of David’s selected photographs was in Cartagena, Colombia, with is dad and cousins. He spoke about being on vacation with them. Betty spoke about her first communion in Colombia speaking fondly about her family over there who attended the party. She described her dress and how she got prepared for the party,

I have a white dress. I had a ribbon in my hair. I got a haircut before. And I have my first communion party, me, my, my brother and my grandma. We had my Daddy. He was Colombia and my uncle.

She then goes on to describe the music that was played and that they were all dancing.

English and Español. Was Marc Anthony and Español. ...Yea I was dancing Salsa. Mark and Marlin and Selena.

Salsa and music in general are a large part of Latino and for Betty, Colombian culture. All the participants spoke about music and the food when they to their native countries. Spanish came up as the language either explicitly stated as what they spoke when there or was implicit because they would switch into Spanish when describing things such as food and phrases used. For example, when speaking to James, when taking about Puerto Rico he would describe the food in Spanish, “Pan con café... Café con leche yah. Um. Guava, mango, pan con queso” [Bread and coffee... Coffee with milk yeah. Um. Guava, mango, bread with cheese]. When I asked him what he did for fun while in Puerto Rico, he said “Oh, dance Salsa”. Even when he was here with is sisters at home he would listen to a mix of Latin and American music all making up his Latino-American cultural identity, just as the other participants.

Music and food the two final codes became intertwined with travel and country of birth since talking about their countries automatically brought up conversations about the types of

food they ate and the music they listened too. Travel either back to their countries or other places became one of the four codes that made up the participants cultural identity, along with all mentioning and talking about the families native Country of birth, the second code. Betty was fortunate enough to go on vacation every year with her parents. They travel aboard annually on one large vacation, her parents and herself. When asked to select only three pictures, she selected 7 to aid in our interview process and she explained “they are all the same”, referring to three out of the 7 pictures. She was in Egypt with her parents this past year. One of her favorites images was with her mom in the tombs of the Pharaoh. She said, “just me, my mom and daddy. We saw tomb of Pharaoh” and when I asked her how that made her feel, she said, “I feel good. I feel happy”. When we spoke about this trip, she was smiling the entire time as she pointed to the pictures telling me all the things they did while there, demonstrating the meaningfulness of their relationship.

It was interesting to discover through Betty’s stories as well as the other participants how their Latino culture is infused into meaning making when it comes to family. I never questioned them about being Latino until our demographic questions at the end of the their interview, yet throughout our interviews, they naturally all identified as being from a Latin country or their parents being from those countries and they were too, although they were born here, as in the case of John when he stated “My mom is from Cuba, but I was born here”. Betty called her Colombian saying, “I am from Colombia” and James identified as being mixed. He said, “My dad is Puerto Rico side. And my mom is the Cuba side”. David said he was Colombian, while Olga said she was Ecuadorian. When telling me stories about their family they mentioned events that happened in those countries or family members from there. The Latin culture identified by

the music, food, language, and naming the country itself organically emerged in all conversations with the participants.

Communication

Family can be considered those people who spend time with you and show you love you. This is not any different for a person with special needs. The aim of the current was not to show that Spanish speaking ability was needed by ADS in order to build relationships. The purpose was to demonstrate how ADS made sense of family in Latino bilingual homes when they were born with Down syndrome. Having been raised in these homes provided intentional exposure to Spanish for 4 out of the 5 participants and unintentional for 1 male participant. Regardless of intent the Spanish language was present and a large part of these adult's upbringing. It is the language of their family and culture, and is evident even through John, who was the participant who spoke the least Spanish, and was intentionally never spoken to nor taught Spanish by his mother. His biological father was not in the picture and mom's boyfriend was American and did not speak Spanish, so it was mom who was in charge of this decision and she followed the advice of the professionals.

It was interesting to learn more about John and his upbringing, because regardless if he was taught to speak Spanish or not, he still picked up the language. He was the least bilingual of all the participants, where we did not sustain a full conversation in Spanish, but he did say he spoke it with family in Cuba, and a Tia [Aunt], as he called her, that happened to be visiting (i.e. staying in their home) for a short while. When describing conversations with her and others he knew did not speak English he would say that he spoke Spanish. He did say a few words in Spanish, like loco, Tia, and primo [crazy, Aunt, and cousin] and then translated for me, without me asking. This demonstrated he knew what he was saying and was purposefully using the

Spanish words. All participants made the choice to speak Spanish at one point or another during our interviews, yet I only asked the question, “what language would you like to speak, Spanish or English?”, at the first interview when I initially introduce the study and began with the semi-structured interview guide. I never again asked them to speak Spanish, or if they wanted to yet, the language naturally became part of the narrative, which was then coded as the verbal portion of this theme.

The choice to use English or Spanish was sub-coded, then coded, and eventually used as part of this theme to gain a better understanding of how the ADS made meaning of family because it is important to learn how they communicated with their family. As stated previously, language became a tool and is a symbol under the lens of symbolic interactionism (Charon, 2004). Symbols, as Mead explained (Charon, 2004), are objects that are created by humans during social interactions. The words, for example “loco or Tia” were intentionally used to describe either a joke (loco) or a family member by John. He could have told me my aunt, or mom’s sister, but he did not. It was normal for him to refer to her by the title that he naturally uses, not thinking what language it is in, nor if another word in a different could be used in its place. When further examining the concept of symbol, it is described as anything the human being intentionally uses, in this case words, to represent something, where the descriptor had to have a learned meaning and value to the person.

When the participants choose to use words to describe food, as in the case of James and David, or family members as in the case of all the ADS, there was intent, value, and meaning that was all created through the social interactions they had with family over the years. The examples of Spanish language usage intertwine with all of the other 4 themes, yet it is worth separating out because of the importance of the choice to speak Spanish has, when making

meaning of family. These Latino families have the languages Spanish and English as an integral part of their internal workings, hence meaning making occurred with the use of both languages. Verbal communication was then coupled with non-verbal to form the final theme of communication.

This referred to all those amazing moments where I go to see the emotions behind the words. I got to see David, Betty, and John's vulnerability and shyness when speaking about their significant other. James and Betty's loss and grief when speaking about their grandmothers. John's joy when spoke about his boys, meaning his best friends that he saw like brothers. David's anger towards his mom, sadness when he missed his father, and stress about the Houston situation with mom. I got to see the smiles on many of their faces as they told me about fun times with siblings, friends, cousins, and parents. The participants body language demonstrated the deep emotions, the sincerity, and authenticity of their words. They did not lie, nor have a reason to when telling me about their lives. They were as honest as they wanted to be showing me how they were making the mental interpretations of all those social interactions, placing meaning on those moments, and eventually defining and gaining a deeper understanding of each the relationships they held with their family members.

Ethical considerations

One of the hardest things I faced when speak to the participants was the fear that they would not understand my questions. Through the reflexive process I constantly thought and thought about this question. In order to give a person a voice, you must make sure it is their voice that is guiding the research. Down syndrome is a cognitive disability where the person is delayed in the areas of comprehension, expression, and understanding. I wanted to make to that I was mindful of this delay, but at the same time not taking advantage of the kindness with which

these individuals received me. Although they are adults and consented to be part of the research, they are still very innocent and trusting which could lead to people taking advantage of them, as in the case of Olga.

When going through the initial protocols I realized how the 5-item criteria protocol was flawed, because when I asked each of the participants if there were between the ages of 21 and 40 I would get a puzzled look. I then had to change the question to “*how old are you?*”, and then say yes you are between those ages. I also confirmed with parents the age of the participant before selecting them as participants. This again went back to the idea, are they understanding what I am say. Researchers must also consider the implications of identifying a person as having Down syndrome. Four of the participants (John, James, Olga, Betty) were able to say yes with certainty that they were adults with Down syndrome. David as mentioned in the introduction of the study, had never been asked, to my knowledge about being an ADS, nor was I aware if anyone had ever explained to him what that label meant. I did not ask any of them what it meant to have the disability, but four of them did say they had it. It is important to not get into conversations that are not part of the study because it was not my place to inquire their level of understanding as it pertained to their disability.

Separating Predispositions from Legal Guardians

It is important that the researcher always keep in mind that the current study is not about fact checking. Individuals with Down syndrome have limitations placed upon them by the disability, but those are not part of the study when referring to making meaning of family. The persons mental representations of family are dictated by the interactions they have with the people in their lives. I am aware that there are issues in timelines, since through our conversations dates and times would change when I asked questions again for clarification. As in

case of John, when spoken about under the section of confidentiality, part of mom's intent of listening behind closed doors was clearly to give me facts that she believed her son was giving me incorrectly. I made sure after this incident, which occurred after the first interview with John, that told mom that what she was doing was not correct, that I asked for privacy and hoped she could respect that, as well as reminding her that the timeline was not an important aspect of my study. In all introductory meetings in one way or another all parents, including my own uncle asked me the question in regard time.

Paraphrasing the common question was "do you know that they do not really understand time". I had to make sure to clarify that this is not about when things happened but rather the interpretation of what happened. How their adult child had made sense of these moments, whether they served as supports, even if they were considered negative moments, to help define family for them. The Turnbull, et al., (2015) was used in this study along with the notion that family is anyone who the participants consider them to be. These definition talks to relationship, vaguely defining family members as those who "carry the functions that families perform" (Turnbull, et al., (2015). These functions are understood through the process of the mind, as defined by symbolic interactionism (Charon, 2004) and explained through the examples and perspectives of the ADS. Making this point clear to the family members, but most important in my head through the research process helped ensure that I kept the information volunteered by the family separate from the meaningful stories I was getting from the participants. I made sure to keep a written note to read and remind myself that it is them who will define family for me, not the care takers, and to not allow myself to be influenced by them when interpreting the stories shared by the participants. I made sure to keep all meetings private learning from the

incident with John's mom and reminding parents that we needed privacy and my intent was just to listen to the stories to get an in-depth understanding of how they made meaning of family.

Summary

Latino adults with Down syndrome were given the opportunity to share their perspectives, providing an understanding on how they develop a sense of family while growing in a bilingual, English-Spanish speaking home. The theoretical lens of symbolic interactionism guided the study. Mind, which is viewed as the acts that the individual makes towards themselves, through inner conversations that can occur in the presence of others, or while the person is alone (Charon, 2004), was used to guide the study and provide the perspective for analysis. In symbolic interactionism, the mind is derived from society (Charon, 2004), meaning the mind comes from the interactions the person comes in contact with. The mind is the place where family is defined, reevaluated, and defined again, on a constant basis, the person is always interacting with loved ones, changing the meaning of this construct constantly. This was evident across the interviews and within them. In this study 3 semi-structured interviews were conducted with 5 Adults with Down syndrome, whereby select photographs were used to aid in communication and the overall understanding of the individuals stories. Through three waves of coding, member checking, an audit trail of audio recorded and written notes from the researcher after each interview, observations, and reflecting on initial conversations with the parents, five themes emerged through data analysis. Collectively, the ADS shared stories about the affection and love shown towards them and them towards family members, moments where they got to spend time together building a sense of companionship, expressing the things that family members did for them giving them the sense of being cared for, naturally expressing stories about their cultural identity, and allowing to gain a better understand how communication was an

intricate part of their mental process, where through the intertwine of these themes I was able to understand how these individuals made meaning of family.

CHAPTER 5: DISCUSSION

Meaning of Family and Language

Adults with Down syndrome, just as all other members of the Latino family are going to build connections and develop a sense of family regardless of the decisions made by parents or caregivers to teach them Spanish and English, since the environment these children are being raised in includes exposure to the Spanish language (Krogstad & Lopez, 2017). The ability to speak and/or understand English and Spanish is inevitable because the context in which this person is making connections is bilingual, as in the case of about 73% of United States Latino families (Krogstad & Lopez, 2017). The most important conclusion that I can draw from this study is that the ability to communicate supports meaning making of the concept of family for Latino ADS, not bilingual capacity, nor the individuals ability to speak Spanish well, even though parents might have decided that English-only was the best way to raise children with DS. A strong sense of family (i.e. familism) for Latino ADS is created within the Latino culture which is embedded in the Spanish language (Cortes, 1995), the use of the Spanish language was simply a natural occurrence within these families.

This is not to say that the Spanish language is unimportant, rather that, usage of one language over another was not found here as an important topic of conversation. What was found to be important was all the interpretations by the ADS about the interactions they have with important people in their lives, that helped solidify their relationship, shaping their meaning of family within a bilingual context. Spanish was a part of this experience, helping build the familial connection for all participants. It could not be separated, rather it was a building block

since ADS interacted with all family members, abroad and local, using the language needed to communicate and have a good time. It allowed them to connect with others in the family, in a way that would not have been possible if they could not speak at least some Spanish and have some understanding of the language, no matter the level of proficiency, an important conclusion found in this study. This supports the conclusion found by Guiberson (2013b), where over 80% of families expressed that bilingualism was a natural occurrence, and that children with disabilities would benefit from being bilingual. As in the case of this study where there was a clear benefit to being bilingual since all the participants were able to connect with family domestic and abroad, without worrying about bilingual capacity, rather they just enjoyed and expressed happy moments with family, that was embedded within Latino culture, that is rooted in the Spanish language.

This finding expands upon the work of Cortes (1995) and Stein (2013), where a strong sense of familism, which is a core feature of Latino culture, is an integral part of defining family when raised in Latino homes. Building a sense of family for each of the participants did not place importance on which language was being used. Rather communication, regardless of which language was being used, helped the individual create the meaning of family, where language was important in only one aspect. It was simply a means to communicate, speaking Spanish fluently or well was not important, neither was English. In the case of Olga, she is a limited English speaker but is still able to build a sense a family with those closest to her regardless of what language is being used. The ADS never expressed the need or desire to speak a particular language. Each of them told stories using the language based on the context of the story. When talking about events that occurred in a foreign country, they tended to speak more Spanish than English, when referring to music, artists, or songs, that were in Spanish they would again use the

language. When describing family members, they used the labels they were taught as children, which again was in either English or Spanish. Throughout the interviews the question was never asked, nor did it seem necessary, if they thought that speaking Spanish was an important part of their family.

This study helps expand upon the work of Stein (2013), where a strong sense of family within the Latino culture includes shared language usage, culture, values, morals, and norms, where the family is held as an important part of their lives (Cortes, 1995). For the Latino adolescents their solid definition of family helped serve as a buffer for depressive symptoms, it gave them a high sense of belonging, and supported their psychological development (Stein, 2013). The current study did not examine the psychological development of ADS, but I was able to view the individuals high sense of belonging where the theme affection and love naturally emerged from. The love, affection, and support felt by the ADS supported the idea that they were important members of their family, in-turn strengthening the familial relationships, and their definition of family overall. Although the work of Stein (2013), did not include individuals with DS, it can serve as a foundation when examining the concept of family within Latino ADS, to gain a better understanding of their definition of family and how that supports their development.

In this study, rapport was built with the participants through the use of symbols such as gestures, body language, and the most significant tool photographs. All of these symbols conveyed a message where the language being used became unimportant and at one point forgotten. I was able to listen and allow them to tell their stories the best way they could, which at times was not even fully based on oral communication. Symbolic interactionism speaks to these very moments, where events, social objects, and tools were a significant part and the basis of communication (Charon, 2004), whereby meaning making is an interpretive process.

Specifically, for ADS, guided by the concept of Mind action, meaning making was a process by which they interpreted the interactions they had with family members, verbally and non-verbally. They spoke about interactions, words spoken, affections shown, and moments where family members supported them.

When speaking about these moments, the words and language used was not contingent upon the idea that they should only be using English to communicate, that there might be something wrong with the way they were speaking. What was most important was the social interactions with family, independent of Spanish. The symbolism and interpretation created meaning. They further spoke about their relationships with loved ones, the acts that others did towards them that were significant and the things they did in return or in reaction to them. They expressed their inner thoughts and feelings in these particular situations. John gave an example of his sister calling him names, which he said he did not mind, but his mother would get upset and openly express her dislike. John would engage with his sister and name call back, stating that he knew it was for fun and it only bothered him sometimes. Situations like these, which can be deemed as typical interactions amongst siblings, did not matter what language was being used, he still talked about his sister and other siblings with a lot of love and how they also loved him very much. Again, this reflects back upon the work conducted by Stein (2013) and Cortes (1995) where a strong sense of family is embedded within the Latino culture, their sense of belonging, and socialization within the family.

Another finding that further supports ability to communicate as the building block for making meaning of family is that there needs to be no intent to teach the ADS Spanish within these Latino families, because making a connection is not contingent upon language. It is dependent upon communication, which was evident through the interviews. Even when parents

made the conscious choice to not teach their ADS Spanish, the participant still learned the language, connected with family in the language, and although they have limited bilingual capacity, the meaning of family was still created with Spanish embedded within it. This finding supports the notion that native language maintenance is inextricably connected to family life (Guardado, 2006; Wong Fillmore 1991, 2000) creating a strong sense of familism (Cortes, 1995). Similarly Guardado (2006) interviewed four Hispanic families in Vancouver, Canada, finding that the ability to speak, understand and communicate in Spanish went beyond the notion that it connects the individual and gives them access to the culture, rather it also helps them establish and maintain their link to family, while at the same time strengthening that relationship. Language is an integral part of the Latino culture, where they two cannot be seen as separate or distinct. Similar to this study where all participants connected with local and foreign family members, who spoke little to no English, yet they still expressed strong relational ties, as in the case of John, David, James, and Betty.

This study also begins to fill the gap in research in the special needs field, since it makes the connection between individuals with disabilities and building familial relationships when raised in a bilingual context. This study begins to push the conversation forward and the need for research to be conducted within the field of family studies that aims to better understand how family relationships are built within bilingual or multilingual families who are raising children with cognitive disabilities studies such as DS and Autism. As demonstrated by the numerous research done by Kay-Raining Bird and her colleagues, individuals with cognitive disabilities such as Down syndrome and Autism can develop bilingually within the capacity of their disability, without it having negative effects on their development (Cleave et al., 2012; Kay-Raining Bird; Kay-Raining Bird et al., 2005; Kay-raining Bird, Genesee, & Verhoeven, 2016;

Paradis, 2016). Hence it is possible for individuals with DS to develop bilingually, as in the case of Latino families who raised children with DS, yet research that directly links Latino family relationship and Down syndrome is missing from the research. This study can be used as the beginning of that conversation, using Kay-Raining Bird's (2005) research as a foundation, since bilingual capacity and its positive effects has already been established (Kay-raining Bird, Genesee, & Verhoeven, 2016; Paradis, 2016). It also provides a unique perspective since these findings were concluded through the direct perspective of the individual with DS rather than previous studies who use the perspective of the parents to gain insight on the development of individuals with disabilities (Guiberson, 2013b; Renty & Roeyers, 2006; Tejero Hughes, Martinez Valle-Risestra, & Arguelles, 2008).

Implications for Future Research

It is important to consider for future studies the careful examination of the interview protocol. The question, what does family mean to you, should have been the asked right at the beginning of the interview. Rather it was placed at the end and used more as a prompt, instead of a centralized idea that was built upon throughout all three waves of interviews. An important question and opportunity that was missed, was asking participants to define family. This question has to be carefully worded since the assumption cannot be made that the participants understand what it means to define a concept, especially ones as important as family to this study. Prompts and synonymous words would have to be added as well as a different way of asking, *to define*, so that the researchers could be sure the participants understood the question. I asked a similar question, but never the direct question of define what family means to them. When conducting a study around the topic of family, regardless of the person's mental ability I think the questions like these should be asked, then the researcher can judge whether the participant understood the

question enough to give an answer. The field of qualitative research is inductive and exploratory, so I believe it warrants asking the question because the answer has value no matter if the research believes they understood what was being asked. The simple question “*what does family mean to you*” can lead to many different answers if the researcher simply allows the participant to be the leader in the conversation. I think that was a missed point in the current study. Future researchers should consider asking such direct questions and not allow the fear or worry, if the ADS will understand the questions to influence in the creation of protocol.

Another aspect to consider is the use of technology. The current study did not include the ability to communicate via text messages or the way images would be sent to researcher. Adding the ability to use social media accounts, cellphone images, and simply giving the ADS the ability to bring things to the interview that are meaningful in reference to research question would aid in communication and understanding. A very important consideration is to ask the ADS in a pre-interview process what things are important to them that they would like to share with me about their family and what family means to them. Opening up the interview process drastically. It allows for the participants to bring other artifacts that I and future researchers might not have thought of or considered important. It also follows the true nature of this study, one that is fully or mostly guided by the participant. A final consideration for future researchers should also take into account co-morbidity. When inviting participants to the student and doing the initial screening, the question must be asked if the participant is dually diagnosed. Since the initial conversations are with parents present, I believe that for future research an initial interview either via phone, video chat, or in person should be done as part of the screening and invitation to participate without the presence of the individual with Down syndrome. Sensitive questions like dual diagnosis and if the participant is aware of or has ever been told that they are an individual

with Down syndrome should be known prior to initial contact with the participant. Ultimately it is them who decides to participate or not, but considering the delicate nature of these two questions, they should be done before hand to lower and minimize harm to the adult with DS. As in the current study, where dually diagnosed (Capone, 2018, Shield, Cooley, & Meier, 2017) individuals were not part of the study, this led to a participant not being able to participate. Adding to the screening protocol questions surrounding this topic that are done directly with primary caretakers will help the researcher identify participants that could be potential candidates for the study easier and faster.

Implications for Practice

Research provides the support for the conclusion that bilingualism and dual language exposure is not determinantal to the development of individuals with Down syndrome (Kay-Raining Bird et al., 2005), where prolonged and consistent exposure is a norm within the family. Within Latino culture familism, a strong sense of family loyalty and obedience stems from shared language, meaning the Spanish language (Cortes, 1995). For Spanish speak Latino families in the United States, who are raising children and caring for adults with Down syndrome, shared language and prolonged consistent exposure to Spanish is inevitable and a norm with their homes. Taking this into considerations, providers should use this study and the notion that there is an intersection between language, communication, culture, and sense of familism within Latino families when approaching families with individuals with Down syndrome. I was able to conclude that a strong sense of family was not contingent upon the ability to Speak Spanish, yet I can conclude that Spanish is a large part of how these individuals build connections within these families, since all of them at one point or another spoke Spanish to communicate with family members. They smiled and happily told me about moments where

they connected with family, while speaking Spanish or immersed in a Spanish-based activity, such as eating food, listening to music, or dancing. Hence, service providers should continue to embrace home-life, home culture, and the language that is predominately used by the family, using it as a support system, tool, and viewing it as an assets to support the development of individuals with DS, eliminating the disconnect that still exist today, where service providers believe that English-only is the best way to support individuals with disabilities (Pena, 2016, Levey & Sola, 2013).

Implications for Policy

The Latino population and the use of Spanish continues to grow in the United States (Ryan, 2013). It is estimated that 1 out of every 1200 people in the United states, consisting of children, teens, and adults has Down syndrome. Coupled with the 93% of individuals with disabilities who are over the age of 21 and continue to reside with family members, this creates a large number, where exact statistic is still unknown, of people who have Down syndrome and have been raised and continue to live in Spanish-speaking Latino homes. Policy makers should take these numbers into consideration when creating rules, regulations, and laws around bilingual education because research has demonstrated that bilingual students have more cohesive family relations and less behavioral problems in school, when native language is preserved and seen as a valuable part of children's development (Portes & Hao, 2002). Previous research has also demonstrated that Latino students who are able to maintain their bilingualism into high school years are more likely to go 4-year colleges and less likely to drop out, and are able to secure higher level paying jobs (Rumbaut, 2015; Santibañez & Zárata, 2014), although this research was conducted with typically developing adolescents, the generalization can be made that home-language preservation through bilingual educational programming positively impacts typically

developing and individuals with DS, since bilingualism does not harm the development of people with DS.

Familial ties are reinforced by common language usage, where a loss of the native language through an education system that continues to project xenophobia and ethnic prejudice (Gándara & Escamilla, 2017; Gándara & Rumberger, 2009), leaves children at a disadvantage and disconnected from family. In this study, I was able to see the deep-rooted sense of pride that all individuals had when they expressed where they were from and where their family was from. They demonstrated pride in being Latino and their families native country, identifying as Colombian, Cuban/Puerto Rican, or Ecuadorian. They also called themselves American, where it was evident that they had a deep-rooted sense of pride to be from both a foreign country and the United States. Policy makers should redirect their focus from pushing an English-only centered education system to a more diverse system adopting bilingualism and multilingualism education system such as Canada and European countries. This in turn would help solidify family ties and build strong connections that can be seen through academic achievement, since research has shown the direct tie between academic achievement and native language loss (Paradis, 2001; Kouritzin, 1999; Toppelberg & Collins, 2010; Thomas & Collier, 2003; Wong Fillmore 2000).

Limitations

One of the first major limitations in speaking with the individuals from the Down syndrome population is their ability to clearly express themselves, referring to issues of intelligibility (Wild, Vorperian, Kent, Bolt, & Austin, 2018). There is a disconnect between what the individual is able to express verbally and what they understand mentally (Wild, Vorperian, Kent, Bolt, & Austin, 2018). All participants except, Olga have difficulty in expression. It was evident through the conversations and comparisons of interviews which participants had better

capability of expression. For example, David, in order to try and overcome this challenge select photographs were used to aid in understanding and clarification. His speech pattern is short, and he is limited in the amount of words he knows to express how he is feeling and thinking. When asked how he knew something, he tended to give silence or say it was good (bien), which was a common answer when asked how everything was going, or how he was feeling.

Another challenge was with the 5-item screening guide for participants. The first question was difficult because of the word adult. It was easier to ask the person, do you have Down syndrome, rather than are you an adult with DS, because it was a generalized label, rather than something more specific or concrete so they could understand. Another limitation with the question was do they identify as adults with Down syndrome. More thought should have been given to the level of understanding of what it means to be a person with DS, as well as if the parents have ever told them about their disability. Further if they have ever questioned if they are a person with DS or what that means. Since parent interviews were not a scope of this research this background information was not collected. The study aimed to get as much as information as possible directly from the ADS, yet this information and other information such as what type of DS they have could have been collected. The second question from this screening guide that caused issues was age. Each individual was aware of their age. This could be explained by birthday cakes and celebrations but asking them if they were adults between the age of 21 and 40 created confusion. I found that I had to reword the question to ask them how old they were and then check off the box when I understood that they were between that age range. The screening guide needs to be modified as broken down to questions asked orally of the participant and those that the researcher checks off as yes or no depending on answer as internal questions.

A third limitation was the initial meetings with parents were difficult, since although families were referred by known and trust parties, the families still received me with fear. It was evident since they became insecure and all questioned why, they as the parents could not be present during the interviews. This seemed to be the hardest part for parents, particularly the moms, since they seemed to be afraid of leaving the ADS with a stranger, even if the referral was a trusted source. Their facial expressions body language, and even words expressed their unease with this process. This is understandable since previous research has shown that parents are over-protective with their children with special needs, especially mothers, a term commonly known as *helicopter mom*. Adding a section where there is a pre-interview process for possible background information of the family and the ADS where the conversation is with the parent could help overcome this challenge. A screening guide could also be tailored to parent pre-interviews and then verified with the ADS at the first interview. Having this first formal interview with parents gives them the ability to ask questions and further learn about the study, most important that interviews will be without their presence.

A final limitation was the lack of experience I had in the field of conducting qualitative interviews. When transcribing I found that I would use loaded questions or ask closed questions, where the response was then short which did not help me combat the natural issues that ADS already have with expression. I found that it was difficult to ascertain their level of understanding. I had to reword and repeat questions in order to get more in-depth answers. The semi-structured interview protocol needs to be edited and more prompts need to be added to help the ADS express themselves better. Other symbolic tools such as objects should be used in order the understand the why and how the participants make meaning of family.

There this study demonstrates that ADS are capable of telling their life stories. It is important to give them an opportunity to be part of decisions that are made for people like them. Children are going to continue to be born with DS and into bilingual or multilingual families. It is important to remember through previous research, such as Wong Fillmore (2001) that a loss of the native language creates a familial disconnect. For people with DS who are born in Latino families, the Spanish language is large part of the culture and regardless of parents teach their children the native language as a means of communicating with one another, they will still learn it. John as a great example, because one of the first things I was told by mom when explaining to her the current study, was that her son did not speak Spanish, yet through our interviews he spoke Spanish multiple times, stated that when in their native country, he communicated in Spanish with his cousins, since they did not speak English. He told stories about playing video games and soccer. Similarly, the mother of James told me that she just spoke to her son in which ever language she could best communicate her message. She remembers being told that she should only talk in English but did not find the benefit of that because her family speaks mainly Spanish, especially when traveling, at family gathers, and with a very special person to James his grandmother, who had recently passed away.

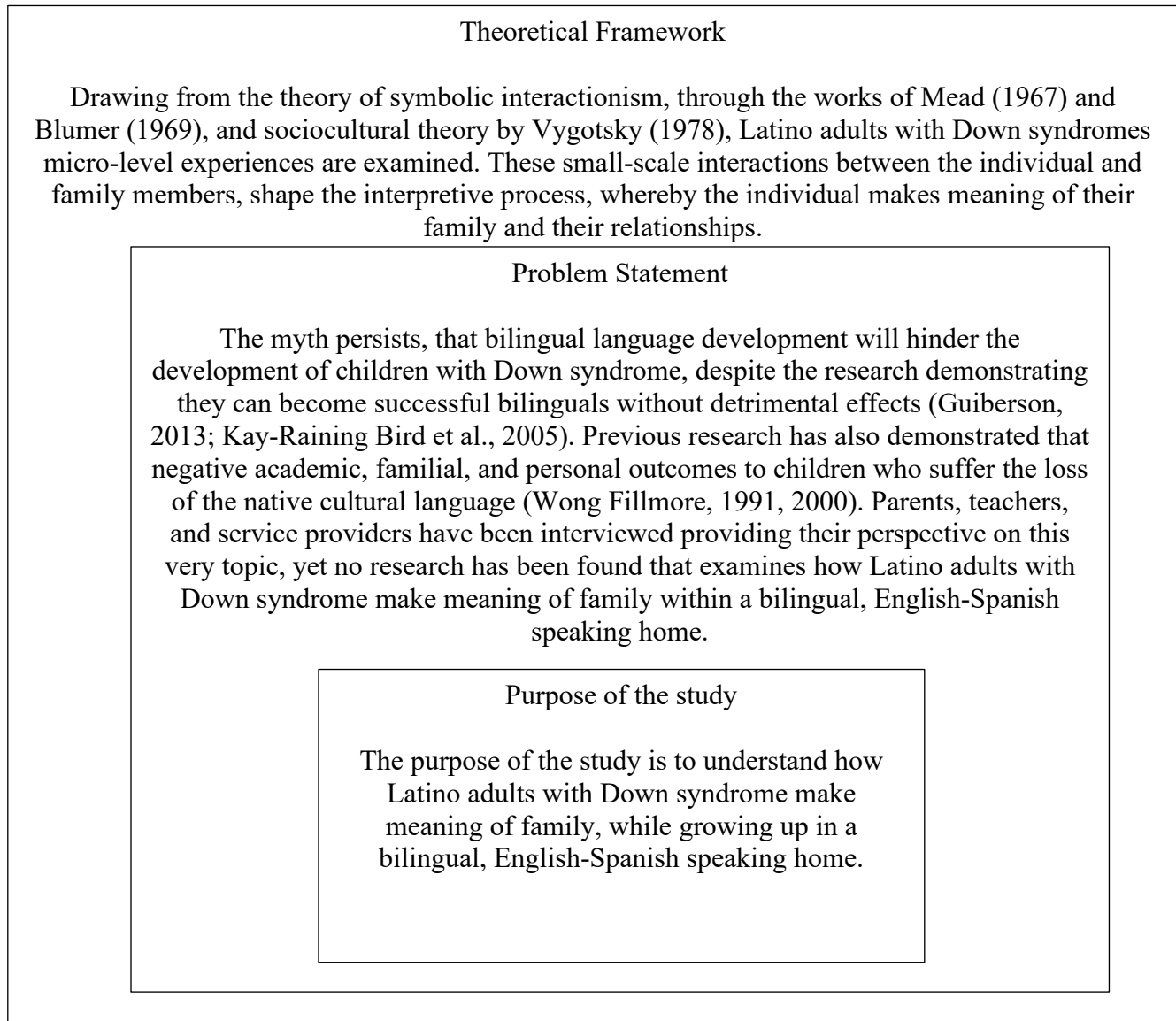


Figure 1. The Theoretical Framework¹

¹Adapted from: Merriam, S. & Tisdell, E. J. (2016); Qualitative research: A guide to design and implementation. California: Jossey-Bass.

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APPENDIX A

College of Education & Humanity

Department of Family & Child Studies

Information Sheet for the Consent Form¹

Research Study: How do Latino adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?



You are being invited to be part of a research study. Before you decide it is important for you to understand why the research is being done and what you will have to do. Please read this and speak to others, if you need.

What is the purpose of the study?

Linda wants to find out what life was like for you.



She wants to know what people with Down syndrome think, feel, and believe about their life when they grow up in a Spanish family in the USA. She wants to find out how to make services and life better for people like you.

Why have you been chosen?

You are invited to be part of this research because you are an Adult with Down syndrome between the ages 21 to 40, and Linda believes that your thoughts matter. You will be one of a group of men and women who will be interviewed.

**Do you have to be part of this research?**

You do **not** have to be part of this research study. You can say 'Yes' or 'No' it is up to you.



You can change your mind at any time, without giving a reason. If you decide not to be part of this research study, this will not affect the care or support you receive.

**What will happen to me if I decide to say Yes?**

If you say "Yes", you will be invited to sit and talk to Linda for 3 interviews. You will get to pick the place where you will meet and talk. You can come alone or bring a family or friend with you.

¹Adapted from: Pointu, A. J. (2017). *The lived experience of older women with learning disabilities*. <http://uhra.herts.ac.uk/handle/2299/17732>



Linda will ask you some questions and listen to your answers.

Each interview will be audio tape recorded. The interview will take about 1 ½ - 2 hours.

You will be asked to bring 3 of your favorite pictures, when you were with your family and important people in your life. We will talk about your life and look at the pictures together during the interviews.

Linda will ask if she can keep a copy of your pictures for her research report.



If you need to stop at any time, you can ask Linda to stop.



Expenses and Travel?

There will be **NO** cost to you if you choose to participate. Linda can travel to you, if you need her to, and light snacks and drinks will be provided at the interview.



What do I have to do?

If you want to take part, you will be asked to verbally consent, initial, and return it. You can return the form to the Gold Coast Down Syndrome Staff members, and they will call Linda, so she can come pick it up. Linda will then telephone you and talk to you about the interview meeting times and location.



What are the disadvantages and risks of taking part?

There are no disadvantages of taking part, although it will take time, and sometimes when we talk about our life it can bring out lots of different feelings; and this can make us feel happy or sad.

If this happens you can talk or ask Linda to stop the interview at any time. You can also speak to your family, friends, or the Montclair State University IRB Board at 973 655 7583.



What are the possible benefits of taking part? There are unlikely to be any personal benefits from taking part. However, we hope that this study will help to make services better in the future.



Will being part of the research be kept confidential? Yes, all information about you will be kept confidential. Your name will not be used in any of the reports, except your personal photographs.



Will the information be kept confidential? All information collected during the study will be in a secure computer and will only be read by the small group of people in the dissertation committee. You will not be identified in any report or publication. Your real name will not be used.

You should know that Florida and New Jersey require that any person having reasonable cause to believe that a child has been subjected to child abuse or acts of child abuse shall report it immediately the Department of Child and Families. It is important that you know, if you tell Linda about a time when someone hurt you and it can be considered Abuse (physical, mental, or sexual), Linda has to tell.



If you have any questions about this study? If you have any questions about this study you can contact Dr. Katia Paz Goldfarb, she works at Montclair State University. She is the Dissertation Chair at 1 Normal Avenue, Montclair New Jersey, 07043. Telephone **973 655 7489**.



Who is organizing and paying for the research?

Linda is undertaking this research as part of a doctorate program at Montclair State University. She is not receiving any money to do this research.



Who has reviewed the study?

All research in the doctoral studies is looked at by a group of people called an Institutional Review Board who protect the

safety, rights, and dignity of people taking part in research. This study was also looked at by the Doctoral Dissertation Committee guiding Linda's research.



What will happen to the results? A summary report that will be easy to read and written for everyone that took part, when the study is completed will be provided.

A full report will be written about the research study, and this may be presented at conferences and published in professional journals.

Thank You



Thank you for reading this information sheet.

Best Wishes from Linda

If you want more information about this study, please contact Linda, see the box for her contact information listed below.

Linda M. Baron Cortes

Montclair State University
1 Normal Avenue,
Montclair, NJ 07043

Telephone: 973 765 3997

Email: baroncortel1@montclair.edu



APPENDIX A1



Consent Form

College of Education & Humanity
Department of Family & Child Studies

Research Study: How do Latino adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?



The participant information sheet was verbally read to me...

I understood the participant information sheet.....

I understand that my information will be kept.....



- 1) in a safe place
2) confidential, unless abuse is reported
3) and it will not have my name on it



I agree to have my interviews tape recorded.....

I agree to share my photographs.....



I agree to take part in the research study.....



I understand that I can change my mind at any time.....

It is ok to use my data in other studies..... yes

no

Initial _____

Date _____

Adapted from: Pointu, A. J. (2017). The lived experience of older women with learning disabilities. http://uhra.herts.ac.uk/handle/2299/17732

APPENDIX B

Letter to Nonprofit Organization: Request for Permission

Linda M. Baron Cortes,
Doctoral Candidate
Montclair State University
1 Normal Avenue
Montclair, NJ 07105

June 30, 2018

Jane Doe,
Director
Non-Profit Organization
Florida

Dear Ms. Doe,

It was a delight to speak to you over the phone. Per our conversation I am completing a Doctoral degree in Family Science and Human Development at Montclair State University in Montclair, New Jersey. My name is Linda M. Baron Cortes and I would like to request your permission to invite Latino adults with Down syndrome who are between the ages of 21 and 40, to participate in my study.

All participants will be interviewed a total of 3 times and will be asked to provide 3 photographs while they were growing up to be discussed with my-self at the interviews. All conversations will be audiotape recorded, transcribed, and a copy of photographs will be kept, utilized during the data analysis phase of the dissertation, and some may be used in publications. All procedures and questionnaires are approved by the Montclair State University IRB and will be duly supervised by the dissertation chair and two committee members, before data collection will begin. A generalized letter to invite participants also attached to aid in clarification of the study to be conducted and to be used for help in recruitment of the Latino adults with Down syndrome.

Below is the official letter needed from your organization, on your organizations letter to be returned and signed. It can be a PDF email version. If you have any concerns or require additional information, please feel free to contact the me via phone or email. Thank you for your consideration in this matter.

Sincerely,

Linda M. Baron Cortes, ABD
T: (973) 765-3997
E: baroncortell@montclair.edu

[Official Letter Head needed]

June 30, 2018

Attn: Institutional Review Board
Montclair State University
1 Normal Avenue
College Hall, Room 248
Montclair, NJ 07043

Re: Latino Adults with Down syndrome make sense growing up in a bilingual Family
Dr. Katia P. Goldfarb (P.I.)

Dear Review Board,

This letter serves to give permission to Dr. Katia P. Goldfarb and Linda M. Baron Cortes to complete their research project, Latino Adults with Down Syndrome makes sense of family while growing up in a bilingual Family during the time period of June 2018 to July 2019 at our facility.

Dr. Katia P. Goldfarb and Linda M. Baron Cortes will have access to our participating families to conduct her research project. The research project has been described to me to my satisfaction.

Sincerely,

[Signature]

Ms. Jane Doe
Non-Profit Organization

APPENDIX B1



College of Education & Humanity
 Department of Family & Child Studies
 Voice: 973-655-4171
 Fax: 973-655-6795

Letter to Invite¹

Linda M. Baron Cortes,
 Doctoral Candidate
 Montclair State University
 1 Normal Avenue
 Montclair, NJ 07105



Date: _____

Dear _____

Research: How do Latino adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?



I am writing you to invite you to take part in my research for my Doctorate in Family Science and Human Development at Montclair State University, in Montclair, New Jersey.

I want to know what life is like for you in a Spanish and English, speaking family.



I would like to know if you would like to be part of my research study? I am sending some information with this letter to help you choose if you want to be part of my research.



Please read the information, if you need have someone assist you, and phone me if you have any questions. Telephone number: **973 765 3997**.

Thank you.

Linda M. Baron Cortes

¹Adapted from: Pointu, A. J. (2017). *The lived experience of older women with learning disabilities*. <http://uhra.herts.ac.uk/handle/2299/17732>



APPENDIX B2



College of Education & Humanity

Department of Family & Child Studies

Voice: 973-655-4171

Fax: 973-655-6795

Information Sheet¹

Research Study: How do Latino adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?

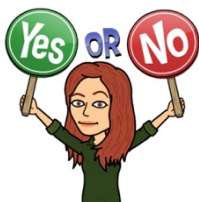


You are being invited to be part of a research study. Before you decide it is important for you to understand why the research is being done and what you will have to do. Please read this and speak to others, if you need.



What is the purpose of the study?

Linda wants to find out what people with Down syndrome think, feel, and believe about life when they grow up in Spanish families in the United States.



Why have you been chosen?

You are an Adult with Down syndrome between the ages of 21 and 40. Linda believes that your thoughts matter. It is important for people to know how you feel. This will help her to explain in her researcher what you think.

Do you have to be part of this research?

You do **not** have to have to be part of this research study. You can say 'Yes' or 'No' it is up to you.



What will you be asked to do?

You will be asked to sit with Linda 3 times to talk about your life. You will be asked to find 3 of your favorite pictures with your family and important people in your life and bring it to all 3 interviews with the Linda to help her talk about your life. She will ask if she can keep a copy of your pictures.



Will my photos be used in a report?

Your photo may be used in a research report.

Thank You



Thank you. If you want more information about this study, please contact Linda at her phone **973 765 3997**.

¹Adapted from: Pointu, A. J. (2017). *The lived experience of older women with learning disabilities*. <http://uhra.herts.ac.uk/handle/2299/17732>

APPENDIX B3











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Research Study: How do Latino adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?



What is the purpose of the study?

A researcher Linda, from Montclair State University in NJ wants to find out what people with Down syndrome think, feel, and believe about life when they grow up in Spanish families in the United States.

	<input type="checkbox"/>		<input type="checkbox"/>	1) Are you an Adult with Down Syndrome?
				<input type="checkbox"/>
				<input type="checkbox"/>
				<input type="checkbox"/>
	<input type="checkbox"/>			<input type="checkbox"/>

Thank You



Thank you. If you want more information about this study, please contact Linda at her phone **973 765 3997**.

¹Adapted from: Pointu, A. J. (2017). *The lived experience of older women with learning disabilities*. <http://uhra.herts.ac.uk/handle/2299/17732>



APPENDIX B4

College of Education & Humanity

Department of Family & Child Studies

Voice: 973-655-4171

Fax: 973-655-6795

Nondisclosure Agreement

This Nondisclosure Agreement (the "Agreement") is entered into by and between Linda M. Baron Cortes ("Disclosing Party") and Ms. Jane Doe ("Receiving Party") for the purpose of preventing the unauthorized disclosure of Confidential Information as defined below. The parties agree to enter into a confidential relationship with respect to the disclosure of certain proprietary and confidential information ("Confidential Information").

1. Definition of Confidential Information. For purposes of this Agreement, "Confidential Information" shall include all information or material that has or could have commercial value or other utility in the business in which Disclosing Party is engaged. If Confidential Information is in written form, the Disclosing Party shall label or stamp the materials with the word "Confidential" or some similar warning. If Confidential Information is transmitted orally, the Disclosing Party shall promptly provide a writing indicating that such oral communication constituted Confidential Information.

2. Exclusions from Confidential Information. Receiving Party's obligations under this Agreement do not extend to information that is: (a) publicly known at the time of disclosure or subsequently becomes publicly known through no fault of the Receiving Party; (b) discovered or created by the Receiving Party before disclosure by Disclosing Party; (c) learned by the Receiving Party through legitimate means other than from the Disclosing Party or Disclosing Party's representatives; or (d) is disclosed by Receiving Party with Disclosing Party's prior written approval.

3. Obligations of Receiving Party. Receiving Party shall hold and maintain the Confidential Information in strictest confidence for the sole and exclusive benefit of the Disclosing Party. Receiving Party shall carefully restrict access to Confidential Information to employees, contractors, and third parties as is reasonably required and shall require those persons to sign nondisclosure restrictions at least as protective as those in this Agreement. Receiving Party shall not, without prior written approval of Disclosing Party, use for Receiving Party's own benefit, publish, copy, or otherwise disclose to others, or permit the use by others for their benefit or to the detriment of Disclosing Party, any Confidential Information. Receiving Party shall return to Disclosing Party any and all records, notes, and other written, printed, or tangible materials in its possession pertaining to Confidential Information immediately if Disclosing Party requests, it in writing.

4. Time Periods. The nondisclosure provisions of this Agreement shall survive the termination of this Agreement and Receiving Party's duty to hold Confidential Information in confidence shall remain in effect until the Confidential Information no longer qualifies as a trade secret or until Disclosing Party sends Receiving Party written notice releasing Receiving Party from this Agreement, whichever occurs first.

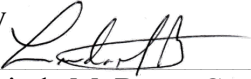
5. Relationships. Nothing contained in this Agreement shall be deemed to constitute either party a partner, joint venture, or employee of the other party for any purpose.

6. **Severability.** If a court finds any provision of this Agreement invalid or unenforceable, the remainder of this Agreement shall be interpreted so as best to affect the intent of the parties.

7. **Integration.** This Agreement expresses the complete understanding of the parties with respect to the subject matter and supersedes all prior proposals, agreements, representations, and understandings. This Agreement may not be amended except in a writing signed by both parties.

8. **Waiver.** The failure to exercise any right provided in this Agreement shall not be a waiver of prior or subsequent rights.

This Agreement and each party's obligations shall be binding on the representatives, assigns, and successors of such party. Each party has signed this Agreement through its authorized representative.

Disclosing Party
Signed By: 
Printed Name: Linda M. Baron Cortes
Title: Doctoral Student at MSU
Dated: _____

Receiving Party
Signed By: _____
Printed Name: Ms. Jane Doe
Title: Executive Director of Non-Profit
Dated: _____



APPENDIX C

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Tell Me About Your Self¹



Please answer the questions below.



1) Are you a man or a woman?



Man



woman

2) How old are you?



3) Did you graduate high school?



Yes

No

4) Do you live:

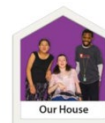
Alone



With others



With family



5) Who lives in your home now?

Mom

Dad

Sister

Aunt

Other

Grandma

Grandpa

Brother

Uncle

None



6) What languages do you speak?

Spanish (Hola)

Other

English (Hello)

Both



7) What languages did your family speak at home when you were growing up?

Spanish (Hola)

Other

English (Hello)

Both



¹Adapted from: Davies, J., & Burke, C., (2016). *Workforce development for people with intellectual disabilities: The perspective from people with intellectual disabilities*. Foundation for People with Learning, D., & National Health Service (NHS), England, H. K.

Spanish (Hola) Other
English (Hello) Both

8) What languages did YOU speak at home with your family when you were growing up ?



9) Who lived in your home when you were growing up?

Mom Dad Sister Aunt Other
Grandma Grandpa Brother Uncle None



Thank You



Thank you for taking the time to answer these questions with me.

APPENDIX D

Semi-structured Interview Script – English

Research Question: How do Latina/o adults with Down syndrome make meaning of family, while growing up in a bilingual, English-Spanish speaking home?

Introduction: Hello my name is Linda M. Baron Cortes. I am a doctoral student and I will be interviewing you today. I want to thank you for taking the time to sit with me today. During our conversation today please feel free to speak English, Spanish, or both, which ever makes you most comfortable.

Today we will be talking about the time you spend with your family and important people in your life.

Can you tell me about your family and important people in your life?

- Can you tell me who are the important people in your life?
- Who do you live with?
- Anyone else that is in your family and person that is important to you that you want to tell me about?

Before we met today, we spoke over the phone or in person, with the help of your parent(s), I asked you to select three pictures with your family and the important people in your life. I gave you the option to bring them today, or text them to me before our first meeting, so we could have a digital copy of the pictures.

Can you show them to me?

- Can you tell me why you choose these pictures?
- Can we talk about one picture?

Which one would you like to talk about first?

- Who is in the picture?
- Can you tell about the people in the picture?

- What is happening in this picture?
 - What were you talking about?
 - What was your family members (friends) talking about?
 - What were you doing?
 - What was everyone else doing?

- How did feel that day?
 - What were you talking about?
 - What would you say to _____ ?

- Why did you choose this picture?
 - What were you thinking about in this picture?

- Can you name the three reasons why you choose this picture?
- Can you tell me about what you were wearing?
 - Why were you wearing those clothes/shoes/hat/accessories?
 - Who picked out your clothes?
 - What do you think about the clothes?

Let's talk about *another* picture?

- Who is in the picture?
- Can you tell about the people in the picture?
- What is happening in this picture?
 - What were you talking about?
 - What was your family members (friends) talking about?
 - What were you doing?
 - What was everyone else doing?
- How did feel that day?
 - What were you talking about?
 - What would you say to _____ ?
- Why did you choose this picture?
 - What were you thinking about in this picture?
 - Can you name the three reasons why you choose this picture?
- Can you tell me about what you were wearing?
 - Why were you wearing those clothes/shoes/hat/accessories?
 - Who picked out your clothes?
 - What do you think about the clothes?

Let's talk about the *final* picture?

- Who is in the picture?
- Can you tell about the people in the picture?
- What is happening in this picture?
 - What were you talking about?
 - What was your family members (friends) talking about?
 - What were you doing?
 - What was everyone else doing?
- How did feel that day?
 - What were you talking about?
 - What would you say to _____ ?
- Why did you choose this picture?
 - What were you thinking about in this picture?

- Can you name the three reasons why you choose this picture?
- Can you tell me about what you were wearing?
 - Why were you wearing those clothes/shoes/hat/accessories?
 - Who picked out your clothes?
 - What do you think about the clothes?
- Can you tell me what family means to you?
 - What does it mean to be part of a family?
 - How do you feel about your family?

Other Prompts:

- Have you traveled to your native (family home country of _____)?
 - Can you tell about a time when you were there?
 - I know they speak Spanish there, what you do speak?
 - What kinds of things do you talk about?
 - What kinds of food do you eat?
 - What kinds of things do you do?
- I notice that your family speaks Spanish, do you speak Spanish?
 - Who do you talk to in Spanish?
 - What kinds of things do you talk about?
 - Do you listen to Spanish music?
 - Do you have a favorite song? Artist?

All interview guides will be provided in either English or Spanish for the comfort of the interviewee and to make sure they fully understand the questions. The English guide with prompts is presented above. The guide is meant to be just a guide, since depending on the level of cognitive functioning, age, and language preferred by the participant. Questions will be adjusted by researcher accordingly. All interviews will be audio recorded and transcribed for analysis.

APPENDIX D1

Semi-structured Interview Script – Spanish
Guion de Entrevista Semiestructurado - español

Pregunta de investigación: ¿Cómo los adultos Latinas/os con síndrome de Down dan sentido a la familia, mientras crecen en un hogar bilingüe de habla, inglés-español?

Introducción: Hola, mi nombre es Linda M. Baron Cortes. Soy estudiante de doctorado y te entrevistaré hoy. Quiero agradecerle por tomarse el tiempo de sentarse conmigo hoy. Durante nuestra conversación hoy, por favor siéntase libremente de hablar en inglés, español o, en ambos idiomas, ¿como usted se sienta mas cómodo?

Hoy hablaremos sobre el tiempo que pasa con su familia y personas importantes en su vida.

¿Puedes hablarme sobre tu familia y las personas importantes en su vida?

- ¿Quiénes son las personas importantes en su vida?
- ¿Con quien vives?
- ¿Alguien más de tu familia o persona importante para ti, de cual me quieres contar?

Antes de nuestra cita hoy, hablamos por teléfono o en persona y con la ayuda de su papa(s), te pedí que seleccionaras tres fotos con tu familia y/o personas importantes en tu vida. Te di la opción de traerlas hoy, o enviármelas por text antes de nuestra primer cita, para poder tener una copia digital de las fotos.

¿Me las puedes mostrar?

- ¿Puedes decirme por qué eliges estas fotos?
- ¿Podemos hablar de una foto?

¿De cuál te gustaría hablar primero?

- ¿Quién aparece en la foto?
- ¿Me puedes contar sobre las personas en la foto?
- ¿Que esta pasando en esta imagen?
 - ¿De qué estabas tu hablando?
 - ¿De qué estaban hablando los miembros de su familia (amigos)?
 - ¿Qué estabas haciendo?
 - ¿Qué estaban haciendo todos los demás?
- ¿Cómo se sintió ese día?
 - ¿De que estaban hablando?
 - ¿Que le dirías a ____?
- ¿Por qué elegiste esta imagen?
 - ¿Qué estabas pensando en esta imagen?
 - ¿Me puedes decir tres razones por cual escogiste esta foto?

- ¿Puedes decirme qué llevabas puesto?
 - ¿Por qué llevabas esa ropa / calzado / sombrero / accesorios?
 - ¿Quién escogió tu ropa?
 - ¿Que opinas sobre la ropa?

¿Vamos a hablar de *otra* imagen?

- ¿Quién aparece en la foto?
- ¿Me puedes contar sobre las personas en la foto?

- ¿Que esta pasando en esta imagen?
 - ¿De qué estabas tu hablando?
 - ¿De qué estaban hablando los miembros de su familia (amigos)?
 - ¿Qué estabas haciendo?
 - ¿Qué estaban haciendo todos los demás?

- ¿Cómo se sintió ese día?
 - ¿De que estaban hablando?
 - ¿Que le dirías a ____?

- ¿Por qué elegiste esta imagen?
 - ¿Qué estabas pensando en esta imagen?
 - ¿Me puedes decir tres razones por cual escogiste esta foto?

- ¿Puedes decirme qué llevabas puesto?
 - ¿Por qué llevabas esa ropa / calzado / sombrero / accesorios?
 - ¿Quién escogió tu ropa?
 - ¿Que opinas sobre la ropa?

¿Vamos a hablar sobre la imagen *final*?

- ¿Quién aparece en la foto?
- ¿Me puedes contar sobre las personas en la foto?

- ¿Que esta pasando en esta imagen?
 - ¿De qué estabas tu hablando?
 - ¿De qué estaban hablando los miembros de su familia (amigos)?
 - ¿Qué estabas haciendo?
 - ¿Qué estaban haciendo todos los demás?

- ¿Cómo se sintió ese día?
 - ¿De que estaban hablando?
 - ¿Que le dirías a ____?

- ¿Por qué elegiste esta imagen?
 - ¿Qué estabas pensando en esta imagen?
 - ¿Me puedes decir tres razones por cual escogiste esta foto?

- ¿Puedes decirme qué llevabas puesto?
 - ¿Por qué llevabas esa ropa / calzado / sombrero / accesorios?
 - ¿Quién escogió tu ropa?
 - ¿Que opinas sobre la ropa

- ¿Me puedes decir que significa familia para usted?
 - ¿Que significa ser parte de una familia?
 - ¿Como te sientes hacia tu familia?

- ¿Has viajado a tu país nativo (el país de tu familia _____)?
 - ¿Me puedes contar sobre una vez que viajaste?
 - ¿Yo se que hablan español allí, que idioma hablo usted?
 - ¿Sobre que hablaron?
 - ¿Que tipo de comidas comieron?
 - ¿Que hicieron?

- ¿Me he dado cuenta de que su familia habla español, usted habla español?
 - ¿Con quien hablas en español?
 - ¿Sobre que hablan?
 - ¿Escuchas muisca en español?
 - ¿Tienes una canción favorita? ¿artista?

Todos los guías de entrevista estarán disponibles en inglés o español para la comodidad de la persona entrevistada y para asegurarse de que ellos entiendan completamente las preguntas. El guía en español esta presentado arriba. Este guía este hecho para ser solo un guía, porque depende del nivel de funcionamiento cognitivo, edad, y idioma preferido, de el participante. Las preguntas se ajustan acuerdo con la entrevista. Todas las entrevistas serán grabadas por audio y transcritas para análisis.