

**Latinx Parents' Funds of Knowledge:  
Participation throughout the IEP Process**

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THESIS

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This thesis is dedicated to my high school guidance counselor who once recommended that I drop out because I was “obviously not capable of going to college.”

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## **LIST OF ABBREVIATIONS**

AoL	Awareness of Cultural Difference
CLD	Culturally and Linguistically Diverse
EAHCA	Education for All Handicapped Children Act
GKS	Gaining Knowledge and/or Support from Others
IDEA	Individuals with Disabilities Education Act
IDEIA	Individuals with Disabilities Education Improvement Act
IEP	Individualized Education Plan
IFSP	Individual Family Service Plan
MAP	Mom as Protector
OT	Occupational Therapy
PKoC	Parent Knowledge of Child

## SUMMARY

Increasingly more families of children with disabilities come from culturally and linguistically diverse (CLD) backgrounds, and varied communications may be needed other than traditional school/parent processes (Harry & Fenton, 2016). It has been found that the stymying of parents' voices is a contributing factor to low engagement levels at individualized education plan (IEP) meetings (Salas, 2004). Furthermore, while most CLD families often possess practical knowledge about their children and communities, research findings indicate they are rarely asked about this knowledge (Rios-Aguilar et al., 2011). Surveys with Latinx parents have shown that they are often more involved with their children at home than at school (Walker et al., 2011). Although IDEA (2004) clearly mandates that parents should participate in the IEP process, there has only been a modicum of progress made to increase their involvement (Stoner & Angell, 2006; Trussell, Hammond, & Ingalls, 2008). An identified hindrance to involvement is professionals who have not been trained in culturally sensitive practices and methods for engagement (Tisdell, Taylor, & Forte, 2013). To counteract this, researchers have argued that parents' contributions to school-related matters need to be gathered and incorporated into the supports and services that schools provide to students (Harry, 2008; Underwood, 2010).

This phenomenological study examined how the lived experiences of seven working class Latinx parents from a large metropolitan area drew from their knowledge, values, and beliefs in the IEP process to better support their children with disabilities. Parents participated in three in-depth interviews a piece to discuss their life histories, familial and cultural knowledge, understanding of their children, and participation practices in the IEP process. Thematic analyses revealed that parents (a) regularly draw from knowledge of their child and incorporated the knowledge of others to advocate for their children, (b) express a complex awareness of how their

## **SUMMARY** (continued)

lived experiences intersect with their knowledge, values, and beliefs about child rearing, and (c) articulate creative views and perceptions of disability, the purpose and function of the IEP process, and their roles as parents. Through a synthesis of the findings, a final composite description of the meaning, or “essence,” of parents’ lived experiences describes how parents leveraged their role as protector and caregiver to resist harmful practices and views toward their children, as well as enact creative processes to support their children. Implications for research and teacher practice are discussed.

## I. INTRODUCTION

### **Parent Participation and the Law**

Beginning in the 1970s and continuing until the present time, legislation, regulations, and educational practices have evolved to address the needs of youth with disabilities. The initial passage of the Education for All Handicapped Children Act (EAHCA, P.L. 94 142) in 1975 has been amended numerous times, with each iteration highlighting provisions for familial, especially parental, involvement (Yell, Shriner, & Katsiyannis, 2006). The 2004 re-authorization, The Individuals with Disabilities Education Improvement Act (IDEIA), provides clear guidelines for parental participation throughout the individualized education plan (IEP) process. Those key provisions include providing important information about a child's history, home life, social and emotional functioning, and strengths and needs (Losinski, Katsiyannis, White, & Wiseman, 2016). Providing that information helps position parents as important participants of the IEP team and ensures that schools involve parents in the IEP process (Yell, Shriner, & Katsiyannis, 2006).

The term "participation" is used in IDEIA (2004) to describe the goal of including parents in IEP meetings (Burke, Goldman, Hart, & Hodapp, 2016; Trainor, 2010a). According to the statute, schools and educational agencies should be committed to "improving the participation of parents of children with disabilities in the education of their children" (p. 118, Stat. 2784). There are continuing disagreements as to what exactly participation at IEP meetings should be, with conflicting viewpoints. Some concede that, at the very least, it entails parents being present at the meetings and answering questions asked by IEP team members (Wagner, Newmann, Cameto, Javitz, & Valdes, 2012). This rather low-threshold for participation is disputed in the literature. For instance, Hammel et al. (2008) preferred to operationalize

participation with the modifiers “active” and “full.” In their focus group study of 63 individuals with disabilities, aged 18-70 years old, researchers asked participants to define participation. When reflecting on the term, participants were not limited to thinking of participation only in the context of education or the IEP process. Rather, participation was more broadly defined as a way of interacting with any number of systems so that participants’ personal definitions of participation were documented. Interview respondents viewed participation in a wide range of ways. Some individuals stated that it was an active, meaningful, and engaging process, while others defined participation as having “access” to activities and then choosing to participate or not (Hammel et al., 2008).

Other scholars in the field of exceptionality have offered different definitions of family IEP participation. In a study on parent advocacy, Burke et al. (2016) pre- and post-tested 90 participants that were part of an advocacy training program on their advocacy knowledge. The researchers defined participation as “advocacy.” They drew on language in the legislation that encourages parents and students to know their rights (see also Burke, 2013). Similarly, in a study of 33 parents’ participation preferences, Trainor (2010a) concluded that parent *advocacy* was implied through the general language of IDEIA, but that the more general term *participation* was the most commonly used within the IEP process. As used in IDEA (2004), the term is cloaked in ambiguity and therefore open to interpretation, Trainor suggested.

Burke et al. (2016) and Trainor (2010a) have attempted to clarify these terms for the purpose of understanding what is meant by “participation.” However, a dilemma arises. If we interpret “participation” to mean being invited to an IEP meeting or a parent receiving a phone call when her/his child is struggling, then schools need not go beyond the perfunctory invitations sent to parents. On the other hand, if we interpret participation to connote an active ongoing

collaboration between parents and school personnel with the aim of producing an IEP document that speaks to students' individual assets and challenges, then that process could be identified as essential. Mereoiu, Abercrombie, and Murray (2016) argue, in fact, that since IEPs are legal documents that are the cornerstone of serving individuals with disabilities (see Farrell, 2009), the IEP process could be an appropriate place to start when designing structured interventions that could help parents meaningfully engage in collaborations with schools.

### **Research on Parent Involvement in the IEP Process**

Despite research that shows parent involvement strongly correlates with academic success (Jeynes, 2005, 2007) and fewer behavior problems in school (Epstein, 2008), the extant research on parent involvement during the IEP process reveals that, overall, parents are not very involved (Childre & Chambers, 2005; Rodriguez, Blatz, & Elbaum, 2014a). Although IDEA (2004) clearly mandates that parents should participate in the IEP process, there has only been a modicum of progress made to increase their involvement, let alone enhance the quality of involvement (Stoner & Angell, 2006; Trussell, Hammond, & Ingalls, 2008). Yet findings suggest that this lack of parental involvement can have a negative impact on the development of IEP documents (Fish, 2006; Rehm, Fisher, Fuentes-Afflick, & Chesla, 2013). Also, parents may be reluctant to become involved when IEP meetings feel like they are following a predetermined script and parents are seen as bystanders in IEP development (Sheehy, 2006).

One additional hindrance to involvement is professionals who have not been trained in culturally sensitive practices and methods for engagement (Tisdell, Taylor, & Forte, 2013). Increasingly more families of children with disabilities come from culturally and linguistically diverse (CLD) backgrounds, and communications different from traditional school/parent processes may be helpful. For instance, in an interview study exploring the relations between

Mexican American mothers and the special education system in the United States, Salas (2004) concluded that the stymying of parents' voices is a contributing factor to low engagement levels at IEP meetings. Furthermore, while most CLD families often possess practical knowledge about their children and communities, research findings indicate they are rarely asked about this knowledge (Rios-Aguilar, Kiyama, Gravitt, & Moll, 2011). Walker, Ice, Hoover-Dempsey, and Sandler (2011) conducted surveys with Latino parents and found that they were often more involved with their children at home than at school. They learned that parents often became more involved when teachers showed a level of interest in their students' home lives, and when teachers sent out additional invitations to attend meetings and events. When this out of school and home knowledge is not recognized by educators and accessed, it cannot become part of the IEP process and potentially add to the child's success.

While this is true for parents from CLD backgrounds (Pang, 2011), it is also true for parents from low-income communities (Harry, 2008; Trainor, 2010a, 2010b). A disproportionate amount of individuals diagnosed with a disability, and the families in which they are members, come from such communities (Artiles, Kozleski, Trent, Osher, & Ortiz, 2010; Harry & Fenton, 2016). In her study of parent advocacy during the IEP process using individual and focus group interviews, Trainor (2010b) found that parents of children with disabilities did not feel that schools were concerned with the social and cultural capital that parents possessed. Rather, there was an implicit presupposition that parents from economically marginalized backgrounds lacked such forms of capital, which included knowledge about school requirements and effective methods of teaching students. The lack of parents' knowledge and input into the IEP process might contribute to the disenfranchisement CLD youth with disabilities experience, and could be part of the troubling findings that youth with disabilities are more likely to drop out of high



school, experience unemployment, and become incarcerated (Cramer, Gonzalez, & Pellegrini-Lafront, 2014; Doren, Murray, & Gau, 2014). To counteract this, researchers have argued that parents' contributions to school-related matters need to be investigated and incorporated into the supports and services that schools provide to students (Harry, 2008; Underwood, 2010).

### **Barriers to CLD Parent Involvement in the IEP Process**

Even though a consensus exists that schools collaborating with parents is a “sound educational practice” (Rodriguez, Blatz, & Elbaum, 2014a, p. 79), barriers remain to parent participation in the IEP process, especially for CLD parents. In a study reviewing literature on the barriers to parental participation in the IEP process, Pang (2011) identified two: use of technical jargon and misunderstandings about class, language, and culture. Additionally, there is research to suggest that embedded deficit-orientations and differing attitudes between parents and educational professionals contribute to poor parent participation (Blue-Banning, Turnbull, & Periera, 2000; Hess, Molina, & Kozleski, 2006; Turnbull & Turnbull, 2001). For instance, Turnbull and Turnbull (2001) discuss how parents are often seen as the cause of their children's difficulties in school, and the families they come from were thus in need of “fixing.” Based on the available research on barriers that hinder CLD parents from more actively participating in the development and implementation of IEPs, I have developed four categories: (1) deficit-orientation, (2) class, language, and culture, (3) technical jargon, and (4) disparate attitudes between parents and schools.

**Deficit-orientation.** Like many large institutions, school systems are reflections of broader sociocultural attitudes regarding correct behavior, assimilation to dominant cultural norms, adherence to organizational hierarchies, and the teaching of particular shared values (Apple, 1979). As such, schools can sometimes be positioned at odds with the parents of the

children they serve because of the embedded institutional assumptions held by professionals (Harry, Kalyanpur, & Day, 1999). In particular, the field of special education has been conceptualized as paradoxical; that is, as an artifact predicated on pathologization of students with deficiencies and their systematic placement into judgmental categories, often called a deficit-orientation (Heshusius, 1986). Concomitant with this, the dominant medical model pervasive in special education has often minimized the social, cultural, and political effects on how disability is conceptualized, which has supported some epistemologically monolithic assumptions in the field (Connor, 2019; Coomer, 2019). Yet at the same time, special education services and supports are purportedly borne from altruistic concerns (Skrtic, 1991). The deficit-orientation regarding students with disabilities adds to parents' levels of stress, possibly making it difficult to authentically collaborate with schools (Blue-Banning, Turnbull, & Periera, 2000; Hess, Molina, & Kozleski, 2006; Summers et al., 2005). There is evidence that parents may intuit the negative ways in which they are viewed and project a reluctance toward any type of participation (Rodriguez, Blatz, & Elbaum, 2014a; Salas, 2004). While models have been developed to address the deficit-orientation, such as response to intervention (RTI) and positive behavior interventions and supports (PBIS), many argue that the deficit-orientation remains deeply embedded within the field of special education (Artiles, 2015). Furthermore, families of children with disabilities continue to confront this embedded deficit-orientation when interacting with schools (Artiles, 2015; Artiles et al., 2010). While IDEA (2004) mandates that schools include parents in decision-making around the IEP process, the mandate cannot erase taken-for-granted and often hidden resilient institutional precepts that situate individuals with disabilities as discrepant and in need of remediation. Those precepts permeate interactions between parents

and school personnel and discursively reinforce themselves by remaining out of sight and infrequently discussed (Skrtic, 1991).

**Class, language, and culture.** Related to a deficit-orientation toward disability, being members of non-dominant language and cultural groups can also become a barrier to participation in the IEP process (Barrera & Liu, 2006; Blanchett, Klingner, & Harry, 2009; Pang, 2011). Parents from CLD backgrounds, specifically, are more likely to experience difficulty interacting with school systems where, in many cases, most of the school personnel do not come from similar CLD backgrounds. Moreover, those personnel may view parents from backgrounds dissimilar to their own through a deficit lens; that is, through a set of views that is dubious and relies on assumption rather than clear evidence (Harry, 2002, 2008). Furthermore, the ways that parents and their children view teachers may be different from dominant viewpoints and could vary among CLD families (Harry, 2008). Blanchett, Klingner, and Harry (2009) recommend that educators engage in an intentional set of processes for learning about the families of the children they are working with in order to better support students and their families. They argue that that could then result in a better utilization of family knowledge (Blanchett, Klingner, & Harry, 2009). This is corroborated in an interview study with CLD parents by Barrera and Liu (2006). They found that when using dialogue techniques such as building rapport and identifying interest for dialogue, parents often explicitly stated the knowledge they had about the educational system and identified areas where they perceived a lack of knowledge.

There is additional evidence that parents from a range of CLD backgrounds may have different involvement patterns than White parents, which could affect the choices CLD parents make to participate in the IEP process (Rodriguez, Blatz, & Elbaum, 2014a). For instance, Mary (1990) found that Latinx mothers often took a stance of self-sacrifice with their children with

disabilities. Related to this, Harry (1992) found that Latinx and African American mothers saw their children with disabilities as “gifts from God,” which is quite different than the dominant cultural perception that children with disabilities are “broken” and in need of remediation (Blanchett, Klingner, & Harry, 2009). Lo (2008) and Cho and Gannotti (2005) reported that Asian-American parents often became confused because of language barriers and were hesitant to fully participate in decision-making processes. In a survey study with 2,702 parents about how well schools were involving parents, Elbaum, Fisher, and Coulter (2011) found that expectations of schools and teachers in terms of academic performance, behavioral expectations, and postsecondary outcomes were different among Latinx and White parents. The scale of this study, along with its representative sample of the ethnic and racial diversity on a national level, adds significant justification for the notion of differences in expectations for parent involvement preferences.

Socioeconomic status is also a factor that contributes to CLD parental involvement. Students receiving special education services are more likely than their general education counterparts to come from homes with lower socioeconomic status, which is associated with a lack of social and cultural capital at the family systems level (Harry, 2008; Lo, 2009). As Rodriguez, Blatz, and Elbaum (2014a) state:

[P]arents from lower socioeconomic status and minority backgrounds may lack the cultural capital and sense of self-efficacy needed to take the initiative to advocate for their child when schools are less responsive (p. 92).

It has been argued that this lack of social and cultural capital leads to an overrepresentation of students who are poor and from racial and ethnic minority groups in special education programs (Artiles et al., 2010; O'Connor & Fernandez, 2006). A contributing factor to that

overrepresentation might be that CLD parents are less likely to know who to turn to if they have issues or questions about the IEP process and how it relates to their child's education (Ong-Dean, 2009; Trainor, 2008, 2010a, 2010b, 2010c).

Though not focused on students with disabilities, work by Reay (1998) is relevant in terms of ways that social class affects parent involvement. When investigating different involvement patterns based on social class, she found that working-class families generally cite “separateness” in their assessments of their relationships with schools; that is, families from low-income communities tend to see schools as dissimilar and distinct from their own personal experiences with society. Conversely, Reay (1998) found that middle- to upper middle-class households tended to see their relationships with schools as interconnected. This could be because families from middle-to-upper income communities have easy access to cultural resources used in schools, such as language vocabularies, communication styles, and common experiences, which might also be indicative of a dominant White middle-class (Skiba, Simmons, Ritter, Gibb, Rausch, & Cuadrado, 2008). What remains less clear is how the interaction of culture and language also affects socioeconomic opportunities at the macro societal levels, and how such interactions and assumptions affect parental involvement.

**Technical language.** Parents of potentially any CLD and socioeconomic class could be affected by the educational jargon and technical language embedded in the IEP process (Jung, 2011; Montelongo, 2007; Pang, 2011). Wolfe and Duran (2013) examined 9 studies published between 2001 and 2011 on CLD parents' perceptions of the IEP process. They found that communication barriers, including the use of IEP-related jargon, were significant in 8 of the 9 studies. In one of the reviewed studies, Cho and Gannotti (2005) interviewed 20 Korean-American mothers of children with disabilities and found that many translators provided by the

school were unable to properly explain the technical intricacies in the language educational professionals used at IEP meetings. That language difference resulted in mothers becoming overwhelmed and confused, further separating them from professionals and making active participation difficult. Furthermore, technical language can be confusing to parents regardless of the community they come from (Zeitlin & Curcic, 2014). For example, through 20 semi-structured interviews with parents from a primarily White, middle-class suburban school district, Zeitlin and Curcic (2014) found that parents became so confused by the language used in IEP meetings that many ended up finding the whole process impractical.

**Disparate attitudes between parents and schools.** Parents often have different attitudes regarding their children's education than do educational professionals who work in schools. The attitudes of teachers and other school personnel are frequently shaped through the vested interests of the schools in which they work, often referred to as a "school culture" (Pang, 2011). For instance, teachers often link the etiology of students' academic or behavioral problems to "bad parenting" (Hornby & Lafaele, 2011). These assumptions that could be intentional or unrecognized can have drastic effects on the ways that schools interact with parents. The assumptions can also extend to social class, as some teachers may assume that parents from lower-income households cannot provide the educational supports for their children to be successful (Harry & Fenton, 2016; Harry, Klingner, & Hart, 2005). Contrary to what many believe, research findings point out that working-class parents show comparable levels of concern about their children's education as middle-class parents (Epstein, 2001; Wolfendale, 1983). Moreover, parents generally value teachers' efforts to support their children and purposely often defer to their expertise on IEP-related matters (Rodriguez, Blatz, & Elbaum, 2014a). This unquestioned trust in teachers has been found specifically in Latinx communities,

where parents may have emigrated from countries where teachers are revered and granted a great deal of respect (Dana, 1998; Montelongo, 2015; Rodriguez, Blatz, & Elbaum, 2014a; Salas, 2004). In those situations, questioning teachers could be seen as disrespectful and frowned upon (Rodriguez, Blatz, & Elbaum, 2014a). This situated perception is important for teachers to recognize when working directly with Latinx families in school settings (Harry & Fenton, 2016).

### **Possibilities for Parent Involvement**

Parents provide the initial interactions that a child has with the world. A child's initiation into language, her formative imaginative worlds and developmental milestones are often first witnessed by parents. Before a child first steps into a school, she has already formulated a nascent worldview, connected deeply with other family members, and developed a unique and distinct personality (Smith, Cowie, & Blades, 2015). Therefore, parents have knowledge about a child that is in-depth, nuanced, personalized, and historical; a knowledge that, if dismissed or ignored, produces an incomplete picture of a child (Kalyanpur & Harry, 2012). This knowledge is indispensable in understanding children as socio-cultural beings interacting within a variety of systems, including their home, school, community, town or city, and culture (Gregg, Rugg, & Stoneman, 2012). Given that, I now explore three possibilities that could increase involvement among parents of children with disabilities.

**Advocacy.** One avenue is parental advocacy. Parent advocacy groups were initially responsible for pushing for the passage of a law specifically geared toward students with disabilities, which eventually became IDEA (2004; Turnbull, Shogren, & Turnbull, 2011). Parent advocacy is a term broadly used in education; however, it typically serves three major functions within literature in the field of special education: (1) advocating for services that meet the specific needs of a child, (2) parents acting as experts for their own children, and (3) protecting

children with special needs from poorly-trained or ineffectual professionals (Burke, 2013; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005).

In response to the issues surrounding parent advocacy, external advocates trained in the laws and processes of special education are being increasingly utilized in schools (Burke, Goldman, Hart, & Hodapp, 2016). External advocates are either paid by an organization to work with families or hired directly by families. There is a current push to produce more advocates to work with families of children with disabilities (Trainor, 2010a). Burke et al. (2016) evaluated one such program, the Volunteer Advocacy Project (VAP). They found that VAP produced significant gains in knowledge of IDEA and the IEP process, as well as parents' confidence in their advocacy skills. VAP has graduated 165 advocates since its inception in 2008, and, because each advocate serves an average of 20 families, VAP has been able to provide advocates for thousands of families (Burke et al., 2016).

**Parents at the center of planning processes.** Increasingly, person-centered approaches have been promoted for work with students with disabilities and their parents. Person-centered approaches vary depending upon context but share a common definition of having “the individual and his or her family and friends form the most critical role in the (IEP) planning process” (Keyes & Owens-Johnson, 2003, p. 147). This is seen as vastly different from the conventional method of IEP planning, wherein educators are at the center of planning efforts (Turnbull, Turnbull, & Blue-Banning, 1994). Numerous structured programs have been developed for implementing person-centered planning. For instance, the Making Action Plans (MAPs) process is intended to engage students and those most connected to the student's life in planning (Forest & Lusthaus, 1990; York & Vandercook, 1990). Person-centered strategies such as MAPs have been shown to increase engagement levels at IEP meetings, both with students



and parents (Chambers & Childre, 2005). Using a different tool called “True Directions,” Chambers and Childre (2005) prepared families and students for IEP meetings by having them fill out forms that could be used at meetings. They found that families found meetings more comfortable by using the forms and receiving some preparation before the meeting (Chambers & Childre, 2005). Possibly, drawing on person-centered approaches to engage families could help address the systemic participation barriers endemic to the IEP process.

**Funds of knowledge.** Though not focused in terms of disability, the funds of knowledge approach developed over two decades ago and focused on language and culture seems also relevant to possibly enhance parent involvement in the IEP process. Luis Moll developed a *funds of knowledge* approach for understanding the skills and values that Mexican American families living in the Southwestern United States possessed (Moll, 1990; Moll, 1992; Moll & Gonzalez, 1994). Funds of knowledge are defined as “...those historically accumulated and culturally developed bodies of knowledge and skills essential for household or individual functioning and well-being” (Moll & Gonzalez, 1994, p. 443). The rationale behind this approach is that understanding the situated wealth of knowledge that families possess and utilize regularly will lead to a greater appreciation of family knowledge (Esteban-Guitart & Moll, 2014a). Recognition of these funds of knowledge could then lead to more authentic communication between families, schools, and other institutions (Esteban-Guitart & Moll, 2014a; Gregg, Rugg, & Stoneman, 2011; Rios-Aguilar, Kiyama, Gravitt, & Moll, 2011). While conducting focus groups with Latinx parents, Gregg, Rugg, and Stoneman (2011) found that parents of young children showed a great desire to share their stories and knowledge. However, they were given few opportunities to do that with people in their children’s schools. A funds of knowledge approach could provide ways to learn about and acknowledge what parents know and believe. Additionally, it could provide

practical measures, such as example questions to ask parents, to gather key knowledge parents have about their children (Esteban-Guitart & Moll, 2014a, 2014b; Moll & Gonzalez, 1994).

### **Statement of the Problem**

Even with evidence about the pivotal nature of integrating parental knowledge into the IEP process, and legislation and policies that mandate parental collaboration, we still lack research about best ways to engage parents in the process, and especially those from historically disenfranchised racial, ethnic, and economic backgrounds. Additionally, we have a lack of documentation about the range of knowledge, skills, and values parents help provide and see as pivotal for their children. In terms of funds of knowledge, we do not have a clear understanding of what ways parents identify as key to passing along and building life knowledge and skills with their children, nor what meanings they ascribe to their choices. These funds of knowledge could be, for instance, intentional on parents' part or a reliance on what is familiar. They could also be the result of those actions and customs that are habitually sanctioned. Overall, we have little understanding about the meanings and values parents give to what they offer their children to support schooling and success within the IEP process.

Within the process, despite ample documentation revealing the overrepresentation of historically marginalized populations and CLD students in special education programs, such populations continue to be disproportionately referred for special education services (Artiles et al., 2010; Harry & Fenton, 2016). Concomitantly, less is known about the involvement patterns and preferences of historically marginalized populations, possibly making it more difficult to find practical solutions to issues of disproportionality and low parental involvement (Barrera & Liu, 2006; Blanchett, Klingner, & Harry, 2009). Knowledge about historically marginalized populations, CLD students with disabilities and their parents, along with the ways in which they

interact with schools, could be a starting point to enhancing authentic engagement and fostering positive relations.

Parent and school collaborations could also develop from a shared sense of learning; that is, both parental and school personnel knowledge could be exchanged to enhance understandings and supports for youth with disabilities. Part of that call arises from the complexity in the intersections of disability, race, ethnicity, language, and social class (Artiles, 2013, 2015; Artiles et al., 2010; Garcia & Ortiz, 2013). Additional research of a qualitative and descriptive nature could be helpful toward building shared understandings (Harry & Fenton, 2016; Waitoller et al., 2010). Such studies might be used as guides to re-envision schools as inclusive centers of learning, where families—regardless of race, ethnicity, disability, language spoken, or socioeconomic status—could be a part of decision-making processes within a trusting and culturally sensitive environment (Garcia & Guerra, 2006). Moreover, creating such an environment could bring intersectional issues to the forefront of IEP-related engagement efforts.

### **Purpose of the Study**

One major entry point for linkages of parents of youth with disabilities and school personnel could be the IEP process. The law mandates that parents participate in the IEP process, yet research findings indicate that parents often feel overwhelmed, intimidated, and confused by the language used in IEP documents and at meetings (Lo, 2008; Mueller & Buckley, 2014; Rodriguez, Blatz, & Elbaum, 2014a, 2014b). This language barrier becomes internalized within the system—lying in *habitus*, as Bourdieu (1986) would say—often remaining hidden to practitioners (Hess, Molina, & Kozleski, 2006). The hidden nature of these barriers means that they are hard to detect and address. As a result, teachers often do not recognize the skills and assets that parents possess (Cobb, 2013; Underwood, 2010). Concomitantly, while scholars have

recommended a variety of best practices to include parents in the IEP process, there are very few methods available that capture parents' funds of knowledge with respect to the IEP process and their children (Moll, Amanti, Neff, & Gonzalez, 1992; Moll & Gonzalez, 1994, Rios-Aguilar et al., 2011).

The purpose of this study was to investigate how Latinx parents of youth with disabilities perceived their knowledge and its value, and the essence of the meanings they constructed about their children in the IEP process and the roles parents play. Using a phenomenological paradigm, I conducted 21 individual interviews with seven participants to glean the essence of parents' thoughts and perceptions about their lived experiences with the IEP process for their children who have disabilities. This study can contribute knowledge to how parents ascribe meaning to the IEP process, as well as develop a process for understanding the knowledge and assets that Latinx parents can contribute.

### **Research Questions**

The following research questions were developed to guide this study:

1. What is the essence of parents' perspectives about the IEP process and their roles in it?
2. In what ways do parents draw on their knowledge, values, and beliefs to support the overall education of their child?

## **II: REVIEW OF LITERATURE**

To examine participation patterns of urban Latinx parents in the IEP process, I drew upon multiple literatures and empirical works. The historic disenfranchisement of non-White populations in schooling intersects with the history and policies that call for parent participation. These intersections are often nuanced and hidden within school structures (Artiles et al., 2010). Therefore, I analyzed each part of the research phenomenon by identifying key words, phrases, and ideas. Three areas emerged. The first area was research about IEP parent participation expectations from multiple perspectives—that is, from parents and school-based personnel. Secondly, to explore the links between parent participation and engagement for historically disenfranchised groups, I looked at research on the intersectionality of disability, race, language, and social class. Lastly, I explored the policy mandates and research about how parent participation has been defined and implemented. I looked to research about participation and engagement in a community as a core activity linked to being part of a collective, like that which is anticipated in an IEP process. Informed by literature on parent involvement and engagement, as well as the values and cultures of those from historically marginalized populations, I then proposed my own definition for parent participation. In part from examination of these areas of research and challenges, I proposed a conceptual framework that provided a guide to the study design and analyses.

### **Parent Participation in the IEP Process**

To search for literature about parent participation in the IEP process, I used the following key terms and phrases to search literature from 2000 to the present: parent participation/involvement/engagement, special education, and IEP (both abbreviated and spelled out as “individualized education plan”). I found two syntheses of empirical works. Additionally,

I found five empirical studies that were not reviewed in the syntheses. Overall, the following themes emerged: (1) overuse of specialized and/or jargoned language, (2) insensitivity to cultural and linguistic differences, and (3) parent intimidation and confusion related to the IEP process. After reviewing the syntheses of empirical studies and highlighting the emergent themes, I discuss each theme and any disconfirming ideas along with and how it is supported by other empirical studies.

**Syntheses.** Sixteen different studies were reviewed in total in the two syntheses. Three studies were reviewed in both of the syntheses. The two syntheses were reviewed in the order of the most recent study published (Wolfe & Duran, 2013). The studies under review do not always make a distinction between IEP meetings and the IEP process. As recommended by experts in the field, I describe the methodologies and procedures for each study in order to ascertain what is actually being studied, using the language of the authors in order to provide accurate descriptions of the findings (Galvan & Galvan, 2017). Many of these studies, such as Fish's (2008) survey study of 51 parents of children with disabilities, were primarily concerned with parents' perspectives on IEP meetings. Other studies, such as Montelongo's (2015) interview study of 5 Latinx parents, focused on "the IEP process". The IEP process generally refers to the ongoing attempts made by schools to support children with disabilities in their classes. In the literature, these attempts usually include: referring students for special education services, scheduling meetings with family members and school personnel, communicating services and notices for IEP meetings in a language comprehensible to families, providing a copy of the procedural safeguards in place to protect students and their families, and collecting information on students' academic and social/emotional levels of performance (Wolfe & Duran, 2013).

In the first synthesis, Wolfe and Duran (2013) reviewed nine studies on CLD parents' perceptions of their roles in the IEP process. All of the studies were from the United States and included the perceptions CLD populations held about the IEP process. Four of the studies focused on Latinx parents' views (Hardin, Mereoiu, Hung, & Roach-Scott, 2009; Hughes, Valle-Riestra, & Arguelles, 2002; Lian & Fontanez-Phelan, 2001; Salas, 2004), three were on Korean Americans' experiences (Cho & Gannotti, 2005; Park & Turnbull, 2001; Park, Turnbull, & Park, 2001), one study focused on Chinese-American parents' perceptions (Lo, 2008), and one study included White, Latinx, and African-American parents (Hernandez, Harry, Newman, & Cameto, 2008). Six of the studies used qualitative-only designs, two used survey designs, and one used a mixed-methods approach. A summary of the methodologies used, demographics of participants, and common themes identified are included below (Table I).

Wolfe and Duran (2013) identified five themes from the 13 studies they reviewed: (1) language and/or communication barriers, (2) insufficient information, (3) cultural barriers, (4) lack of respect for the parent, and (5) perceived negativity toward child. Of the five identified themes, language and/or communication barriers was most prevalent across studies, being found, to some degree, in 8/9 of the studies. Two of the studies (Cho & Gannotti, 2005; Park et al., 2001), for instance, found that parents were dissatisfied with the service of the provided interpreter at IEP meetings and felt less able to participate in discussions about their children. One part of the language/communication theme, found in 6/9 studies, was use of jargon and acronyms by educational professionals in IEP meetings that was confusing and an added challenge for non-native English speakers.

Table I

*Study Characteristics and Themes Identified (1)*

Study	Population	Method	Common Themes Identified				
			Disrespect	Negativity towards child	Lack of information	Language & communication	Cultural barriers
Cho & Gannotti (2005)	Korean American	Interview	X	X	X	X	X
Hardin et al. (2009)	Latino	Focus Groups			X	X	X
Hernandez et al. (2008)	African American, Latino, White	Survey	-	-	-	-	-
Hughes et al. (2002)	Latino	Questionnaire (interview n=17)			X	X	
Lian & Fontanez-Phelan (2001)	Latino	Survey				X	
Lo (2008)	Korean American	Observation & interview	X	X	X	X	X
Park & Turnbull (2001)	Korean American	Telephone interviews		X	X	X	X
Park, Turnbull, & Park (2001)	Korean American	Telephone interviews	X	X	X	X	X
Salas (2004)	Latino	Interview	X	X	X	X	X

*Note.* Adapted from “Culturally and linguistically diverse parents’ perceptions of the IEP process: A review of current research,” by K. Wolf and L. Duran, 2013, *Multiple Voices for Ethnically Diverse Exceptional Learners*, 13(2), pp.7-8.



***Language and/or communication barriers.*** Language and communication barriers were found in 8/9 of the studies reviewed. The phrase “language barrier” referred to situations in which limited English proficiency was a hindrance to effective communication between parents and school personnel. A “communication barrier,” on the other hand, was in reference to the overuse of technical or jargoned language, which hindered communication. While in some instances parents were provided interpreters (Cho & Gannotti, 2005; Lo, 2008), in others parents were not (Park, Turnbull, & Park, 2001). However, experiences with interpreters varied widely, and parents were sometimes dissatisfied with the communication skills of interpreters (Cho & Gannotti, 2005). Parents in six studies spoke to the jargoned and technical language in IEP meetings as confusing and a hindrance to communication. Parents expressed at times being overwhelmed and found it to be a significant barrier to participation (Park & Turnbull, 2001; Salas, 2004).

***Insufficient information.*** Parents often felt unprepared for IEP meetings because they were unfamiliar with the structure and processes imbedded in meetings and had little knowledge of how the special education system operated. For instance, Cho and Gannotti (2005) found that even after several Korean-American parents attended trainings on IEP meetings they still were unable to effectively participate at meetings. Wolfe and Duran (2013) opined that this could be due to cultural differences between educational personnel and CLD parents.

***Cultural barriers.*** Parents in five of the studies reviewed noted cultural differences as a significant barrier to meaningful participation in IEP meetings. Wolfe and Duran (2013) defined cultural differences as “challenges that were attributed to differences between parents and professionals with regard to worldview, beliefs and/or traditions” (p. 11).

***Lack of respect for the parent.*** Parents in four of the studies perceived school personnel at IEP meetings as disrespectful to them or their children (Cho & Gannotti, 2005; Lo, 2008; Park & Turnbull, 2001; Salas, 2004). A repeated concern among these parents was the devaluing of parental knowledge and expertise. Parents felt that what they had to say was not recognized as meaningful by school personnel. In three of the studies (Cho & Gannotti, 2005; Park et al., 2001; Salas, 2004), parents linked this perception of disrespect with a devaluing or inability to recognize their cultural differences.

***Perceived negativity toward child.*** Parents in three of the studies experienced professional's opinions as being negative toward their children. Parents felt educational personnel focused too heavily on their children's deficits and too little on their strengths (Cho & Gannotti, 2005; Salas, 2004).

Wolfe and Duran (2013) found that the experiences of CLD parents with the IEP process has not significantly changed since the 1980s. While most studies on IEP participation report negative experiences of parents across racial, social class, and language categories (Hernandez, Harry, Newman, & Cameto, 2008; Zeitlin & Curcic, 2014), they point to Fish's (2008) finding that White parents from higher-income brackets have mostly positive experiences with IEPs as evidence that there are differences in parents' perceptions based on race and language. The authors state the identified themes are most likely due to a variety of intersecting factors related to race, class, and language. As has been found in other studies, these intersections could lead to negative attributions of CLD populations (Donovan & Cross, 2002; Harry, Klingner, & Hart, 2005). Wolfe and Duran (2013) conclude that the small number of studies identified reveals the need for further research on the perceptions of CLD parents about the IEP process.

In another synthesis for the Center for Appropriate Dispute Resolution in Special Education (CADRE), Reiman, Beck, Coppola, and Engiles (2010) reviewed ten studies from 2004-2010 that focused on the experiences of parents or primary caregivers with the IEP process (Table II). Much like Wolfe and Duran (2013), they found that parents overwhelmingly had negative perceptions of the IEP process. However, unlike Wolfe and Duran (2013), the purpose of the review by Reiman et al. (2010) was to highlight recommendations to improve parent participation throughout the IEP process. Out of the ten studies, Fish's (2008) oft-cited survey of mostly middle to upper-middle class White parents was an outlier, in that most parents perceived their experiences with IEP meetings to be positive. This is contrary to an earlier study with seven parents of children with autism by Fish (2006). In that study, all seven parents reported having negative experiences with the IEP process, stating that the IEP process was intimidating and not very inviting. In his limitations to the study, Fish (2006) stated that the consistent negative attributions across participants could be a result of parents all having children with autism. Lo (2008), on the other hand, interviewed five Chinese-American parents of children with a variety of disabilities and found that, while they mostly had negative experiences with the IEP process, their critiques were more varied. For instance, one father reported that he always took notes of things he would want to state at meetings, while the 4 other parents stated that IEP meetings were mainly for teachers and other educational professionals. This was similar to other studies reviewed where it was found that professionals had already made up their minds about various aspects of a child's IEP before the meeting actually occurred (Childre & Chambers, 2005; Fish, 2006).

Table II

*Study Characteristics and Themes Identified (2)*

<b>Study</b>	<b>Population</b>	<b>Sample Size</b>	<b>Method</b>	<b>Common Themes Identified</b>
Children & Chambers (2005)	3 African American & 3 White families	6 families	Interview	Passive participation, cultural differences
Cho & Gannotti (2005)	Korean American mothers	20	Interview	Cultural differences, language barriers, technical language
Esquivel, Ryan, & Bonner (2008)	N/A	18	Survey, Interview	Importance of relationships, communication differences
Fish (2006)	N/A	7	Interview	Poor treatment, intimidating
Fish (2008)	80% White	51	Survey	Positive experiences, feeling valued
Lo (2008)	Chinese American	5	Observation, Interview	Cultural barriers, language barriers, confusion
Lo (2009)	Chinese American	2 families	Observation, Interview	Cultural barriers, language barriers
Salas (2004)	Mexican American mothers	10	Interview	Cultural barriers, language barriers, overwhelming/intimidating
Simon (2006)	Teachers: 53% African American, 36% White, 4% Latinx, 1% Asian American  Parents: 40% African American, 27% Latinx, 21% White, 2% Asian American	241 (98 teachers & 143 parents)	Questionnaire	Communication barriers, lack of knowledge
Stoner et al. (2005)	N/A	8 (4 married couples)	Interview	Confusion, dissatisfaction with IEP meetings

*Note.* Adapted from “Parents’ experiences with the IEP process: Considerations for improving practice” by Reiman, J.W., Beck, L., Coppala, T., and Engiles, A., 2010, *Center for Appropriate Dispute Resolution in Special Education (CADRE)*.

Based on their review of empirical literature, Reiman et al. (2010) listed several recommendations for educators and parents to increase engagement in the IEP process. For schools and educators, based on recommendations from Esquivel, Ryan, and Bonner (2008), it is important to share knowledge of students' strengths and avoid only discussing weaknesses related to their disabilities. This sharing of knowledge can help to define a student as an individual with a unique set of skills, knowledge, and personality traits. Based on Fish's (2006) findings from asking parents how IEP meetings could be improved, it is recommended that meetings become more democratic so that parents feel like they are key stakeholders in their children's education. Lastly, based on a questionnaire administered to 98 teachers and 143 parents about their perceptions of IEP requirements (Simon, 2006), it is recommended that teachers provide parents with forms before meetings to help them think about possible issues to be discussed at IEP meetings. Recommendations for parents include becoming more educated on special education laws, the logistics of IEP meetings, and being persistent in stating their perspectives on what services their children should receive (Fish, 2006). For CLD parents, it is recommended that parents who have limited abilities to communicate in English should meet with translators before IEP meetings (Lo, 2008) and request that educators and translators speak clearly and allow appropriate time for information to be translated and then comprehended by parents (Cho & Gannoti, 2005).

Although not a synthesis of the literature, Pang (2011) sought to abstract the barriers to involvement of CLD families in the IEP process. Similar to Wolfe and Duran's (2013) synthesis of the literature, it was found that language and culture were primary barriers. CLD parents frequently have different views on their roles than parents from a dominant White middle-class, and will often defer to the role of experts (Lo, 2008, 2009). This deferment prevents CLD

parents from engaging in meetings and asking questions that might challenge the prevailing viewpoints of IEP team members. Pang (2011) recommends pairing CLD families with interpreters and advocates that have similar backgrounds so that cultural nuances are understood and not minimized or ignored. For instance, Wang, McCart, and Turnbull (2007) found that many Chinese-American families believe disability to be something that brings shame to a whole family. Having this knowledge could be instructive for how educators should discuss disability with families. Other recommendations include making IEP meetings more accessible in terms of language and topics to be discussed, providing training opportunities for CLD families so that they understand the IEP process, and Harry's (2008) suggestion that teachers become better acquainted with the cultures of the families with whom they work.

Despite recognition of the barriers to parent participation in the IEP process (Lo, 2008, 2009; Pang, 2011; Underwood, 2010), there is still a dearth of empirical studies specifically examining parents' experiences with the IEP process. Beginning with the passage of the initial IDEA in 1975, researchers started investigating parent participation at IEP meetings (Cho & Ganotti, 2005). Most of the early studies used surveys and questionnaires (Gilliam & Coleman, 1981; Lynch and Stein, 1982; Gerber, Banbury, Miller, & Griffin, 1986), or observations of parents at IEP meetings (Goldstein, Strickland, Turnbull, & Curry, 1980; Vaughn, Bos, Harrell, & Lasky, 1988). The general consensus in these original works were that the field of special education was failing to live up to the promise of including parents that was stipulated in the initial passage of IDEA (1975). Numerous barriers to parent participation in IEP meetings were identified and possible solutions recommended (Lynch & Stein, 1987; Benson & Turnbull, 1986). Then, in a seminal position piece, Harry (1992b) argued for new roles for parents to shift the power balance from educational professionals to more parity between schools and families.

Although specifically directed toward African American parents, Harry (1992b) addressed the power imbalances present for all parents and provided a rationale for future studies on parent involvement in the fields of special education and disability studies.

**Themes.** Overall, the major themes of specialized and/or jargoned language, insensitivity to cultural and linguistic differences, and intimidation and confusion by the IEP process emerged from sixteen studies reviewed across the two syntheses. While Wolfe and Duran (2013) included the general location of where studies took place (e.g., state or geographic region), neither synthesis reported if the participants in the studies reviewed were from urban areas. Knowing this would allow for a more meaningful consideration of how geographic contexts may intersect with race, language, social class, and disability. I now will examine each theme to create a robust mosaic about parent participation in the IEP process.

**Specialized and/or jargoned language.** The specialized and jargoned language endemic to IEP documents, as well as the language professionals use to discuss IEP-related matters, hinder meaningful parent participation. Harry (1992b) has pointed to the technical language and many acronyms used in special education as reductionistic in nature, in that these are terms regularly used across meetings and not tailored to the specific language styles of parents. Jargon, it is reasoned, is often used to exclude and not include (Dabkowski, 2004; Kalyanpur & Harry, 1999). Analyzing barriers to parental involvement from a structuralist framework, Goss (2017) found the use of jargon to be indicative of a presumption that parents were familiar with the technicalities of special education. This presumption then becomes internalized within the structures of school systems, often leading to negative perceptions of parents who are not educated in the intricate details of special education processes (Goss, 2017). This highly specialized language and form of communication can be especially confusing to CLD families

whose first language is not English (Harry, 1992a; Pappas, 1997). These misunderstandings may convey certain communication patterns that hinder participation of parents and reduce the amount of crosstalk throughout the IEP process (Salas, 2004). In a study with ten Mexican American mothers, Salas (2004) found that participants were regularly confused by the language in meetings and avoided speaking up out of fear that they would be deemed uneducated or ignorant. In this context, the jargon used by educational personnel was exclusive and intimidating.

The confusion arising from technical language is not only confusing to CLD parents, however. Zeitlin & Curcic (2014) conducted semi-structured interviews with twenty parents in order to capture their perceptions of IEPs as a product and process. Most of the families were White and from middle-class backgrounds. The rationale for using an interview approach was that a review of literature found that parents often reported the IEP process as a more positive experience on surveys and questionnaires (Esquivel, Ryan, and Bonner 2008; Fish 2006, 2008; Reiman et al. 2010; Salas 2004). The authors thus sought to offer more nuanced explanations of parents' experiences with the IEP process. Parents experienced the IEP as a process of depersonalization—that is, they felt that they had little say in decision-making processes and the whole meeting (e.g., the agenda, asking questions to team members) was a formality. Parents felt that IEP meetings were something that educators do regularly as part of their jobs and often with little energy or passion. Parents also experienced IEP meetings as emotionally intense and often felt put on the spot. A large part of this depersonalization was the language that professionals used to discuss IEPs with parents. Parents reported not being able to understand the jargon and layout in IEPs. This despite many of the parents in this study being highly educated, with one mother a veteran elementary school teacher of 15 years. Parents by-and-large saw the IEP



documents as formulaic and confusing, and therefore reported never referring to them after the meetings.

**Insensitivity to cultural and linguistic differences.** The structures and communication patterns used by professionals at schools is derived from educative and pedagogical beliefs inherent to a White middle-class (Goss, 2017; Harry, 1992; Salas, 2004). These beliefs juxtapose with the values and cultural traditions of many CLD families, often producing exclusionary and demeaning practices. In a study gauging the perceptions of four African American parents on the special education system, Williams (2007) found that parents saw special education as a “tool to control kids that the teachers do not want to invest additional time in” (p. 252). Similarly, the structurally embedded practices of school personnel when interacting with parents around the IEP process send the message to parents who come from diverse racial, ethnic, or economic backgrounds that their opinions do not matter (Kalyanpur & Harry, 1999).

Cho and Gannotti (2005) interviewed 20 Korean-American mothers of children with disabilities on their perceptions of special education services offered by the schools where their children attended. Specific questions regarding their interactions with educators and translators at IEP meetings were included. Parents reported often being confused, concerned that their translators were not conveying their questions and responses, and potential cultural misunderstandings. All of the mothers reported feeling marginalized and disenfranchised to varying degrees due to their limited English proficiency and paucity of knowledge about special education law and services. The authors recommend better training for translators in schools and cognizance of the “culture clash” CLD parents could experience in meetings, which, they contend, causes a “heightened level of stress” for parents (Cho & Gannotti, 2005, p. 8).

Montelongo (2015) interviewed 5 Latinx parents about their perceptions of IEP meetings using 18 open-ended questions. Many of the parents interviewed described their experiences at IEP meetings as a “*lucha* or fight” (Montelongo, 2015, p. 125). They attributed this attitude to lack of understanding about parents’ home language and culture. Parents also reported that teachers were surprised when they did fight back, something they thought might be due to preconceived notions about their culture. The author argues that educators and translators need further education in cultural and linguistic sensitivity, seeing this as a stepping stone to increasing parent engagement at IEP meetings.

In an earlier study, Salas (2004) interviewed 10 Mexican American mothers about their experiences at IEP meetings. Two of the major themes discovered during analysis were language alienation and a lack of respect for mothers’ situations. All of the participants reported that they did not feel heard at meetings due to their limited proficiency in English. Despite desiring to participate more in IEP meetings, Salas (2004) contends that their voices were silenced in overt and covert ways throughout the IEP process. The formality of the IEP process—notice of conferences sent home, parents asked pre-determined questions at meetings—left mothers feeling like educators did not care to get to know them. This led to the mothers feeling both frustrated, for not being able to voice their concerns, and embarrassed, for not knowing more about special education laws and not having the English skills to challenge team members without the aid of a translator.

**Intimidation and confusion by the IEP process.** The language used in meetings and the presumption that parents are educated in the technicalities of special education processes ultimately leads to parents feeling intimidated and confused by the IEP process (Goss, 2017). Parents from historically disadvantaged communities tend to be particularly sensitive to the

perceived authority roles of teachers and other educational professionals (Harry, Kalyanpur, & Day, 1999). Salas (2004) found that Mexican American mothers held the cultural belief that teachers should be respected and listened to. This respect for authority figures can lead to parents feeling intimidated in the IEP process and often translates to parents not sharing information with schools (Jung, 2011; Salas, 2004). The effect of withholding information in the IEP process then places a further strain on collaborative events with educational personnel (Jung, 2011).

In an interview study with six families, Childre and Chambers (2005) found that parents often felt alienated at IEP meetings. One parent, when discussing parental roles in IEP meetings, stated: “My ideas were not accepted, were valueless” (p. 224, Childre & Chambers, 2005). Parents in this study often found themselves confused by the technical language used in the IEP process, the specialized and formulaic way in which meetings were run, and would passively accept this circumstance as normal. This normalization of ineffective collaboration techniques can lead to deeply embedded practices within school structures (Goss, 2017; Kalyanpur, Harry, & Skrtic, 2000).

In other instances, intimidation arises from accusations made by IEP team members against parents. Fish (2006) found that most of the seven participants interviewed had, at some point, felt hostility from other members of the IEP team. This hostility was often the result of someone on the IEP team finding a parent’s suggestion for more services unreasonable and impractical. Rather than collaborate with parents and come to a compromise, educational professionals would accuse parents of not understanding the limitations of school services. It was also found that teachers would not empathize with some of the behavioral issues that may be a manifestation of a disability. When parents expressed their opinion that a certain consequence was too extreme or unwarranted they were quickly silenced and, either overtly or covertly, told

that they did not understand the role of teachers as disciplinarians. Parents would often capitulate to these accusations out of fear of having further punishments inflicted on their children.

**Exceptions.** While most of the extant literature revealed that parents often had negative experiences and perceptions of the IEP process, there were notable exceptions. For example, Hughes, Valle-Riestra, and Arguelles (2002) interviewed 16 Latino families and conducted questionnaires with 44 Latino families on their experiences and perceptions of their children's special education program. They found that the participants were overall satisfied with their children's special education program, as well as their involvement in their children's schooling. It was also found, however, that some families wanted more information about their children's classes and were sometimes frustrated with the communication methods of school personnel, with parents' limited proficiency in English being the main factor (Hughes et al., 2002).

In another exception, Fish (2008) surveyed 51 parents of students in special education programs from one family support agency about their perceptions of the IEP process. The demographics of the sample were as follows: 80% White, 6% Black, and 12% Hispanic, with 43% of parents considered middle to upper-middle income and 16% low-income. Most parents interviewed reported having positive experiences with IEP meetings. Seventy-eight percent of parents felt they were treated with respect and were considered primary decision-makers. This ran contrary to previous research that showed parents felt alienated because educators were perceived as the primary decision-makers (Cho & Gannotti, 2005; Fish, 2006; Turnbull & Turnbull, 1997; Vaughn et al., 1988). Fish (2008) stated that the positive attributions parents made about IEP meetings could have been due to the effectiveness of the family support agency where participants were recruited.

Rodriguez, Blatz, and Elbaum (2014a) used individual and focus group interviews to investigate the perceptions of 96 parents of children with disabilities on schools' efforts to engage families. The quantitative component came in the form of quantifying the occurrence of codes as a priori indicators of their importance. Of the 91 parents, 55% indicated they were White, 24% were Latino, 17% were Black, 3% were multiracial, and the remaining 9% indicated unknown. The parents' socio-economic status was not reported. Parents overall were more concerned with their children being successful and not in whether or not schools were adequately involving them. The authors state that this could be because "[p]arents who perceive that schools are doing a good job of providing services may not feel the need to interact as frequently with teachers as those perceive their children are not receiving needed supports" (Rodriguez, Blatz, & Elbaum, 2014a, p. 91). Based on the findings from their study, the authors suggest that schools that provide significant supports to children with disabilities may not need to increase engagement efforts with parents as much as schools that are under-resourced and have poorly managed special education programs.

Underwood (2010) sought to differentiate "involvement" from "engagement." She interviewed 31 parents to determine what involvement and engagement efforts schools were making according to the perspectives of parents. Demographic information for participants was absent. This makes it difficult to compare to other studies that examine similar phenomena. There was an additional questionnaire administered to parents' about their participation and satisfaction with their children's programming. Underwood (2010) concluded that engagement is a more active and central role than involvement for parents. Engaging parents goes beyond a simple invitation to a meeting, a characteristic that the author applies to involvement. Underwood (2010) challenges schools to deeply connect with parents and use their voices as

nascent guides to render services and design interventions. Similar to Rodriguez, Blatz, and Elbaum (2014a), findings from this study suggest that parents are more concerned than just attending a meeting or two. They are concerned that their children are placed in an appropriate program and doing well in their studies. Underwood (2010) concludes that while parents might not be very engaged in the IEP process, they are deeply concerned with their child's education. This finding, from the perspective of the parents in this study, was of greater importance.

In summary, research on parents' perceptions of and experiences with the IEP process varied greatly in terms of method, findings, and conclusions. For example, Fish's (2008) survey study that showed parents were generally satisfied with IEP meetings stands as an outlier. Harry (2008) suggested that surveys are capable of capturing the breadth of participant perspectives, but do not provide the depth needed to understand why certain responses were chosen. Findings from semi-structured and open-ended interview approaches allow researchers greater latitude in conducting in-depth and nuanced investigations into the subjective experiences of participants (Zeitlin & Curcic, 2014). This literature review corroborates those findings (e.g., Cho & Gannotti, 2005; Fish, 2006; Montelongo, 2015; Salas, 2008; Zeitlin & Curcic, 2014). Additionally, studies where participants were a majority White and middle-class (Fish, 2008; Rodriguez, Blatz, & Elbaum, 2014a) or no demographic information was given (Underwood, 2010) differ greatly from studies including mostly CLD participants. This finding is corroborated by other studies that showed CLD parents generally experienced the special education system as negative and deficit-oriented (Harry, Klingner, & Hart, 2005; Lo, 2008). Also, though not as well-documented, there is evidence that socioeconomic status (SES) greatly influences the engagement levels of parents at IEP meetings (Lalvani, 2012). Jones and Gansle (2010) did an experimental investigation of conducting a mini pre-conference with parents before IEP

meetings. They found that parents with higher SES participated more regularly in IEP meetings regardless of if they were in the pre-conference experimental group or control group. The authors reason that this could have been because parents from higher SES backgrounds might be more familiar with the technical language used in IEP meetings. Moreover, parents from economically disadvantaged backgrounds might be lacking the dominant cultural vocabularies needed to meaningfully participate in IEP meetings (Artiles et al., 2010). More research will be needed to fully comprehend the ways in which social class may hinder a parent's ability to participate in the IEP process. Understanding this could then lead to programs that are designed to be more inclusively engaging.

### **Parental Participation and Intersection of Disability, Race, Language, and Class**

A disproportionate amount of individuals diagnosed with a disability, and the families that they belong to, come from non-White culturally and linguistically diverse backgrounds (Artiles, Kozleski, Trent, Osher, & Ortiz, 2010; Ferri & Connor, 2005a; Harry & Fenton, 2016). Harry and Fenton (2016), in a review of fifteen studies that examined factors leading to the disproportionate placement of minorities into special education, found that disproportionality was a complex phenomenon. It requires an examination of issues related to disability, race, language, and class at the school and societal levels. The discourses around race and disability have been historically predicated on deeply ingrained beliefs about superiority/inferiority (Blanchett, Klingner, & Harry, 2009). Emerging in part from that are discursive arguments for continued segregation of certain groups based on race, socioeconomic status, and language (Ferri & Connor, 2005b). Special education programs seem to continue with this model of segregation by targeting what students are assessed and placed into special education. Artiles et al. (2010) traced the development of special education from 1968-2008 and found that deficit views of

historically marginalized groups continue to exist. They linked this to a discourse centering on “color-blind research” and poverty as the singular cause for disproportionate representation (Artiles et al, 2010; O’Connor & Fernandez, 2006). These inconsistencies, historical injustices, and simplifications of complex issues have motivated counter-narratives that have been distilled into ideas about the intersections of disability, race, ethnicity, language, and class (Garcia & Ortiz, 2013).

Emerging from narratives and counter-narratives is a new intersectional lens (Crenshaw, 1991). Intersectionality has been increasingly used to situate disability within racial, ethnic, linguistic, and socioeconomic contexts (García & Dominguez, 1997; García & Guerra, 2006; Ortiz & Yates, 2008). Although no agreed-upon definition exists, intersectionality is often seen as “...a critical lens [that draws] attention to marginalized or oppressed groups ... [in order] to explicate the complexities of experiencing discrimination on the basis of two or more markers of identity and difference” (Garcia & Ortiz, 2013, p. 33-34). It is a particularly robust lens when looking at the complexities of families of children with disabilities, since disproportionate amounts of these families are from CLD and low-income communities (Artiles et al., 2010). Critical race theorists often use the lens of intersectionality to understand the ways in which people experience discrimination based on two or more markers of identity and difference (e.g., race, disability, gender, or social class; Garcia & Ortiz, 2013). Moreover, researchers such as Garcia and Ortiz (2013) contend that this is a particularly appropriate lens for the field of special education since children from CLD and low-income communities are more likely to be diagnosed with a disability during their schooling (Harry, 2002, 2008; Harry & Fenton, 2016).

A key aspect of an intersectional lens is linking inequities at the societal level, where discriminatory structures are reinforced based on identity and difference (Ferri & Connor, 2005a,



2005b). In terms of CLD families, several factors have enormous impacts on their ability to interact with personnel in special education programs in schools (Harry, 2008; Harry & Fenton, 2016). Families that belong to CLD and low-income communities are more likely to drop out of high school, experience unemployment, become incarcerated, and die prematurely (Ferrera, 2015). They are also less likely to be involved with activities at schools and more likely to see school as an intimidating and judgmental place (Ferrera, 2015).

The implicit racial, ethnic, and class-based biases embedded within school structures has also been found to negatively impact CLD and low-income families (Harry, 2002; Harry & Fenton, 2016). Skiba, Simmons, Ritter, Kohler, Henderson, and Wu (2006) conducted 64 interviews with school practitioners, including special and general education teachers, principals, and psychologists. They found that poverty stood out as the greatest variable affecting the disproportionate placement of CLD students into special education classrooms. Practitioners mentioned high-stakes testing and misunderstandings about students of color as issues contributing to this disproportionate placement (Skiba et al., 2006). These structural constraints, in tandem with a lack of multicultural understanding, have real-world consequences, which contribute to the overrepresentation of African-American male students in special education (Harry, 1992a, 1992b, 1992c, 2002). Other studies have shown similar perspectives among practitioners. For example, Shippen, Curtis, and Miller (2009) conducted separate focus groups with general education teachers, special education teachers, and counselors. Similarly to Skiba et al. (2006), they found that educational professionals most often blamed disproportionate placement on poverty and the education levels of parents.

Other studies of school personnel's perspectives have also found that poverty was one of the main factors in explaining disproportionate placement of students of color in schools (Hardin

et al., 2009; Kearns, Ford, & Linney, 2005). There might be an impulse, moreover, to list poverty as the primary mediating factor in explaining disproportionality and inequitable treatment of CLD families. However, this ignores the possibility that practitioners might be reluctant to list race, ethnicity, or language as possible factors (Harry & Fenton, 2016). Doing so might leave them vulnerable to charges of racism or prejudice, which are generally perspectives that practitioners in education try to separate themselves from. While a case can be made that class is the primary factor causing inequity—in fact it has been made for centuries (see Marx & Engels, 1848/1992)—in doing so, the deep intersections of disability, race, ethnicity, and language are minimized. It is only through an intersectional framework that the complexities of phenomena become manifest to a degree in which language can then become a mediating force to explain them.

Overall, research findings are lacking on the analysis of intersectionality of race, ethnicity, class, language, and disability. Harry and Fenton (2016) were only able to identify 15 qualitative studies that examined the overrepresentation of CLD students in special education. Similarly, Waitoller, Artiles, and Cheney (2010) were only able to identify 42 studies that explored this phenomenon, with only 5 being qualitative. Harry and Fenton's (2016) call for more qualitative studies is important to consider because few studies have gone beyond descriptions of beliefs about disproportionality or who makes decision about special education placement—that is, teachers or families. This paucity of studies looking at other variables—such as new approaches to engaging individuals from historically marginalized communities—greatly limits researchers' abilities to provide a rounded picture of intersectional issues.

**Strategies for working with historically marginalized communities.** When working with CLD and low-income families, researchers must be reflexive in their subjective

understandings of culture and socioeconomics (Garcia & Ortiz, 2013). The language and context of families are inextricably related and must be carefully understood before engagement with families begins (Artiles et al., 2010; Harry, Kalyanpur, & Day, 1999). Additionally, the context of the school and/or community organization in which research takes place must be thoroughly examined to identify potential conflicts between research agendas and the cultural understandings of families (Garcia & Guerra, 2006; Garcia & Ortiz, 2013; Harry, 2008; Trainor, 2010a, 2010b, 2010c). It may be important for researchers to re-conceptualize schools as interactive spaces for the learning of students and centers of communications for families (Garcia & Guerra, 2006). By doing so, researchers can ensure a posture of cultural reciprocity with families and schools, whereby judgments are held in suspension and beliefs, values, and attitudes are reflexively examined (Harry, Kalyanpur, & Day, 1999).

Harry (1992a, 1992b, 1992c, 2002) has pointed to the importance of trust and cultural sensitivity that schools must foster for school-related partnerships with CLD families. Families, in general, want to be involved in their family members' education but are sensitive to the underlying cultural perceptions that schools may hold (Rodriguez, Blatz, & Elbaum, 2014a). CLD parents, particularly, have been shown to request more guidance from schools in their children's education (Gould, 2011), yet, ironically, are often less likely to receive such guidance (Kalyanpur & Harry, 2012). Researchers, therefore, have recommended additional trainings for parents to ensure they are aware of their rights and familiar with school policies (Trainor, 2010a). There is also an ongoing request for more research into the intersections of disability, race, ethnicity, language, and class (Artiles, 2013, 2015; Artiles et al., 2010; Garcia & Ortiz, 2013), with some calling on more qualitative studies, specifically (Harry & Fenton, 2016; Waitoller et al., 2010). Such studies could be used as guideposts to re-envision schools as

inclusive centers of learning, where families—regardless of race, ethnicity, language spoken, or socioeconomic status—are able to be a part of decision-making processes within a trusting and culturally sensitive environment (Garcia & Guerra, 2006). Moreover, creating such an environment could bring intersectional issues to the forefront of addressing the lack of engagement of disenfranchised families.

### **Parental Participation, Involvement, and Engagement**

The terms participation, involvement, and engagement are at times used interchangeably in the literature. At other times stark differences are noted between the terms (e.g., Underwood, 2010). IDEA (2004) requires that “[e]ach public agency must take steps to ensure that one or both of the parents of a child with a disability are present at each IEP Team meeting or are afforded the opportunity to participate” (§300.322). Although not defined in IDEA (2004), the term “participation” has been defined as “participation in all aspects of decision making for students receiving special education” (p. 474, Lalvani, 2012). In this section, I compare and contrast the terms participation, involvement, and engagement before offering an operational definition of participation.

**Participation.** Participation is often used broadly in research literature. The Oxford Dictionary defines participation as follows: “The action of taking part in something” (Oxford Online Dictionary). In education, participation often refers to students, families, and communities taking part in school-related activities (Pushor, 2007; Pushor & Murphy, 2004). The adjective *active* is often used to modify the noun *participation* in order to show a higher degree of participation (Pushor, 2007). In terms of special education, participation is important because it is the phrase used in IDEA (2004) to describe the way schools and parents should collaborate in IEP meetings (Burke et al., 2016; Trainor, 2010a).

**Involvement.** The Oxford Dictionary defines involvement as “The fact or condition of being involved with or participating in something” (Oxford Online Dictionary). Involvement refers to any number of interactions that may exist between parents and schools (Underwood, 2010). Epstein’s framework for parental involvement is the most widely cited (Connors & Epstein, 1995; Epstein, 1987; Epstein, 2001; Epstein, Salinas, & Jackson, 1995; Epstein & Sanders, 2002). Three different types of involvement strategies are identified: school-based, home-based, and community-based (Epstein & Sanders, 2002), which are closely aligned to the concept of *spheres of influence* (Epstein, 2001). Epstein (2001) lists six different types of involvement: parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community. Involvement usually comes in the form of one-way communication: phone calls, letters sent home, mass emails, and invitations to volunteer for school-related events and activities (Ferlazzo, 2011). Ferlazzo (2011) quotes one of the dictionary definitions of involvement to highlight its denotation: “to enfold or envelope” (p. 12).

**Engagement.** Engagement is defined as “the establishment of a meaningful contact or connection” by the Oxford Dictionary (Oxford Online Dictionary). Researchers focus on the term “meaningful” as a key characteristic that distinguishes “engagement” from “involvement” (Underwood, 2010). Underwood (2010) defined the distinction:

Parent engagement is characterized as being qualitatively different from involvement because it requires relationship building, understanding of experiences on the part of both parents and teachers, and opportunities for parents to have their voices heard in relation to the teaching and learning activities of schools, rather than as fundraisers or in special events. (p. 19)

In order to be engaged, one must be actively attending and listening to an interlocutor and be able to manifest responses that show comprehension of the content being presented (Ferlazzo, 2011).

Dewey's notion of democracy and education, and his use of the term "engagement" within that, is noteworthy here. Although Dewey did not provide an operational definition of the term, others have pointed to his work when discussing the need for an engaged citizenry (Giroux & McLaren, 1986; Hildreth, 2012; McCoy & Scully, 2002). Dewey believed that a true democracy uses public discourse—at the local, state, and federal levels—to resolve conflicting interests (Dewey, 1935). These interests should be brought out into the open where special claims can be discussed and evaluated in "...light of more inclusive interests than are represented by either of them separately" (p. 56). Dewey thought that experience signified an active engagement with the world in which humans live (Dewey, 1938). Engagement, therefore, is inextricably linked with experience.

For this study about parental participation in the IEP process, I adopted the term "participation" and defined it with the depth needed to identify when it was happening, and the breadth necessary to contextualize it within the unique lifeworlds of parents. The use of a narrower definition helped avoid the pitfalls of purposefully broad or vague definitions by mitigating any ambiguities and clearly delineating what participation was and what it was not. I used a modified version of Underwood's (2010) and Ferlazzo's (2011) definitions, integrated with notions of democracy and experience (Dewey, 1916, 1938) and a posture of cultural reciprocity (Harry, Kalyanpur, & Day, 1999), to define participation. The latter two ideas were chosen because of their *a priori* intersects with the concept of participation. This integrative

definition helped ground the way in which interactions in this study were seen and interpreted.

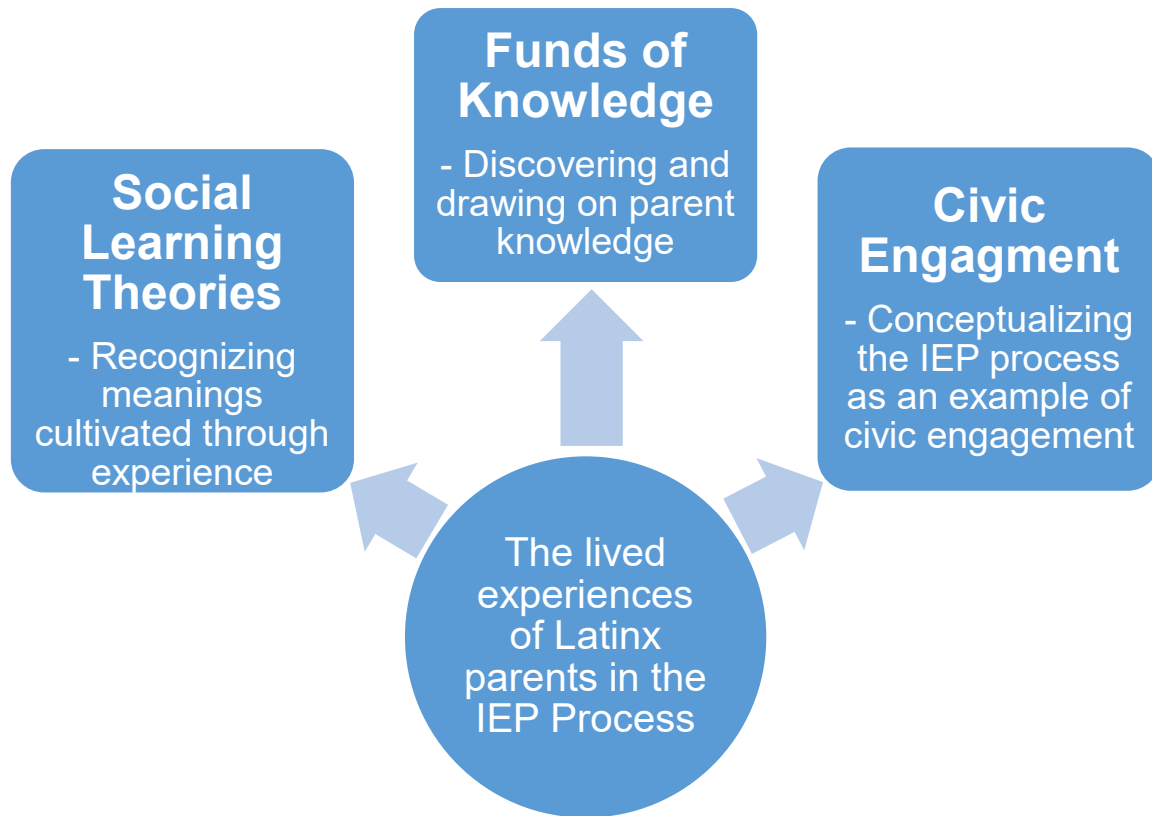
The operational definition of participation for this study was as follows:

Participation for families and schools is a mutual act of relationship building, understanding, and open discussion, where all voices present are heard, and with a respectful and positive regard given to the cultural experiences of all persons present, in order to come to agreements that are inclusive of the needs of families and the interests of schools.

### **Conceptual Framework**

The conceptual framework for this study emerged from ways in which personal and collective knowledge is constructed. The framework provided a priori guides to develop the design and research questions, as well as situate phenomena as I analyzed findings. In line with phenomenological investigations that make use of a variety of theoretical perspectives in order to imaginatively vary data (Moustakas, 1994), I proposed a multifaceted approach to understanding the experiences of Latinx parents throughout the IEP process. I drew on the following four ideas: (1) social learning theories, (2) funds of family knowledge, (3) civic engagement as a process of individual and collective actions aimed at bettering a community, and (4) phenomenology.

Figure 1 illustrates the interrelatedness of the different theories and approaches that comprised the conceptual framework in this study. I drew upon social learning theories in order to understand and analyze the meanings parents construct of their experiences. Related to this, a funds of knowledge approach allowed me to discover and draw on the knowledge, skills, and values that parents possessed. These two core ideas aided in focusing on the authentic descriptions parents provided of their experiences in the IEP process and meanings they ascribed to them.



*Figure 1.* Conceptual framework.

Additionally, parent participation in the IEP process has been seen as an important civil right that must be safeguarded and monitored (Kalyanpur & Harry, 2012). The IEP process can then be viewed as an example of civic engagement—one in which there is parity between parents and educational professionals—and supports the spirit behind legal mandates such as IDEA (2004). Lastly, I applied a phenomenological framework to help interpret the lived experiences of Latinx parents in the IEP process. The process of phenomenological inquiry, as well as the epistemological framework from which it emanates, allowed me to see participants' thoughts, words, and actions as part of the meanings they ascribed to rearing a child with a disability.

**Social learning theory.** Often ascribed to the work of the psychologist Albert Bandura, social learning theory posits that human behaviors are learned through imitation, observation,



and modeling (Bandura, 1977). In education, social learning theories have a long history. In reaction to behaviorist models whereby people's environments are considered the main determinant of their behaviors, in social learning theories human behavior is believed to be self-directed and learned through interaction with others (Ormrod, 2013; Rogoff, 1990). Humans are seen as cultural beings affected by the beliefs, values, and tools that are socially available to them (Vygotsky, 1978). There is evidence that Vygotsky's and Bandura's ideas about learning are, in fact, valid. For instance, Freund (1990) conducted a study where children had to make decisions about which area to place certain pieces of furniture in a doll house. Two groups were designated: one group played with their mothers in order to learn through conversation and imitation, while the other group played with the furniture independently. It was found that children who were allowed to play with their mothers showed the most significant improvements in placing furniture in the correct area of the house. This was believed to show the participatory and social influences on learning (Freund, 1990).

Participation in social and cultural activities lays much of the groundwork for psychological functioning and how children interact with their environments (Wertsch, 1991). Since children, even at such a young age, are cultural and historical beings that are involved in a diverse array of social processes, it follows that these processes must be shared and discussed. This understanding situates individuals as complex beings interacting with the world around them through social and cultural schema (Rogoff, 1990). Furthermore, the ways in which outside systems interact with children and their families often illustrates larger culturally-held beliefs about the value of family, community, and school (Lave & Wenger, 1991). Social learning theories helped me situate experiences within the lifeworlds of Latinx parents and draw upon the

meanings they attach to their experiences. This approach helped ensure that my descriptions of parent's experiences, beliefs, and values were rich, authentic, and contextualized (Rogoff, 1990).

**Culture and funds of knowledge.** Funds of knowledge grew out of a dearth of knowledge about the forms of capital that working-class Latinx families possessed (Rios-Aguilar, Kiyama, Gravitt, & Moll, 2011). This lack of knowledge often made it difficult for teachers to cultivate relationships with Latinx families and design appropriate curricula that made use of their skills to benefit their children's education. As a result, Moll (1990) and Velez-Ibanez and Greenberg (1992) first introduced the concept of funds of knowledge to explain the ways that working-class Mexican families used their social networks to mediate uncertainties endemic to their economic situations. The burgeoning funds of knowledge approach was rooted in anthropological methods of inquiry. It used in-depth interviews, often at families' households, to ethnographically document the common activities, division of labor, perceptions on childbearing, social and labor history, and values regarding education and learning (Moll, Amanti, Neff, & Gonzalez, 1992). This approach countered the dominant deficit narrative of working class families, which positioned such families as both poor economically and in regards to the experiences they provided children, by documenting the various bodies of knowledge that encapsulate families' productive activities (Moll et al., 1992). Moll and Gonzalez (1994), while studying literacy approaches of Mexican-American families, defined funds of knowledge as:

Those historically accumulated and culturally developed bodies of knowledge and skills essential for household or individual functioning and well-being. As households interact within circles of kinship and friendship, children are "participant-observers" of the exchange of goods, services, and symbolic capital which are part of each household's functioning (p. 443).

Several studies (Andrews & Yee, 2006; Ares & Buendia, 2007; Licona, 2013) have used this theoretical framework to show that when funds of knowledge are incorporated into curricula it helps facilitate practitioners' abilities to use family and cultural knowledge to connect with students on a deeper level. For instance, Andrews and Yee (2006) presented two case studies of children from ethnic minority communities in the United Kingdom in order to recognize and value the knowledge and expertise that these children and their families possessed. In order to create a robust representation of the two cases, the researchers first built rapport with the children to avoid essentializing their lives and experiences. The research, therefore, was seen as a collaborative, rather than an outsider, or *etic*, approach. This is consistent with recommendations for discovering families' funds of knowledge (Moll et al., 1992; Moll & Gonzalez, 1992; Rios-Aguilar et al., 2011). Andrews and Yee (2006) found that there were a variety of ways in which the children engaged in learning outside of school. For instance, one of the children collected lost coins from his father's taxi business to be donated to charity. In order to accomplish this task, the child had to first locate money and then a charity in the community that accepted donations. This kind of knowledge was present outside the school context and could be valuable to teachers when designing ethics lessons about altruism or mathematics activities on money.

Esteban-Guitart and Moll (2014b) argue that the concept of funds of knowledge can be extended to identity. In this conceptualization, termed "funds of identity," identity is more than just a personality trait; identity is part of a larger matrix that takes into account general cognitive patterns, culture, family, language, and racial/ethnic identity. Identity then becomes a more complex system that is infinitely varied. The focus would then be on understanding the unique lived experiences of individuals in order to provide pedagogical and engagement practices that are situated within their lifeworlds (Esteban-Guitart & Moll, 2014a, 2014b). I used the funds of

knowledge and funds of identity approaches to better understand parents' knowledge, beliefs, and values as it related to the IEP process and the education of their children.

**Civic engagement.** Civic engagement "... includes individual and collective activities intended to identify and address issues of public concern, and enhance the well-being of one's community and the society" (Chan, Ou, & Reynolds, 2014, p. 1830). The concept of civic engagement was originally used in the context of younger people, usually in reference to service learning (Celio, Durlak, & Dymnicki, 2011); however, it has since been extended to adults of all ages (Adler & Goggin, 2005; Freedman, 1999). It is a broad category for understanding and supporting notions of citizenship, democracy, and *civic solidarities*—that is, how citizens identify and connect with certain civic issues (McCoy & Scully, 2002).

A key feature of civic engagement is its democratizing effect; that is, engaging people in civic activities promotes an open and non-judgmental space for discourse, as well as fosters the development of civic solidarities (Morgan & Streb, 2001). Concomitantly, it is believed that civic engagement can have an emancipatory effect upon individuals by focusing on lived experience as central to participatory actions (Hildreth, 2012). This conceptualization could be extended to the ideas of participation and intersectionality that was a central focus of my study.

Reframing home-school relationships as a civic activity, whereby families are viewed as possessing invaluable information about the students that schools serve, could help foster structural changes that counteract dominant perceptions about families (Foster-Bey, 2008). These changes could very well lead to increases in parent participation. This could be particularly impactful for families of children with disabilities, as re-envisioning the IEP process as a civic activity could lead to members with different civic solidarities being considered of equal value. Families and educational professionals could then create new models for open and democratic

discourse. In this way, civic engagement in the IEP process denotes an epistemology stemming from notions of social inquiry found in the works of John Dewey (1935, 1938). While Dewey did not quite develop a theory of knowledge in the traditional sense of epistemology, he did identify inquiry—and the ways in which it is socially construed—as a means by which people co-create knowledge and use it to exert control over their environments (Stone, 1994). Moreover, the IEP process may be capable of illustrating how knowledge can be constructed through social inquiry.

**Phenomenology.** This study used a phenomenological orientation to study and interpret lived experience. Phenomenology has a rich history within philosophy. Its theoretical underpinnings are usually traced to philosophers who were influenced by Hegel (1807/1967) and rejected the (then) unquestioned validity of positivist inquiry in the human sciences (McPhail, 1995). Because it has been fed by multiple streams of philosophical discourse and developed into a practical research design in the human sciences, phenomenology is not just a method but a way of discerning the world and the uniqueness of subjective experiences (Giorgi, 1997). It is also inextricably bound to a hermeneutical, or interpretive, process of inquiry (Van Manen, 2014). This multifaceted nature positions phenomenology as a holistic approach to understanding human experience, since we can speak of phenomenology as historical, rational, intuitive, experiential, scholarly, scientific, humanistic, hermeneutical, and artistic, and yet refer to the same construct.

The central tenet of phenomenological research is the description and interpretation of lived experience. In the traditions of Husserl (1913/1982) and Heidegger (1927/1962), it is a descriptive methodology that attempts to systematize subjective experiences through the textual expression of the essences of phenomena (Giorgi, 2006). Descriptions of lived experience require an inductive, reflexive, dynamic, and open-ended approach, as well as an explanation of

the way things are, rather than as they “objectively” appear (Moustakas, 1994). Through intuition, reflection, and a rigorous method of documenting lived experience, researchers can then begin to comprehend the meaning and essences involved with a phenomenon.

According to Moustakas (1994), the term phenomenology was used by philosophers as early as 1765, and at least peripherally present in Kant’s writings, but was not reified for practical application until the early 19th century, when Hegel (1807/67) conceptualized it as knowledge as perceived in consciousness. Knowledge—thus conceived as a priori, intuitive, and dynamic—stood in contrast to the prevailing epistemology based upon purely positivist presuppositions. This eventually led to Husserl’s (1913/82) development of the notion of *epoche*. Epoche, often referred to as “bracketing” by phenomenological researchers, is the suspension of presupposition and the constant appearance and activation of doubt in order to better understand phenomena. It allows the researcher to seek meaning and discover the essence of a phenomenon through open-ended investigations. Similar to Cartesian and Kantian thought, for Husserl, intuitive knowledge always heralds empirical knowledge. This intuition is thought as it appears in consciousness. Because intuition is experiential, almost visceral, it requires reflection to understand its essence (Van Manen, 1990). The understanding of essence ipso facto necessitates a hermeneutic, since reflection is always an interpretation of a phenomenon from a future point of reference (Giorgi, 1997). Consequently, phenomenology requires the interpretation of past experiences to form a discursive and honest portrayal of the essence and underlying meaning of an experience.

The conventional dichotomy between object and subject do not apply in phenomenological investigations; rather than mutual exclusion, subjectivity and objectivity are re-conceptualized as interrelated, synergistic, and governed through reciprocal motion, as a cog

in a piece of machinery moves in tandem with other parts (Martinez, 2006). This interrelation means that a researcher cannot be “objective” in the traditional sense. Rather, as Van Manen (1990) states, “objectivity means that the researcher remains true to the object” (p. 20). The subject then becomes the guardian of the essence of the object, the keeper of an object’s most genuine nature. A phenomenologist is therefore placed in dialogical relation to her participant, who, because of the synergism and interrelatedness introduced in the dialogic, is now given parity with the researcher. This is why participants are often called “co-researchers” in phenomenological research (Moustakas, 1994).

In terms of practical applications in human science research, the dialogical and reciprocal relationship breaks free from the monologisms and technocracies of experimental designs. A monological relationship, in which researchers isolate areas to investigate and separate themselves from their subjects, has been categorized by some as oppressive, autocratic, and a vestige of Westernized notions of perfection and organizational hierarchicalism (Heshusius, 1986; Apple, 1979). Moreover, the separation between object and subject, researcher and participant, and teacher and student is salient in special education, which has been primarily informed by positivist approaches to remediation and categorization (McPhail, 1995).

Researchers have slowly begun to use phenomenological methods with diverse populations, such as those with disabilities, and incorporate equitable relations between subjects and researchers (e.g., Cornett-Devito & Worley, 2005). However, there is a dearth of these types of studies in special education. Moreover, a phenomenological orientation allowed the right amount of breadth to value multiple ways of knowing, while also allowing enough depth to capture the uniqueness of participants’ conscious experiences.

### III. METHODOLOGY

I used a phenomenological design to enable me to gain insights into the meanings that parents made individually while discussing their experiences with the IEP process. I developed a study in which I interviewed seven Latinx mothers of children with IEPs. The focus was on the mothers' personal biographies and knowledge related to their children, their perceptions of their engagement and involvement during the IEP process, as well as their reflections on conversations that occurred during interviewing. I chose a phenomenological approach for two reasons. Firstly, because the intent of my research questions was to investigate meaning, phenomenology as a method and historical framework for understanding lived experiences offered an approach pliable enough to access and gather meaning-making. Secondly, because part of the nature of this study was grounded in a belief in the primacy of subjective experience, a phenomenological approach allowed me to be a part of this study, rather than apart from it. Phenomenologists recommend that researchers develop a "participatory consciousness"—a recognition that they are not separate from the world through which the data emanates (Heshusius, 1994). This stance and view of being a part of the same world as participants also required that I reflect on my role as a researcher, which is another recommendation in phenomenological research (Moustakas, 1994).

Additionally, many argue that the field of special education is steeped in positivistic traditions that value objectivity, science, and generalizability of findings above all else (Heshusius, 1984; McPhail, 1994; Skrtic, 1999). As an active professional in the special education community for the past 13 years, I saw that this orientation could not account for the meaning-making that I see occurring in schools, communities, and families. I thus looked to holistic methodologies that could capture experience and give life to the richness of being in and



of the world. As a methodology, phenomenology allowed the voices and narratives of parents to be at the center of this study.

### **Research Design**

As the phenomenologist Maurice Merleau-Ponty (1942/67) argued, a person's lived experience constitutes "...an inventory of consciousness as of that wherein a universe resides" (p. 215). Because the nature of this study was to explore parents' experiences and the meanings they gave to those experiences, I used a phenomenological design. By doing so, I was able to document parents' histories with and perceptions of the IEP process. A qualitative interview approach was used because the resulting data analyses allowed me to provide rich descriptions of experiences (Patton, 2002) and embedded meanings constructed by individual parents, as well as identify any commonalities and differences across the individuals. Phenomenology positions subjective experience as "absolute truth" and can therefore be used by others trying to come to a deeper understanding of an experience or phenomenon through the eyes of the participants (Colaizzi, 1978; Giorgi, 1971). As such, phenomenological approaches allow researchers to search for meanings, or "essences," rather than measurements or explanations (Moustakas, 1994). This study capitalized on this method in order to gain insight into the perceptions and experiences—what Moustakas (1994) refers to as *lifeworlds*—of parents.

### **Setting and Participants**

The participants for this study were recruited from a community organization in the metro area of a large Midwestern city that operated three community centers with daycare and after-school programs (A, B, and C) geared toward individuals with disabilities and immigrant populations. The early childhood program worked with more than 4,000 families who had a child 5 years or younger, and the rehabilitation program worked with more than 1,000 individuals with

disabilities, ranging in ages from 16 to 70. Ninety-five percent of the families that engaged with the site were bilingual and 91% were low-income. The large public school district where all of the families in this study sent their children for the whole or partial day had an enrollment of 371,000 students, 77% of which were economically disadvantaged. The racial makeup of the district was 47% Latino, 37% African American, 10% White, 4% Asian American, 0.2% Hawaiian/Pacific Islander, 0.3% Native American/Alaskan, and 1.1% Multi-Racial. Eighteen percent of students were English Language Learners (ELLs) and 14% of students in the district had IEPs.

Seven Latinx parents of children with disabilities who had IEPs ( $n=7$ ) participated in this study. My IRB request was for between six and eight participants (see Appendix D). This number fell within the range often recommended by researchers for attaining saturation in interview studies (Guest, Bunch, & Johnson, 2006; Morgan, Fischhoff, Bostroff, & Atman, 2002). Data saturation is often used as a guide by researchers to determine sample size (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles, & Grimshaw, 2010). Glaser and Strauss (1967) first operationalized the term as meaning the point in data collection in which little to no new data is found to help develop themes and categories further. Additionally, as in other studies used to determine appropriate sample size to achieve saturation (Morgan et al., 2002), Guest et al. (2006) found around 80% of all identified themes emerge in the first five or six interviews. In my study, since each participant was interviewed three times a piece, the total number of participants ensured that some level of saturation was reached, while avoiding the redundancies endemic to over-sampling (Francis et al., 2010). The sample size of seven participants also fell within the range recommended to do in-depth phenomenological interviews (Creswell, 2007; Seidman, 2006).

In Table III, I display the participants' demographics and the settings for interviews.

Table III.

*Participant Demographics and Setting for Interviews*

Participant	Participant Age	Parent/Child Ethnicity	Setting (Interview Number)
Juliana	22	Mexican American	Café A* (1) Café B (2) Phone (3)
Fatima	27	Mexican American	Community Center A* (1, 2) Phone (3)
Mariana	45	Mexican American	Community Center B (1) Restaurant (2) Café A (3)
Amelia	23	Mexican American	Community Center A (1, 2, 3)
Isabel	25	Mexican American	Community Center B (1, 2) Phone (3)
Cecilia	30	Mexican American	Community Center C (1, 2, 3)
Guadalupe	36	Mexican American	Café C (1, 2) Phone (3)

*\*Note.* This study was conducted in three different community agency locations in three different areas of the city. These are noted as *Community Center A*, *B*, and *C*. There were also three different cafés where interviews took place. These are noted as *Café A*, *B*, and *C*.

Participants in the study all identified as either Latina or Mexican American and were the biological mothers to all of their children. The ages of participants ranged from 22 to 45, with an average age of 30 ( $M=29.71$ ;  $Mdn=27$ ). All of the participants had two or more children and at least one child with an IEP. The ages of the children that were the focus of the interviews ranged from four to nine, with an average age of 5.14 years old ( $M=5.14$ ).

In Table IV, I display the demographics and disability label of the participants' children that were the focus of interviews.

Table IV

*Child Demographics and Disability Label*

Participant	Child	Age of Child	Disability Label
Juliana	Natalia	5	Developmental Delay
Fatima	Carlos	5	Developmental Delay
Mariana	Benjamin	9	Autism
Amelia	Abidan	4	Autism
Isabel	Jesus	5	Speech/Language Impairment
Cecilia	Hector	4	Autism
Guadalupe	Armando	5	Developmental Delay

The children ranged in ages from four to nine years old ( $M=5.14$ ;  $Mdn=5$ ). Six of the children were male and one was female. Three participants identified their children as having an autism spectrum disorder (ASM), three identified the global category of developmental disability, and one identified speech/language impairment.

**Recruitment Process.** I used a purposeful, homogeneous sampling method to focus on potential participants who could help me answer the research questions (Creswell, 2014; Patton, 2002). Potential participants had to meet all screening criteria in order to participate in the study. This was done to expand the extant literature on the lived experiences of Latinx parents with the IEP process. The term *Latinx* was used from the outset of the research study so that any parent, regardless of gender identity, could participate as long as they met the screening criteria. All participants ended up self-identifying as Mexican American mothers.

Participant recruitment began in May of 2018, as soon as Institutional Review Board (IRB) clearance was received, and was completed in August of 2018. After locating a number of

agencies and community centers with populations conducive to the sampling method, I began recruitment by crafting introductions to potential sites. These introductions were debriefed with my doctoral advisor and a school administrator. Emails explaining the study and what was being asked of the recruitment site were sent to community agencies and centers in the Chicagoland area with and without a disability mission or focus. I first sent emails to agencies with a clearly-stated disability focus. In order to determine that, I read the agency's or center's mission statement, if available, and gathered as much information as possible about the populations they served before making contact. These sites were identified purposefully in order to be strategic in the sampling method (Patton, 2002). Sites that were "information rich" and relevant to the phenomena under investigation were chosen in order to provide an appropriate venue for in-depth study (Patton, 2002, p. 242). In the present study, information rich sites were those that served Latinx families of children with disabilities. Within one week, the site director of a local community center with a disability focus replied to my inquiries and an in-person meeting was setup with staff members. After discussing the purpose of my study and sharing all of my recruitment materials, staff at the site agreed to participate and the site director signed a support letter to allow recruitment to occur. The support letter was then sent to IRB as an amendment so that the community center could be added as a recruitment site.

After receiving approval to conduct research, I contacted the representative of the community center to begin. I then provided all IRB approvals and recruitment materials to staff at the community center. I met once more with a designee from the community center to review recruitment procedures. After answering any questions and ensuring that the procedures were understood, recruitment began. The designee of the community center, a community advocate,

first independently identified participants that met the screening criteria of the study and provided them with the recruitment materials, which included my contact information.

I began receiving contacts, through text messages and emails, within one week of presenting the recruitment materials to the designee of the community center. Five of the seven participants contacted me directly through text or email. The other two participants provided the designee their contact information and requested that I contact them. These last two participants were present at a two-part workshop on the IEP process I did at the community center in order to build a capacity for trust and understanding within the community (Joseph, Keller, & Ainsworth, 2016).

In each case, I scheduled a phone call with potential participants to review the recruitment procedures with them. This included reviewing the screening criteria, interview procedures, and voluntary commitment to participate in the research. Participants were also told they would be given two \$25 gift cards—one after the first interview and one after the third interview. Eight of the twelve potential participants I talked to on the phone agreed to participate in the study. Four of the potential participants did not meet at least one of the screening criteria. Additionally, one participant dropped out of the study before the first interview due to a family emergency. After verbally consenting to participate, the first interview was set up at a public location convenient to the participant. Written consent was obtained before the first interview for every participant in the study (see Appendix E).

**Sampling criteria.** Participants had to meet all of the inclusion criteria to participate in the study (see *Screening Tool*, Appendix A). Criteria included: participant must (1) have a child (or children) between the ages of four and nineteen, (2) have a child that currently attends an urban public school, (3) have a child with a disability identified on his or her IEP, (4) self-

identify as being Latino/Latina/Latinx, (5) have attended at least two IEP meetings for their child, and (6) speak and understand English. Mothers, fathers, and primary caregivers of children with a disability were invited to participate in this study. There were no limitations placed on age of the participants, as long as the participant had reached the age of majority (18) before participating in the study. There were also no limitations placed on disability category.

Participants that did not meet the aforementioned inclusion criteria were excluded. The exclusion criteria were as follows: Participants who (1) did not have a child currently attending a public primary or secondary school with a disability as listed on his or her IEP, (2) had never attended an IEP meeting, (3) did not self-identify as Latino/Latina/Latinx, and (4) could not communicate in English were not invited to participate in this study.

**Parent workshops.** Before recruitment began, I provided two workshops on the IEP process at the request of staff members at the community center. Staff members believed that these workshops would help mitigate my role as an “outsider.” As a White man working in a largely Latinx community for the past 12 years, I was familiar with strategies that could be used to build capacity for understanding and cultivate a space for cultural reciprocity (e.g., Harry, Kalyanpur, & Day, 1999). After discussing the possibility with other researchers, I agreed to create a one-hour workshop for parents. The design of the workshops was sent to staff members at the community center, including the site director. After receiving feedback, I finalized the design and scheduled the workshops. These workshops were conducted at two of the three community center locations. The workshops were accompanied by a translator. The translator was a first-generation Mexican American Spanish teacher at the high school where I teach. She had experience translating at parent events, community trainings, and IEP meetings. The content of the workshops was on parental rights in the IEP process, the basic contents of an IEP

document, and discussions about how to best advocate for children in the IEP process. At the end of each workshop, a staff member from the community center explained that I was doing a study on parents' experiences with the IEP process and stated that they would share my contact information with anyone interested. I, nor the translator, talked about my research study during the workshops in order to mitigate potential coercive influences. Two of the participants in this study, Mariana and Amelia, were present at the workshops. The rest of the participants were recruited through staff members directly reaching out to parents who might qualify for the study.

### **Instrumentation and Data Collection Procedures**

**Individual interview protocol.** A semi-structured interview protocol was the primary instrument used to collect data (Appendix B). The use of a semi-structured protocol ensured that all participants were asked the same questions, in the same order, but also allowed space for exploration of in-the-moment ideas and thoughts that presented themselves (Patton, 2002). The individual interview was open-ended. Therefore, while questions were scripted, the answers participants provided could not be preconceived. Most questions were created so that participants shared their thoughts and feelings about a variety of issues related to their life histories, family and cultural knowledge, and the IEP process (Patton, 2002). As the phenomenologist Giorgi (1997) stated, "questions [should be] generally broad and open ended so that the subject has sufficient opportunity to express his or her view point extensively" (p. 245). Thus, the creation of broad questions was intentional to allow participants to discuss their lived experiences openly and extensively (Creswell, 2007; Patton, 2001). The format of the interview protocol was adapted from common recommendations for narrative and phenomenological interviewing (Jovchelovitch & Bauer, 2000; Seidman, 2006). These included an initiation to each major topic discussed, a main narration with guided questions and probes, and a memory



protocol the interviewer creates after the interview event. A memory protocol occurred when I wrote down major ideas and concepts right after finishing the interview (Jovchelovitch & Bauer, 2000).

I used Seidman's (2006) "three-interview series" to organize the interview protocol and provide an opportunity to have in-depth conversations about participants' lived experiences. Per Seidman's (2006) recommendation, I interviewed each participant three separate times. This is in line with Moustakas's (2015) recommendation for phenomenological inquiries, mainly that in order to capture the "essence" of experiences a researcher must provide "... full and complete depictions of the experience from the frame of reference of the experiencing person" (p. 264). Interview one was a focused life history, where participants were asked to reconstruct the details of their lived experiences. This included histories of their families, schooling, family and cultural knowledge, knowledge of their child, and views on the IEP process. The second interview centered on the details of their experience with the phenomenon of the IEP process. This was where participants discussed their experiences with the IEP process, special education, and supporting their child's needs. The third and final interview was a reflection on the meaning of the first two interviews. Participants were asked to return to the broad themes discussed in the first two interviews and reflect on any possible derived meaning. A number of probes were used in the interview protocol to encourage participants to clarify their answers in order to seek deeper meaning about their perspectives (Appendix B; Seidman, 2006).

**Domains.** The interview protocol contained four domains drawn from the research questions. The domains closely followed Seidman's (2006) three interview process. The only addition was that interview one was divided into two domains, since the content of the questions differed in the two halves of the first interview. Thus, the first interview focused on the two

following domains: (1) focused life history and (2) experience with a child with a disability. The second interview focused on the (3) lived experience in the IEP process and the third interview focus was (4) reflection on meaning. A member check also occurred after the three interviews but was not considered a domain since the purpose of a member check is to check for accuracy, not collect additional data (Patton, 2002).

**Piloting.** In order to incorporate practical measures into the creation of an interview protocol, I designed questions to be asked in the vocabulary and language of the individuals being interviewed (Benner, 1994). This would allow access to the perspectives of the interviewees unfettered by theoretical terminology. To accomplish this, the first iteration of the interview protocol was piloted with three Latinx parents. All three parents were bilingual mothers, fluent in English and Spanish and from an urban setting. All had at least one child with a disability. Additionally, two special education teachers and two members of my doctoral committee provided feedback on the interview questions. The suggestions of the mothers, researchers, and special education teachers were then used to revise the interview protocol. These suggestions were: shorten the interview guide by cutting redundancies and questions irrelevant to the IEP process; re-organize the interview domains for clarity; and begin the second and third interviews with a short overview of what had been discussed up until that point. The final iteration, including the inclusion of suggested revisions, was the only protocol used in the study.

**Data collection and procedures.** Data consisted of interviews and member checks, field notes after each interview, and research and analytic memos. All data were collected from June 2018 through October 2018. Memo writing continued through December 2018.

For interviews, after verbally consenting to participate via phone and then receiving written consent in-person, participants were interviewed at a public location that was convenient to them (see Table III). Four of the seven third interviews, and all seven member checks, were done via phone.

Twenty-one interviews were conducted in all for a total of 898 minutes (14 hours and 58 minutes) of audio recordings. The average length of the interviews was 42.8 minutes (range=17-76 minutes), with the average of each interview being successively shorter (59.4, 48.6, and 20.3, respectively). Member checks were not audio recorded but were generally less than 15 minutes.

At the conclusion of each interview, the proceeding interview was scheduled. All but one participant was interviewed three times within one month. The exception (for Guadalupe) was due to a busy work schedule. Her third interview was conducted one month and three days after the first interview. Locations for the interviews varied. Seven different locations, including all three community center locations, coffee shops, and restaurants were used for interviewing. In most instances, participants chose the locations. However, in three instances I chose the location at the request of the participant. I captured details about all locations in my memos to be used in data analysis and discussions to help contextualize and humanize the data. This technique is common in phenomenological studies, since the environs where interviews take place is valued as a part of the research (Van Manen, 1990).

One potential risk I discussed with participants was maintaining the privacy of participants. I therefore ensured that all transcripts were de-identified and stored on a password protected hard drive. Each participant, and any of their children discussed in the study, was given a unique pseudonym so that they could not be identified in any writing that I did. During the final interview, I asked participants if they would like to choose their own pseudonyms. Three

participants responded that they would and provided pseudonyms distinct from their real names. These were retained for this study to exemplify their role in exploring the phenomenon under investigation.

**Member check.** At the end of the third interview, I explained my reason for wanting to have an additional phone call conversation as a “member check” to ensure I had captured each participants’ beliefs and knowledge. I then explained the process. Participants had the chance to add, modify, or delete any part of the summary statements. Within 14-21 days after the third interview, for each participant I created a document with interview response summary statements (of two - three sentences) from each response. I then sent that to the participant’s email as a .pdf file. After being assured that each participant had a chance to read through the summary statements, I conducted a member check phone call. I asked if the participant had questions about the overall document and the intent of the member check. After reading the summary of interview data to participants during the member check, I asked participants the following question based on Dowling (2007): “How do my descriptions of the interviews compare with your experiences?” This ensured, to the greatest extent possible, that my descriptions of the data were true to participants’ perceptions of their experiences. Member checks occurred between July 2018 and October 2018, between two to four weeks after the third interview for each participant.

**Field notes.** While interviewing, I wrote field notes in my journal to aid in understanding participants’ thoughts and ideas (Creswell, 2014; Seidman, 2006). These consisted of important words and phrases that I heard during each interview. Immediately after each interview, I looked over my notes in order to flesh out ideas, e.g, write a question to gain clarity during the next interview, add in field notes about gestures and/or facial expressions I observed, write about

emotions I observed. After that, I then wrote “memory protocols” for between 10-15 minutes as attempts to distill some of the meaning I intuited from the interviews (Jovchelovitch & Bauer, 2000). I also recorded all that I saw in the setting in order to begin contextualizing interview data (Patton, 2002). As an example of what I wrote, during interview one, Amelia brought her younger child to the interview because she could not find a sitter on that particular day. During my memory protocol, I wrote, “P [participant] seemed unaware of her young son crying as she talked with passion about her growing up with her father largely absent” (Int. 1, 06/22/2018).

**Research memos.** I also wrote five memos while collecting data. The purpose of this memoing process was to begin reflecting on what I was seeing in the interviews (Van Manen, 1990). These memos were then shared with my doctoral advisor, and we made typically one - three exchanges as a way to begin conversations about interpretations, assumptions, and biases as well as overall meanings I was beginning to intuit. The five memos were spaced fairly evenly apart, with about one memo written approximately one to two weeks during the final months of data collection. The research memos were between three to five single-spaced pages in length and were written freely; that is, the research memos were intentionally not given structure so that I could record a priori musings, preconceptions, and judgments. As such, these writings also aided in the phenomenological stage of *epoche* in that I was later able to look back at the memos and begin clarifying any biases or misassumptions I had (Moustakas, 1994).

## **Data Analysis**

The intended purpose of qualitative data analysis is “to make sense out of text and image data” (Creswell, 2014, p. 245). The data, often construed in the form of notes or interview transcripts, is segmented and taken apart and then reassembled in order to reveal and interpret themes and descriptions (Creswell, 2014; Mertens, 2014). When analyzing qualitative data,

Creswell (2014) suggests the researcher will follow a general process of analysis before taking specific steps to analyze the data according to the research design chosen (Creswell, 2014). This could mean integrating data into evidence to support existing theories or to form new theoretical ideas (Patton, 2002; Strauss & Corbin, 1998).

This study used a phenomenological design and followed analytic procedures that helped me generate meanings linked to the data. To do so, I focused on what Moustakas (1994) called gleaning “the essence” from the data. I used Moustakas’s (1994) framework for finding the essence of parents’ perspectives about the IEP process and their roles in it. That framework included the following steps: *epoche*, *phenomenological reduction*, *imaginative variation*, and *synthesis*. By using this structure, I gained help in having a clear process for establishing and sustaining research-based rigor. This kind of process is commonly used in phenomenological research to provide vivid descriptions of the lived experiences of individuals (Creswell, 2007). It allows researchers to describe what and how individuals experienced a phenomenon in order to gain an overall sense of it—akin to what Van Manen (1990) refers to as gaining “a grasp of the very nature of the thing” (p. 177).

I added an additional step of the member check often recommended in phenomenological research that involves reflecting upon the written descriptive experience (Dowling, 2007). Colaizzi (1978) believed that it was important to return to the interviewee one final time to read the description of the essence of the experience, acknowledging that there was an interpretive as well as descriptive element to analysis. This is similar to Van Manen’s (1990) concept of *Bildung*, the idea that reflecting on experiences transforms the individual, so that experiential descriptions are seen as malleable rather than static.

**Fieldnotes.** By continuously consulting my fieldnotes taken during interviewing, I was able to incorporate reflection throughout the analysis process. The fieldnotes not only contained important words and phrases spoken by participants; they also revealed my presumptions—most demonstrable in the memory protocols. Two of the codes in the codebook, “gaining support from others” and “parent knowledge of child,” emanated from the a priori musings recorded in the fieldnotes. Additionally, these early reflections became especially important during the synthesis stage of analysis (which I write about in Chapter Five). There were several moments during analysis where these early reflections only made sense when I looked at the whole of the experience of gathering and analyzing data in this study. Moreover, the zooming in and out across time in this study allowed me to approach the question of essence with a greater understanding.

**Epoche.** For this study, epoche was conceptualized as a method for suspending personal judgments and understandings to foster a sense of curiosity and reflect on their potential impact, rather than a complete bracketing of biases, which seemed unreasonable given the interpretive nature of the research (Creswell, 2007; LaVasseur, 2003). I engaged in a few processes to help myself suspend judgment. After each interview, I used a memory protocol to immediately reflect on the meaning of what was discussed (Jovchelovitch & Bauer, 2000). This was one method I used to “bracket,” or put aside, my judgments and understandings (Moustakas, 1994). Also, throughout the interviewing process, I wrote five research memos to gain an intuitive sense of the possible meanings of the data *in situ*. That memoing process also provided a general structure to begin analyzing data.

**Phenomenological reduction.** After I completed the data collection phase, I began analysis by first reading through the interview transcripts for each participant and jotting down

any ideas, insights and wonderings I had. I did this by re-reading all the research memos and comments from my doctoral advisor. That helped me relive the co-constructed experiences and begin to intuit meaning from the data (Colaizzi, 1978; Moustakas, 1994; Van Manen, 1990). During this reliving process, I took notes in the margins of the transcripts in order to begin to discover meaning. These notes were also used as reflexive tools to ensure that biases and presuppositions were bracketed so that any subjective positions that may have influenced interpretations were recorded (Moustakas, 1994).

Once my initial intuitions and presuppositions were recorded, I began to prepare the data to be coded. From notes I had taken during the first readings of the transcripts, I identified similarities across participants' ideas as well as statements and ideas that stood out as unique to one individual and/or to one of the interviews. In the first phase of coding, I created a spreadsheet. I randomly chose two participants. I arrayed their responses to each interview question on the *y* axis, and arrayed each participant on the *x* axis. I looked for repetitions of phrases and ideas within one participant's interviews and across both participants' interviews. However since participants' narratives arced across all three interviews, pulling out distinct phrases or ideas decontextualized their words. It became apparent that identifying small snippets of phrases and developing an emergent coding method, such as the one recommended by Corbin and Strauss (2008) or Charmaz (2014), would not enable me to capture participants' meaning-making. Each interview was filled with the narratives situated within the life experiences of the individual. Additionally, I was concerned that waiting for an answer or theory to "emerge" from the data—an epistemological assumption endemic to grounded theory (Strauss & Corbin, 1998)—would have the unintended effect of essentializing the experiences of the participants.



Overall, I realized I was looking in too much of a fine-grained manner in the sense of slicing the data into too small of elements to analyze.

Since there is no agreed-upon, universal procedure in qualitative coding (DeCuir-Gunby, Marshall, & McCulloch, 2011), I began searching for alternative possibilities. I looked at using a priori codes derived from theories as suggested in Blair (2015) and DeCuir-Gunby et al. (2011). Methodologies they suggest would have allowed me to situate data within extant theories. However, I ultimately decided against this approach due to the fear that the arbitrariness of fitting data into theory-driven a priori categories would, once again, run the risk of essentializing the experiences of participants.

However, DeCuir-Gunby et al., (2011) argue that use of a hybrid coding schematic is not uncommon when analyzing semi-structured interview responses since the variegated data often times might require more than one approach. They posed two kinds of coding that seemed to align with the arcs of the narratives across the three interviews in my study; that is, structural-driven and data-driven coding. Structural codes arise from the research questions, while data-driven codes emerge from interpretations of the raw data.

I began by selecting structural codes that directly related to my research questions. There were five: role perceptions, knowledge, values, beliefs, and the IEP process. I then read ten transcripts and highlighted each phrase that corresponded to each code. I used a different color for each of the five codes. However, the same problem arose again; that is, this method could not account for the depth and the arc of the participants' narratives. Yet again the coding was too distinct and threatened to be essentializing to the lived experiences of the participants.

In an attempt to get at the nuances of what participants revealed across their interviews, I explored adding data-driven codes to the structural codes. I identified over 20 codes that seemed

to capture participants' ideas across interviews. At that point, along with my doctoral advisor, we began coding transcripts again. I randomly chose four transcripts. We each coded the same transcripts independently. After doing that, we engaged in approximately 8 - 9 hours of discussion in-person, via phone, and through email. We shared preliminary definitions we each developed as we coded. We shared examples from the transcripts of the code. We argued to reach consensus about the names of the codes, definitions, and examples from the transcripts. We then re-coded using the new code names, definitions, and examples. The interactive process resulted in ten codes with definitions and examples. Those became the codebook (see Appendix C).

While coding the four transcripts multiple times and having multiple discussions, it became apparent that in the transcripts, participants' experiences were often embedded in scenarios or vignettes. At times the vignettes were a few lines long, and at other times they spanned pages. Along with my doctoral advisor, we began to talk about how "chunks" of data needed to hang together as one unit in order to fully demonstrate participants' thoughts, ideas, and experiences. Therefore, we began to identify chunks of text that exemplified codes. It became clear that the size of the chunk could be variable. Most importantly, however, the chunk needed to be a discrete example of the code. Within those chunks, codes did not overlap, that is, each code corresponded with one code. There was a certain coherency in participants' narratives, and the chunks enabled us to show that. Saldana (2009) referred to this method as "lumping," in which a large chunk of text is lumped together.

This iterative coding process took almost three months to develop, refine, and finalize. At that point, I met with a doctoral student familiar with qualitative data analysis methods who agreed to be my second coder. We first met to review the codebook that included the research

questions, goals, and codes. We discussed the coding process. At the time, we looked together at one transcript. Together, we coded it. After that initial meeting, given questions the second coder asked, I added additional examples to the codebook for clarity. We then independently coded three of the same transcripts. We then met again to compare our coding and ensure that an 85% agreement was reached—a percentage often recommended by researchers to ensure intercoder reliability (Miles & Huberman, 1994). Intercoder agreement for the three transcripts was 96.96%, 90.47%, and 92.30%, with an average of 93.24%. After reaching that, the second coder then coded an additional six transcripts. Therefore, 43% were blind coded (9/21 of the transcripts). The formula used to calculate intercoder reliability was to divide the number of agreements by the number of agreements plus disagreements and multiply this number by 100 (Miles & Huberman, 1994).

After the coding of all transcripts was completed, the iterative process continued. During the second phase of coding, I worked with my doctoral advisor to reduce codes by collapsing them further into categories. The categories were then analyzed thematically. Themes were arrived at through consensus. The resulting themes were then used to describe how participants experienced phenomena related to the two research questions.

**Imaginative variation.** The third stage of the Moustakas's (1994) framework, imaginative variation, is gathering the lived experiences and looking at them through varied theoretical lenses and frameworks. These lenses and frameworks could be confirmatory or disconfirmatory to gain a deeper sense of the data. In this study, as I show in the next two chapters, I draw on a funds of knowledge framework, civic engagement framework, and sociocultural theories.

One way I did this was the development of seven analytic memos written during analyses of the data. These were my first attempts at giving structure to the experiences participants spoke of in this study. This structure was also part of the hermeneutic that I progressively applied as I zoomed out from the data (Van Manen, 1990). It was often the case that a word, thought, or hunch mentioned in the analytic memos were given form in the writing of this study. When writing the analytic memos, I used my fieldnotes, research memos, interview transcripts, intuition, and theories and frameworks that grounded my study. Once again, the memoing process provided segues for me to explore the essence of the phenomena.

**Validity.** In order to mitigate threats to validity, qualitative researchers often take several steps to ensure trustworthiness. Trustworthiness is focused on establishing five elements: credibility, transferability, confirmability, dependability, and authenticity (Creswell, 2014, Elo et al., 2014). Using data triangulation (interview and fieldnotes), member checking, and peer debriefing through the memoing process, I aimed to confirm authentic descriptions of participants' lived experiences. Throughout the interviewing process and data analysis, I kept a journal for memoing ideas, reactions, and thoughts about the data. I consulted my journal notes as well. Those techniques helped establish credibility in my findings. By gathering approximately 2.5 hours of interview data per participant, and just under 15 hours in total, I developed a corpus of data richly filled with deeply personal stories tied to a specific phenomenon. In addition, I lay out a clear process for my data collection and analysis, which could be replicated. The amount of data, the quality, and the robust description of methods all add to the transferability possibilities other scholars might choose (Lincoln & Guba, 1985).

In order to ensure that the research approaches were dependable throughout the study, several qualitative procedures were used (Creswell, 2014; Gibbs, 2007). First, transcripts of all

interviews were carefully checked for mistakes and inconsistencies. Secondly, a qualitative codebook was created and employed to ensure that the definition of codes did not significantly “drift” from their codified meanings during the coding process (Creswell, 2014). Throughout coding, the codebook was consulted to ensure consistency. After meeting with the second coder and discussing some ambiguities, additional examples were added to the codebook to ensure clarity. Lastly, my doctoral advisor and a doctoral student familiar with qualitative research processes cross-checked my codes to ensure intercoder agreement (Guest, MacQueen, & Namey, 2011). Overall, the use of these techniques strengthens the trustworthiness of this study.

## IV. RESULTS

I organize this chapter by using my two research questions: (1) What is the essence of parents' perspectives about the IEP process and their roles in it? and (2) In what ways do parents draw on their knowledge, values, and beliefs to support the overall education of their child? To address the research questions, I draw on all three interviews, my journal notes, and analytic memos. One comment about my use of terminology. I chose to use the term "mother" and, where appropriate, "parent," instead of "participant" as I display the data. After much thought, I decided that the term mother honors the role these participants played, as well as the gender that they identified. Also, in this study I sought to learn what shapes parents' participation in their child's education. Since all of the parents in this studied self-identified as mothers, using the term "mother" therefore seemed best.

### Life Histories

In this section, I display key background information about each mother to help me understand how parents draw on their knowledge, values, and beliefs to support their children, as well as how they perceive their role in the IEP process. I draw on the following interview questions from domain one of the first interview (see Table V). To analyze responses to these questions, I created tables with key information. In Table VI, I gathered mothers' educational experiences, including their postsecondary experiences, in order to begin to see patterns and relationships between what mothers said in later interviews that might relate to their own histories. I gathered mothers' ages, birthplaces, whether they had an IEP in school, cumulative number of primary and secondary schools they attended, and their postsecondary experiences. This allowed me to analyze how mothers' educational experiences may have informed their knowledge, values, and beliefs about their children's schooling.

Table V

*Interview Questions in Domain I*

Interview Questions	
1a.	Can you tell me about your own schooling experiences?
1b.	Can you tell me about your family?
2a.	As you think about your own experiences growing up, can you identify with something significant—something important—that you’ve experienced? Could you tell me about that?
2b.	As you think about your own growing up, can you identify something significant—something important—that you’ve experienced? Could you tell me about that?
3.	Tell me stories about growing up that you have shared with your child.
3a.	What, if any, kinds of things does [child name] know about your schooling, what your family was like growing up, or some of those important experiences you mentioned?

Table VI

*Mothers’ Educational Experiences*

Mother	Age	Birthplace	IEP in School	Schools Attended	College
Juliana	22	Chicago*	Learning Disability	2	Associates Bachelor’s degree in progress
Fatima	27	Chicago	Learning Disability	3	Associates
Mariana	45	Chicago	N/A	7	Some college
Amelia	23	Chicago	N/A	2	Some college
Isabel	25	Chicago	N/A	4	N/A
Cecilia	30	Mexico	Learning Disability	2	Associates OT certification in progress
Guadalupe	36	Mexico	N/A	2	Associates

\*The parents of all seven families emigrated from Mexico to Chicago.

Table VII

*Key Information about Children of Mothers*

Mother	Child of Focus	Age / Gender of Children	Disability of Child	Home Language*
Juliana	Natalia	4/ girl 2/ boy	Developmental Delay None	English/Spanish
Fatima	Carlos	5/ boy 3/ girl	Developmental Delay None	English/Spanish
Mariana	Benjamin	21/ boy 9/ boy 7/ boy 4/ twin boy 4/ twin boy	AD/HD Autism None Speech/Language None	Spanish/English
Amelia	Abidan	4/ boy 2/ boy	Autism Developmental Delay	Spanish
Isabel	Jesus	5/ boy 4/ girl	Speech/Language Speech/Language	English/Spanish
Cecilia	Hector	8/ boy 5/ boy 4/ boy 1/ girl**	None Speech/Language Autism None	Spanish
Guadalupe	Armando	18/ boy 14/ girl 5/ boy	Learning Disability None Developmental Delay	English

\*Primary language spoken in home is listed first.

\*\*Cecelia was pregnant with her fifth child at the time of interviewing.

In Table VII, I examined the mothers' children. I looked at the age and gender of each child, disability label, and language spoken at home. This allowed me to see the variation in the children of the mothers and the connections, or lack thereof, between them. The information overall is useful as a backdrop to interpretation.



We see in Table VI that mothers ranged in ages from 22 to 45 years old ( $M=29.71$ ). Two of the mothers, Cecelia and Guadalupe, were born in urban areas in Mexico. Cecelia was brought to the U.S. with her family when she was five and Guadalupe when she was three years old. Both Cecelia and Guadalupe completed all of their schooling in the U.S. All of the mothers completed all of their schooling in Chicago except for Mariana. She attended elementary school in a suburb of the city and high school in Mexico City, Mexico, before returning to the U.S. after graduating high school. Three of the seven mothers had an IEP in their own schooling. Juliana, Fatima, and Cecelia all disclosed that they had a learning disability while in elementary school. Four of the mothers attended two schools for their primary and secondary schooling: one elementary school and one high school. Fatima attended two elementary schools and one high school, Mariana six elementary schools and one high school, and Isabel three elementary schools and one high school. Six of the mothers attended public school for both elementary and high school. Juliana attended private Catholic schools for elementary and high school. All of the mothers graduated high school in Chicago and six of them had at least some college. Additionally, Juliana, Fatima, Cecelia, and Guadalupe had earned associates degrees from local community colleges. Juliana was working on a Bachelor of Science in Nursing (BSN) and Cecelia was just about to begin an occupational therapy (OT) certification program at the time of interviewing.

There was only one female child out of the seven children who were the focus of the interviews (Table VII). The children ranged in ages from four to nine years old ( $M=5.14$ ). Four of the mothers had two children, while the rest had between three and five ( $M=2.86$ ). Fifteen of the 20 children of the mothers in this study were male. The age ranges of all of the children was 1–21 ( $M=6.45$ ). Five of the mothers had more than one child with a disability. Of the children that were discussed in-depth in interviewing, three had autism, three had a developmental

disability, and one had a speech/language impairment. The disability labels were disclosed by the mothers at the first interview. Four of the mothers spoke both English and Spanish at home, two spoke Spanish only, and one spoke English only. All of the mothers and their children were, however, receptively bilingual in English and Spanish.

**Summary.** Mothers in this study ranged in ages from 22 to 45 years old, with the oldest two mothers, Mariana and Guadalupe, having adult children and, thus, the most experience rearing children. All of the mothers attended schools, at some point, in the Chicago area. Consequently, mothers were able to make direct comparisons between their schooling experiences and that of their children. Mothers had a range of educational background and capital. Five of the seven mothers' children were younger than 8-years old, so we hear a collection of stories about getting supports and services for children at a young age. Five of the mothers had more than one child with a disability, which meant that they had attended IEP and individual family service plan (IFSP)<sup>1</sup> meetings outside of the ones they discussed in interviews. Lastly, of the seven mothers, six raised their children in homes where Spanish and English were used, thereby helping their children learn two languages simultaneously.

### **Thematic Analyses**

I now turn to the cross-case thematic analyses related to the research questions. Five themes emerged: (1) parent knowledge of child, (2) gaining knowledge and/or supports from others, (3) self-awareness, (4) mom as protector, and (5) awareness of cultural difference. Two of these five themes directly address parent knowledge. The third theme, in part, emerges from how parents perceived their knowledge, skills that emerged, and values that informed their

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<sup>1</sup> Individual family service plans, or "IFSPs," are specialized service plans for children under the age of three who have a developmental delay. An IEP is put in place once a child turns three.

knowledge; that is, how they see themselves. The last two themes are connected through how mothers expressed their cultural understandings. The fourth theme, mom as protector, in some occurrences, included awareness of cultural difference; however, there were also occurrences of awareness of cultural difference outside of mom as protector, hence this became a standalone theme. For each theme, I begin by introducing and defining the theme. I share the major keywords mothers used when describing the idea. I then organize each theme into sub-themes that emerged during analyses. I conclude with a summary in each theme.

Table VIII

*Themes, Number of Occurrences, and Sub-Themes*

Themes	# of Occurrences	% of Total	Sub-Themes
Parent Knowledge of Child (PKoC)	93	20.9%	Noticing Development Observations of Child Parent/Child Interaction Outside School
Gaining Knowledge and/or Support from Others (GKS)	103	23.2%	Getting Help from Professionals Getting Help from Family and Friends Finding Resources
Self-Awareness	111	25%	Awareness of Emotions Difficulties of Rearing a Child with a Disability Acceptance of Disability Confusion about Assessment and Services
Mom as Protector (MAP)	114	25.7%	Advocacy Conflict with School Conflict with Family Safety Concerns in the Community
Awareness of Cultural Difference (AoD)	23	5.2%	Language Culture Race/Ethnicity
Total	444	100%	

In Table VIII, I list the themes and sub-themes in the order they are discussed. I also show the number of coded occurrences and percentage for each theme. Themes were ordered from the least to greatest number of coded occurrences to reflect the importance that mothers seemed to place on each theme. This was seen as a sort of narrative arc, where there was a natural buildup to the more prevalent themes. Awareness of cultural difference was ordered last, however, because it linked more strongly with mom as protector. In both themes, mothers discussed cultural knowledge and its impact on their knowledge, values, and beliefs. Additionally, awareness of cultural difference seemed to be informed by mothers' role as a protector of their child.

### **Parent Knowledge of Child**

One major theme was parent knowledge of child (PKoC). I defined PKoC as the personal, in-depth, and at times nuanced knowledge parents had of their children. There were 93 coded occurrences of PKoC theme, which was 20.9% of the total number of coded occurrences. When speaking about knowledge of their child, mothers often used words such as know/known, notice/noticing, good (at)/smart, feel/feeling, and speech/speaking/talking that revealed that their knowledge often rested upon observations of their children. What they shared was historical information as well as observations and experiences of their child outside the school setting; that is, the knowledge derived from birth to the present time. Three sub-themes emerged from the broad theme of PKoC: (1) noticing development, (2) observations of child, and (3) parent/child interaction outside school.

**Noticing development.** Mothers often referred to developmental patterns they noted. Often, those kinds of observations were raised several times and/or across more than one interview. Often, observations about developmental patterns appeared woven into other stories

mothers told. For instance, when speaking about Carlos's stomach problems, Fatima observed her son's inability to walk at the right time as potentially significant:

I started noticing certain things at some age, probably like age one. He will touch his stomach like his stomach will hurt, but I did not know what was going on with him. Then he was about the age of one, he was not walking. A year and a half he was not walking. He was doing every single thing what a normal kid needs to do, but the walking was just the problem (Int 1, 06/13/2018).

Fatima continued to worry about Carlos's potentially related constipation problems and inability to walk, which she observed did not seem developmentally appropriate. While living in Texas, a therapist came to her house to evaluate Carlos. "The therapist came and he saw his feet, and the reason why he was struggling with walking is because he needed some implants on his feet, which they gave it to him, and I just refused to put it on him, because it will hurt him. But eventually he walked fine. After addressing his walking issues by using the implants that helped him become ambulatory, Fatima once again began noticing developmental patterns that did not seem right in her eyes. She said:

Basically from there, he was delayed on walking only, but not only that. I noticed he was getting delayed on speech. So from Texas from age two, they were giving him speech. They were giving him OT, speech, and the other one for the feet (Int. 1, 06/13/2018).

Fatima was confused by these comorbid conditions and the pace of Carlos's progress. She noticed that he would learn new words but then quickly forget them. "All of a sudden he just stopped. He has never said that word again. So there's words that he's said in the past that he will forget."

Like Fatima, other mothers spoke about the frustrations, of both parent and child, related to observing and making sense of the developmental oddities in their children. While retelling me where her daughter Natalia needed the most support, Juliana stated:

She had a hard time expressing herself verbally. She only said one word instead of saying two to three words or a full sentence, and that was a big issue because since she wasn't able to express herself, she would always get frustrated and end up crying and having those little moments where she's frustrated (Int. 3, 06/29/2018).

Similar to Fatima and Juliana, Cecelia discussed the frustration she had figuring out what was wrong with her son Hector. According to her recollections, development for Hector seemed different. She explained:

And the reason I realized something different with him was because he wasn't speaking and he skipped crawling to walking. Like, nine months, he started walking. That's early. But then when he was one and a half, he went to crawling but he would crawl on his butt, like, squat. I don't know. It was like he would scoot himself. He wouldn't wanna walk anymore. So like, lazy ... (Int. 2, 07/12/2018).

Some mothers also realized that these developmental delays were impeding their children's ability to interact with others. For instance, Guadalupe stated:

I had an issue at the beginning, because of his hearing problem. He wasn't able to express himself because of the hearing. His speech was delayed because he couldn't understand what you were saying. I understood him but, if you were to have a conversation with him, you would be like, "huh?" (Int. 1, 09/27/2018).

Like Guadalupe, Juliana noticed that her daughter Natalia was getting frustrated because she could not communicate clearly with others.

She had a hard time expressing herself verbally. She only said one word instead of saying two to three words or a full sentence, and that was a big issue because since she wasn't able to express herself, she would always get frustrated and end up crying and having those little moments where she's frustrated (Int. 3, 06/29/2018).

Juliana and Guadalupe both saw their children's frustrations as linked to their speech delays and noted any progress in their development. In an earlier interview, Juliana opined: "I noticed a big change from her not saying any words at all to her saying a whole full sentence" (Int. 2, 09/21/2018).

Some mothers, like Mariana and Cecelia, who both had sons with autism, linked the etiology of their children's disabilities to vaccinations and expressed frustration about the advice to get vaccinations.

I thought he was fine and everything, and then the age two happened, he had his shots, and I thought it was the shots, but they say no, but I swear that he just had this big fever for a couple days, and I know fever comes from one thing, and that's it, with the shot (Mariana, Int. 1, 06/13/2018).

Mariana, even after being told by doctors that her son Benjamin's autism was not caused by vaccinations, went on to explain how she refused to get the same series of vaccinations for her next child: "So I'm like, 'Okay, you know what? My next baby,' which is Isaiah. Like, 'No. You're only going to give him one of those.'" Cecelia echoed Mariana's conviction that there was a developmental regression after her son Hector received his vaccinations: "Before he was born he was great. After he turned two and he received a shot, he started changing. He stopped walking. He started back to crawling" (Int. 2, 07/12/2018). In other instances such as these,

mothers described their perceived causal links to developmental anomalies they noticed in their children.

**Observations of child.** Mothers constructed knowledge about their children that emerged from and seemed linked to their observations and interpretations. This theme emerged from seeing instances where mothers observed their children acting and behaving in ways that were not ostensibly tied to their development. Rather, these were instances where mothers talked about their observations, their wondering about what they observed, and their interpretations linked to their child's likes, assets, and/or challenges. The instances were situated and complex in nature, and usually part of larger narratives mothers related about their children.

Amelia provides a good example of a parent's observations of her child being part of a larger narrative. Her 4-year old son, Abidan, had autism. Amelia talked of when she began to notice his desire to self-stimulate through playing with blocks and obsessing over the tactility of objects. After discovering his diagnosis of autism, Amelia then began to change the way she interacted with Abidan.

So before he would bang himself on the wall, so now what he does is he puts his eyes up and he just sits to himself like that. Before I knew his diagnosis, I didn't know what to do. I would just try to calm ... sit with me all the time, [we] didn't really go out. Like I have to go out because he's my son, so once I found out his diagnosis I would try to give him compressions. I would try to walk him to the park. I would let him jump on the bed (Int. 1, 06/22/2018).

Amelia then described observing and interpreting new skills that Abidan was acquiring, many of which were concealed before learning of his diagnosis. She noticed that "he likes to kind of memorize" and will "memorize everything all the time." She also began noticing that Abidan



behaved differently with her than at school. Abidan seemed to do well with the structure of the program he was in at daycare, but would often cry to get his way when around Amelia. She interpreted that as him knowing she had a “soft spot.” Amelia, while observing Abidan’s cunningness with getting his way, responded by making sure she followed through with her requests of Abidan. For instance, Amelia would tell Abidan, “I’m sorry, but if you want the phone, if you want to do something, you have to clean. So he will then actually clean up.”

Mothers’ knowledge through their observations and interpretations were often focused on things they knew their child liked. For instance, Isabel discussed what 5-year old Jesus likes and dislikes. She then ended this short interpretation by discussing why he likes certain things and not others.

He’s really active. So, just jumping, running, dancing. He finds school difficult so he doesn’t like that very much. I guess with his speech it’s harder for him with reading the words and in kindergarten they’ll start with words and things like that. So, with his speech I think that he finds it more hard for him. Math, he’s really good at (Int. 1, 06/25/2018).

Isabel then continued to discuss what Jesus liked: “Well, he likes the friends and the science. He likes animals and things like that.” Other mothers described similar observations and interpretations of their child’s likes and also dislikes. Guadalupe said of 5 year old Armando:

He’ll talk to strangers. Even though, he couldn’t, he had problem with his speech, he will try to communicate. He’s very open. Very friendly. He’s very affectionate. He likes to hug all the time. When I pick him up from daycare, he hugs his friends (Int. 1, 08/24/2018).

Guadalupe continued to discuss traits and behaviors of her son that let her know who Armando was as a person, often with the absence of verbal language because of his delays in speech.

**Parent/child interaction outside of school.** Another aspect of mothers' knowledge of their child emerged from their interactions, mostly outside school. To differentiate this theme from that of observations of child, I looked at those instances where mothers directly stated that their interactions with their children occurred outside of school (e.g., at home, the park, or in the community). Since a child's world is shaped through interactions with her parents (Smith, Cowie, & Blades, 2015), it makes sense to look at those experiences that occur organically between mother and child, which overwhelmingly occur outside of school settings. Cecelia's stories about her interactions with her son Hector (who is 4 years old and has autism) provide a good example. She highlighted in different ways what Hector was like at home. For instance, she said that "Hector is a really smart and intelligent kid. When I say intelligent, even though he's a solo child, playing alone, he's able to build a puzzle" (Int. 1, 07/09/2018). She also witnessed his quirks: "Anywhere we go and he sees a bus and he just says, 'school bus, c'mon let's go.'" During a different interview, she retold a story of how Hector does not like going out of the house. She then stated: "Because I would just see myself in him when I was little." When asked what she meant by seeing herself in him, Cecelia elaborated:

When he would do things at home, he would just stand there and that's exactly what I would do. When my mom would tell me to go somewhere, let's go to the park, "no I don't want to go." Or "let's go here." I would always just want to be home. That's just like Hector doesn't want to go a lot of places. I'm not autistic that I'm aware of (Int. 2, 07/12/2018).

Cecelia slowly and methodically told the story of how she came to understand who Hector was as a person. She talked of how she saw his personality blossoming, even though others saw a small non-verbal boy that was difficult to deal with. As our conversation continued, Cecelia began to sob and laugh at the same time when she retold a story of one of her favorite moments with Hector.

Cecelia: The best things I've done with him was ... let's see ... I don't know. What's best?

When he had finally started calling me "mom" because he would call me grandma, dad. Every time I would pick him up "daddy" and I'm like, "No, I'm your mom." [Cecelia was laughing and smiling and crying at times as she said this.]

Joe: Sorry, I'm not trying to laugh.

Cecilia: No it is, because it's funny. His teachers would be like, "Why does he call you daddy?" I don't know if it's probably easier for him, I don't know. I'm way nicer than daddy. Daddy is very impatient with him. He wants him to understand things like if it was easy. [Cecelia was laughing and smiling at times as she said this.]

Joe: So when did that happen? When he started calling you Mom?

Cecilia: I would say about six months ago.

Joe: Okay, so just recently.

Cecilia: Yes just recent, that's why I'm like I like it when he calls me mommy and he can identify that I'm his mom in pictures. Because before he was like "oh daddy" and like "who's that," "daddy," "so you have two daddies?" "Yeah," and I'm just like "Okay. Cool, you have two daddies" (Int. 2, 07/12/2018).

The memories embedded in the story show Cecilia's interactions with her child are situated in time and space, and can happen spontaneously. The linkages between and across time and settings are revealed through the story Cecilia created. For Cecilia, this story and the knowledge about Hector that it revealed seemed also to have great significance.

Other mothers also spoke to the knowledge acquired from interactions with their children. Like Cecilia, many of the stories mothers told about their memories with their children evoked a sense of joy and nostalgia. These reflections on memories almost always brought smiles to mothers as they relayed the interactions to me. Amelia, for instance, spoke about a trip she took with her sons, Abidan and David, and family on the Fourth of July. She told of how Abidan, David, and the other kids liked it and how she liked taking trips. "I like roaming around. Like one time we went to [border state] last year for the fireworks, and we would just let [the kids] loose and they would just be running, running, running, until they tire themselves out" (Int. 1, 06/22/2018). In another example, Fatima told me about Carlos recognizing his therapist's office, and how he always knew it. "Every time I drive where his therapist is, on [name of local hospital], he knows the building. He knows that the building is where the therapists are. So, he, whenever I park the car, he already knows where he's going" (Int. 1, 06/20/2018). Finally, Mariana relayed a funny antidote about her 9 year old son Benjamin who likes to cook.

He's in the kitchen all the time, and like, "Okay, Benjamin, I think you're going to be a cook." "A cook, a cook? I cook Mom." "Okay, you cook. But what are you going to cook?" "Pancakes." I'm like, "Not pancakes again, no." And he laughs because I'm like, "Oh, okay, chicken pancakes" (Int. 2, 07/06/2018).

**Summary.** Three key components or sub-themes of parent knowledge of their child (PKoC) seemed centered on observation. One was focused on developmental patterns, and

mothers' capacities to draw on their observations and interpretations to identify concerns about what they perceived to be irregular development. Another was focused on their child's likes, assets, and/or challenges, which also revealed mothers' knowledge of their child's personality traits and capacities. Lastly, mothers constructed knowledge through their numerous interactions with their children across multiple contexts outside school. Most often, those were in the home. Mothers seemed both to reveal and construct knowledge of their child from their observations and interpretations, which came through in the stories they told in response to several interview questions. The stories, typically rich with multiple observations and often with repeated ideas and key phrases, seemed to weave together a tapestry of in-depth knowledge over a range of kinds of observations mothers made along with the range of ways mothers' beliefs and values seemed to be shaped.

### **Gaining Knowledge and/or Supports from Others**

In part, those beliefs were often supported by others. Another major theme that was illuminated during thematic analysis was gaining knowledge and/or supports from others (GKS). GKS was defined as parents gaining knowledge and/or support from advocates, school personnel, therapists, family members, and resources. There were a total of 103 occurrences that related to GKS, which was 23.2% of the total number of coded occurrences. Mothers referred to an array of individuals that helped them gain knowledge and supports, such as school personnel, therapists, and family and friends. Mothers also often referred to online resources, books, articles, and trainings/workshops as important resources they used to better understand the IEP process, disability, parental rights in the IEP process, and available services. When speaking about GKS, mothers used words such as teachers/teaching, school, community center, therapy/therapist, know(ing), understand(ing), help, read/reading, Google/You

Tube/internet/Facebook, book(s), friend(s)/family, and autism. Three sub-themes exemplify how, when, and where parents gained this knowledge and support: (1) getting help from professionals, (2) getting help from family and friends, and (3) finding resources.

**Getting help from professionals.** To highlight the sub-theme of getting help from professionals, I looked at those instances where mothers directly referred to professionals that helped them gain knowledge and/or supports. Professionals is here defined broadly, and includes teachers, case managers, social workers, advocates, community center staff, specialists, and therapists. In most of these instances, professionals and staff members worked for a school or community center with a school-oriented program. However, mothers also referred to professionals outside of schools, such as applied behavior analysts (ABA), occupational therapists, and medical doctors and nurses. It was often the case that professionals provided a multitude of services for mothers. Mothers often gained knowledge about their child's disability and how to best support it, and also professionals connected them with resources and services to better support their child.

Mothers often spoke about the community center in which many of the mothers participated and which provided a recruitment site for this study. They spoke of it as an important resource to learn about services for their child and their parental rights. For instance, Juliana was reluctant to get her 4-year old daughter Natalia an IEP in school. She slowly learned about the benefits of having an IEP in school from staff at the community center. "They kept on encouraging me, the teachers at the day care, to take my daughter and make sure that she got [an IEP]. Cause they're like, 'It's very beneficial to her'" (Int. 2, 06/21/2018). Upon having Natalia evaluated and discussing potential services, Juliana talked about some of the supports she received during the first IEP meeting she attended:

Well trying to calm her down because she still had that issue that she would get really frustrated and start crying. So, they did say that that was an issue. So, that was another goal to try to have her relax and notice what the problem is, notice how big the problem is (Int. 2, 06/21/2018).

Teachers at Natalia's school then began using strategies to help her cope with her fears and anxieties, such as breathing techniques and talking to her about why she was crying. The strategies started to work at school but Juliana noticed that Natalia would still cry a lot at home. Juliana then began using at home strategies she learned from school personnel. While it took over a year of being consistent with Natalia, eventually Juliana said that there was great improvement. Juliana then stated that Natalia's crying could now be interrupted very easily: "I would just look at her. I would give her this look, and she knew that she needed to stop."

The community center was often one of the first tangible support systems that mothers had. After getting a diagnosis of autism at the behest of family, Amelia discussed how nervous she was at her first IEP meeting: "I was nervous 'cause there was like, everyone had their laptops there" (Int. 2, 07/02/2018). Amelia then went on to explain why she was so nervous: "Because I knew I really had to kind of explain everything of what he does and what he doesn't do." This nervousness was mitigated by the presence of the classroom teacher and family advocate from the community center who attended the meeting with her. "She came in so I was really confident that I was really calm once I knew they were gonna be there. It was less stressful and so they took me in transportation from [community center] over to there." Amelia, moreover, felt a new sense of confidence through the supports given to her from community center staff. For example, she discussed how the health supervisor at the community center ordered her an Uber and, in Amelia's words, "...walked me to the car and she's like: 'He's gonna take you to the place you

have to go.” Mariana stated something similar when she said that she “started feeling confident” when an advocate from the community center attended an IEP meeting with her (Int. 2, 07/06/2018).

Mothers also talked about how personnel at the community center would notice certain things about their child that were mysterious. For instance, Guadalupe’s son Armando had been in and out of the hospital for issues he was having with hearing. However, she did not always correlate his hearing issues with some of the behaviors he exhibited. At some point, she communicated with personnel at the community center, and she realized that Armando needed to return to the audiologist to get further evaluations. She said, “But more daycare, they noticed more at daycare, cause they, I guess they have activities and things that, you know, are his age. So that’s when daycare noticed a little bit more than I did” (Int. 2, 09/07/2018). It was through these conversations that Guadalupe then went and sought help from professionals external to schools, such as audiologists and speech/language therapists, to better support Armando’s needs.

Staff at the community center were often the catalyst for mothers to find external services that would address issues their children were experiencing. Mariana, for instance, was connected with an ABA specialist. She discussed how she learned many strategies from him on how to support her son Benjamin who had autism. She then went on to talk about how the ABA specialist attended an IEP meeting for Benjamin:

I was knowing more stuff now. I took [ABA specialist] who is his ABA teacher, his ABA place worker. I took him [to] the last two meetings with me and he did most of the talking for me. I was just agreeing [with] everything that he was saying. “So that’s what you want?” “Yes, that’s what I like” (Int. 2, 07/06/2018).



It was often the case that professionals provided more than just services for the children of mothers. Fatima, for example, talked about the resources of both the knowledge and emotional support she received from one of Carlos's therapists.

The person that helped me was a therapist because I went with Carlos. It was just one session. She just guide me and she just opened my eyes and [I] realized, you know, what I was doing. It was right, but I just need to accept the things. Not every kid is gonna be in special ed, and some of the kids are going to be in special ed (Int. 2, 06/20/2018).

Fatima was having trouble accepting that Carlos had a disability, confiding that many parents thought "...the special ed program is for dumb people." She struggled to see Carlos as he was, and instead put off having him evaluated for as long as possible because other parents were interpreting special education as a pejorative. It then took the help of a specialist to allay her fears and reluctances. This allowed Fatima to seek out the best possible services and supports for Carlos.

**Getting help from family and friends.** In addition to professionals, mothers also received support from family and friends. It was sometimes the case that family members would notice problems that parents did not notice, or were reluctant to acknowledge, and would thus encourage parents to seek out professional help. In other cases, family members and friends would provide verbal support through the provision of knowledge that they had acquired while supporting their own children with disabilities. In yet other instances, parents would make friends with other parents at the community center or some other organization. These ad hoc support networks often relieved mothers' anxieties and provided them a space to openly discuss themselves in relation to their children. A good example of the latter can be found when Isabel discussed meeting other mothers while taking Jesus to therapy: "At his other occupational

therapy. The moms just talk about stuff for the kids that came out and I was like, ‘Oh, I want to try that!’” (Int. 1, 06/25/2018).

In several instances, family members were the first to notice issues with the children of mothers in this study. Mariana, Amelia, and Cecelia all spoke directly to this, and Juliana and Fatima mentioned similar occurrences, albeit less directly. Amelia, for instance, told a story about her brother-in-law who was studying for nursing. He began pointing out that her son Abidan’s behaviors were typical for a child with autism. Amelia was reluctant to acknowledge this but did eventually take Abidan to get evaluated by a professional.

And then one of my brother-in-laws are studying for nursing. He’s the one who told his dad. He’s like, “he probably has autism ‘cause he looks like he’s doing this—this act.”

And then I was kind of like, “No, he’s fine.” ‘Cause he was my first born so I didn’t thought he had [autism] (Int. 2, 07/02/2018).

Upon taking Abidan to the doctor and stating that she thought he might have autism, she was told: “No he’s fine. He’s gonna talk later. He’s probably a late talker. He’s gonna talk later.” However, at three years old Abidan was not talking and her brother-in-law continued to say that his development was “typical” for a child with autism. She then made another appointment with the doctor and was given “...the developmental sheet where it’s a questionnaire and [the doctor was] like, ‘Fill it out.’” After completing a full evaluation, Amelia was told that Abidan had autism. Amelia was confused and anxious, so she turned back to her family for support. Her mother and her mother-in-law went to the next doctor’s appointment with her and encouraged her to see it through. Amelia’s mom was eventually able to find supports through the local community center. Amelia stated that she “didn’t know nothing about that” before her mother had located these supports.

In other instances, mothers would turn to family for advice about what to do. Fatima had a younger sister with Down syndrome, as well as a learning disability herself, and would often discuss with her mother how to best support her son Carlos. Fatima's mother had been a strong advocate for Fatima's younger sister and would often tell Fatima that the most important thing is to accept your child for who she is. Fatima struggled with this and often ignored potential issues in hopes that they would simply disappear. She told her mother, "Carlos will be normal again," to which her mother replied, "But what is normal? So what is normal to you?" (Int. 1, 06/13/2018). This was not the last time that Fatima's mother intervened on her grandson's behalf. Later on, Fatima refused to go to the Social Security Office to get benefits for Carlos because she believed that would be admitting there was something permanently wrong with her son. According to Fatima:

My mom dragged me to the social security and told me, "You're going to stay here and you're going to receive that for Carlos. You don't realize that it's not for you. It's for him, so you can get yourself a part-time [job] and focus on him (Int. 1, 06/13/2018).

Like Fatima, Juliana sought the support of others. For her, it was her co-workers because they had more knowledge about the IEP process and disability than her. When I asked if she ever discussed Natalia's disability with anyone outside of the school, she stated:

Just to my coworkers and my supervisor, 'cause they also told me that they had relatives that went through that, too. Cause I really didn't know what was going on, and I wanted to see if anybody else knew what was it about and stuff like that (Int. 2, 06/21/2018).

**Finding resources.** It was often the case that mothers took it upon themselves to increase their knowledge of and supports for their child. In these cases, more often than not mothers turned to online resources, books, and presentations/workshops on a variety of issues related to

the IEP process and disability. Sometimes mothers intentionally sought this information out; at other times, mothers came across resources serendipitously.

One example of a mother unexpectedly coming across resources can be found in Isabel. I had asked Isabel how she located all of the services and resources that she was discussing. One of her responses was the following:

I used to take my kid a lot to the library and they have the information like at the desk.

They have a bunch of flyers and things like that, that give you that kind of information.

That's how I found out a lot of programs and things like that too (Int. 2, 07/02/2018).

This small event of serendipitous discovery ushered numerous subsequent discoveries of programs geared toward children with disabilities. Isabel enrolled Jesus in programs through the park district, disability networks, and community agencies. Jesus was, at the time of our interview, taking swimming lessons, enrolled in a horse therapy program, and gymnastics. At one point, Isabel acknowledged: "There's just too many" (Int. 3, 07/09/2018). Isabel had also utilized Facebook pages on an autism network to help find more resources, as well as books. She talked about the advantages of reading more about disability:

And the book that I read really helped in knowing the IEP more, like the goals and modifications that can be done. It's good for like parents that are new to it cuz it kinda trains you on what to say about disability, so you can go in and understand at the meeting (Int. 2, 07/02/2018).

Cecelia, like Isabel, turned to a variety of resources to learn more about autism so that she could better support Hector. She talked about the books she read, and what she learned from them: "I mean we bought books about sign language. We put pictures at home for him to know this [is] a door, this is a chair, this is a table, and then when he wants something, everything is

labeled at home” (Int. 1, 07/09/2018). In a later interview, Cecelia discussed how she learned all she knew about autism.

Yeah. I went to the library and Googled “autistic.” Then on Facebook I would put recommendations like, “Anybody have any recommendations for autistic children?” Now suddenly I have like three friends that have autistic kids. I’m like, “Why didn’t you tell me about this? I didn’t know you had an autistic [child].” I was like, “Okay, well now we can go in a group and take our children somewhere” (Int. 2, 07/12/2018).

In Cecelia’s case, she was able to not only learn more about autism through consulting resources, she was able to find a support network through the shared experience of being a mother with a child with autism. However, this all emanated from queries on search engines and posts on social media. When I asked Cecelia what advice she would give to parents about the IEP process, she once again referred to the resources that supported her own knowledge development.

I would say thanks to god that Google exists. Let’s research an IEP together. I don’t know how to explain an IEP. It’s really difficult. Yeah. It gave me so many different resources and I’d be like, “Which ones should I choose? There’s so many.” It gives you a lot of information (Int. 2, 07/12/2018).

Finally, mothers also discussed trainings and workshops they attended to gain more knowledge about the IEP process. Amelia was one of two mothers in this study that attended a workshop I did on parental rights in the IEP process. She mentioned this several times during interviewing. At one point, I asked her about how she would continue her learning about IEPs. She then referred back to the workshop: “That day at the presentation you explained to us about the rights for him [Abidan]. I was really happy about that because that’s a good thing. I think it kinda helps me know more” (Int. 2, 07/02/2018). Mariana was also at my workshop and had

discussed other trainings and presentations she had attended. At one point, she told me that an advocate at the community center wanted her to do her own presentation to share the knowledge she had gained from others. She expressed her hesitation when she stated: “I don’t want to present to no one” (Int. 2, 07/06/2018). I then asked her if she did a presentation.

What am I going to do? What am I going to say? They’re like, “Don’t worry, [advocate from community center] will be there with you. She’s going to ask you the questions and you got to answer them. Okay.” So she’ll always ask the right questions and I answered, and a lot of people were like, “How did you do it?” They started crying and I knew how they felt. I know how they feel. Like the more you know, I told them, the more you know, the less you’re crying, the stronger you are (Int. 2, 07/06/2018).

Mariana was at first hesitant to share the knowledge she had acquired to other parents. However, when I asked her how she felt after the presentation, she responded: “It felt good. It felt nice. It feels nice to share. There has to be more like that, more that type of thing, ‘cause that’s the only way we’re going to know stuff.”

**Summary.** Mothers acquired knowledge about the IEP process, their child’s disability, and special education services through a variety of sources. Whether it was from the mouth of a professional, a Facebook post on an autism support network, or unexpectedly coming across flyers about services at the library, mothers assimilated this knowledge and used it to better support their children. Additionally, the knowledge that mothers acquired often informed their beliefs about disability and the IEP process. Mothers talked about the confidence they gained, often evidenced by them speaking more in IEP meetings. We also see instances of mothers seeking knowledge; that is, their intentionality in getting it and how several became increasingly adept at gaining and developing new knowledge and skills. The next theme strongly relates to

how mothers saw their knowledge and skill, and how they often drew upon it to reflect on their own awareness of self.

### **Self-Awareness**

Taken together, 44% of coded occurrences had to do with knowledge (both gaining it and drawing on it; that is, the last two themes). Mothers' knowledge and linked skills, beliefs, and values also affected their self-awareness, another major theme that emerged from thematic analyses. There were a total of 74 occurrences of statements that directly related to mothers' self-awareness, which was 25% of the total number of coded occurrences.

Mothers often told larger stories about their experiences as learners, family members, caregivers, partners, and advocates for their children. Within those stories, mothers often perceived of and shared their awareness of their own viewpoints and emotions related to rearing their children. They demonstrated various kinds of self-awareness that seemed to emerge from the multiple roles they played, the knowledge and values that helped shape their interpretations, and any emotions they shared. During interviewing, mothers often used specific words to signal their self-awareness, such as understanding, school(ing), know(ing), feeling/felt, protective/overprotective, mom, nervous, accepting/acceptance, time, learn(ing), and normal. Their words and stories informed the development of the following definition for the theme: Self-awareness occurred when mothers demonstrated an understanding and perception of their knowledge, skills, values and emotions in relation to rearing their child. Taken together, these stories seemed to capture perceptions that mothers had around their changing and sometimes conflicting conclusions about their own schooling and how it related to their child's schooling, and what was occurring actually within the process of their child's school. I illustrate this theme around four sub-themes: (1) awareness of emotions, (2) difficulties of rearing a child with a

disability, (3) acceptance of child, and (4) confusion about assessment and services. I will first discuss and situate each sub-theme before using mothers' stories to illustrate their presence in this study.

**Awareness of emotions.** It was often the case that mothers would reflect on their emotional states at various points in the lived experiences they shared. The emotions ranged in quality and intensity from, for instance, profound joy and immense pride to self-blame and overwhelming anxiety. This spectrum of emotion was situated and complex, often emanating from larger stories about interactions with their children, their families, and school-based personnel and situations.

Mothers often expressed joy and gratification when discussing interactions with their children. For instance, Juliana discussed how her mother watched her youngest son while she worked. She then described her emotional reaction to her 2 year old son's response to seeing her when she arrived home: "He's very needy, and now he's always attached to me. Soon as I get home, he always wants to be with me. I love that, though. I love it. It's like the best feeling ever" (Int. 1, 06/07/2018). Later in the same interview, Juliana described how much she appreciated having unadulterated time to spend with her children when her family made an annual trip to Mexico.

We go to Mexico every year, so I love that, because it's a time where I get to give them my attention. My full attention. Yeah, I get to actually be with them 24/7. When I'm in school [Juliana attends school herself], I hardly get to see them. So when we go to Mexico, it's just like, "Oh," you know? "I finally get to be with you." I get to understand [Natalia] better, you know?



Cecelia also echoed the feelings of joy that emanated from spending quality time with her children. She shared an extended story about taking her child with autism, Hector, to therapy downtown with friends she had met through an autism support network. Cecelia described how she and her friends at times would begin to share frustrations or concerns about their lives, and how she would intervene and focus the group of mothers on having fun with their children.

We just let them be on their own. When we do, we start talking and then one gets sentimental, the other one gets mad, and then I started getting aggravated. I'm like, "You know what? Every time we come here, we just forget about the kids. We just focus on whatever career you're doing. [But] just focus on your child. Make sure he doesn't run somewhere else." We ended up just being with the kids on the slides. We'd slide with them and play with them. That's how you know time flies really quick (Int. 2, 07/12/2018).

On the other hand, Guadalupe and Juliana discussed the conflict between the joy they felt and the misgivings they experienced. Both became mothers early in life, Guadalupe at age 17 and Juliana at age 16. Guadalupe illustrated this mixture of emotions and awareness of how her perceptions of life were transformed when having her first child, who is now 21 years old and who was identified with having AD/HD when he was in school.

To become a mother at an early age, it was very numb. It changed my whole perspective about life, and in a way I am very grateful, because my son kinda pushed me to become a better person every time I seen him, and I mean I don't regret having him at an early age. The experience was a little bit hard because I did it an early age what I shouldn't of gone through it. But it helped a lot to what I am now and I can teach my kids to keep on going

no matter what happens or what goes on in life. You have to keep on fighting. Keep on going. No matter what happens at all times. It made me very strong (Int. 3, 09/27/2018). Similarly, after discussing her regrets that she did not get to go away to college, Juliana laments that getting pregnant at a young age was an “eye opener because it kinda told me, get your life together. You have to do something. That you can’t just depend on your parents. You have to get a job, make sure you’re going to school” (Int. 1, 06/07/2018).

As Juliana also shared, mothers’ awareness of their emotions sometimes stemmed from empathy for their children and a sense of confusion about how to best support them. As opposed to joy, Juliana also discussed the sense of sadness that came about from realizing that her daughter Natalia was struggling with her speech:

I was kind of sad because I was like, “Oh my daughter’s struggling.” You never want your kids to struggle, and that was kind of an eye opener for me. I was like, “Oh we might need to start spending more time with her and realize that she’s not a baby anymore.” ‘Cause I used to see her as a little baby, and not realize that she’s growing up (Int. 2, 06/21/2018).

Fatima also discussed her emotional reactions to seeing her son Carlos struggle: “I feel like nervous because I’m like, ‘Somethings going on with Carlos and I just don’t know. I know it’s not daycare, for sure. It has to be the school, has to be the school’” (Int. 2, 06/20/2018). Fatima went on to describe how she did not know what teachers at the school were doing to help Carlos with his speech issues. She shared feeling that in part due to a lack of communication with the school. Later in the same interview, she said that she realized that Carlos was not getting all of the speech services she thought he needed: “I feel that the one speech per week, it’s not enough.”

Moreover, her original feeling of nervousness seemed to have evolved into a call for more services for Carlos.

**Difficulties of rearing a child with a disability.** Mothers often spoke to difficulties they experienced rearing their child with a disability. They spoke to the emotional maelstroms that arose from having a child that did not quite fit into their and other's conceptions of normative child functioning. These difficulties were sometimes directly tied to ostensible behaviors that they perceived as part of their children's disabilities. At other times, mothers seemed to be reacting to an awareness of the perceptions and characterizations of disability expressed by others, including school personnel, family, friends, and partners. There were times when mothers directly stated the difficulties they experienced rearing their children; at other times, the meaning of their words were gleaned through a closer reading of the whole of their accounts.

An example from Fatima shows her direct statement about some difficulties she experiences with having a child with a disability. "It takes a lot of time to support a child with an IEP," she offered. This came in response to a question about reflecting on a mother's role in the IEP process. When I asked Fatima what she meant by it taking a lot time, she responded:

Having children with an IEP takes a lot of time from you. No, you have to sit with him, you have to remind him. I mean, it's consuming time. So at the end of day, you might not see the progress but overall, in a year or two, you will see it (Int. 3, 07/05/2018).

Fatima had stated something very similar in the first interview when first describing her relationship with her son Carlos. She went on to say that, with patience, parents can see improvement in their child. Isabel, on the hand, discussed her frustration with seeing how her son (Jesus) would react differently to her than teachers at Jesus's school.

Well, at the beginning, it was kind of frustrating because sometimes your kid doesn't work as well with you than with other people. He would just like not do as well [with me] as with other people, or you don't know how to get his attention or things like that. For him being my first child, it was like everything was new, especially like kind of the process of getting him to talk. Like for a newborn, you would think that they just come in steps, you know? (Int. 2, 07/02/2018).

Isabel realized that many of her frustrations came from being a new mother and not knowing how to best support Jesus, who had a developmental delay in speech. She also saw how Jesus would respond differently to teachers at school. In the school setting, he appeared to Isabel to be more compliant and less likely to have tantrums. In the third interview, Isabel articulated how she felt more positive about her ability to support Jesus after learning several strategies from teachers. As an example of this, Isabel related, "I learned a few calming strategies, like tools really, to calm [Jesus] down. They showed those to me at [the community center]." She also later reflected, "I'm glad I learned how to calm him because it's like, like I wouldn't have known that on my own."

Amelia, unlike some of the other mothers, often experienced Abidan's difficulties not as a problem to be figured out but rather as a failure of her as a parent. Abidan was diagnosed with autism about a year before I met Amelia, but before she knew that he had autism she blamed herself for his behaviors. "I thought I was kind of a failure honestly. 'Cause he was my first born and I was really protective over him so I really thought I was like a failure" (Int. 2, 07/02/2018). Amelia's in-laws kept repeating that Abidan might have autism, but Amelia was reluctant to bring him to a specialist for an evaluation because she felt that Abidan was just going through a phase: "I was really reluctant about it because he was my first born and I thought it was normal."

Through the community center, Amelia finally brought Abidan for an evaluation and he was diagnosed with autism. Knowing this, however, did not improve Amelia's emotional state. She stated, "I was so scared. I was like really, really scared. Honestly, I was really, really anxious and nervous because I thought ... he's gonna do this, he's gonna do that, he's gonna run around." Additionally, her concern for how Abidan's disability might affect other people made Amelia "nervous" and "anxious." I asked how she dealt with this, to which she replied:

Did I forget to tell you I have anxiety? I have anxiety and depression. This I had, but more of anxiety. With Abidan that's how I got anxiety and depression, and after Abidan was born it was fine. Once he was two that's when I got anxiety completely. I couldn't control myself (Int. 3, 07/09/2018)

It seemed that Amelia was suffering with guilt over her inability to support Abidan. As with other mothers, some of this guilt may have stemmed from difficulties accepting that her child had a disability.

**Acceptance of their children.** In addition to discussing the difficulties they experienced rearing a child with a disability, mothers often demonstrated an awareness of how they came to accept their child. While instances of mothers' acceptance of their child occurred at various points during interviewing, I also noted that in several instances mothers talked about the notion of acceptance at the end of a particular discussion about difficulties they experienced. Thus in many ways, the themes of difficulty and acceptance are quite interrelated. They appear to be a process born of self-awareness over time.

One vivid example of the interrelatedness is Mariana's discussion about her son, Benjamin, who has autism. She discussed the conflict within her family. Many family members saw a problem, but Mariana believed it would go away. Mariana illustrated part of that conflict,

saying, “[Benjamin] didn’t like all these people, all the family coming, so he will get frustrated” (Int. 2, 07/06/2018). She then admitted: “I did not want to accept that he was autistic. I didn’t want it as a mom. I think it was silence and denial, and it was really hard for me to take up to this evaluation for him.” However, Mariana did eventually take Benjamin to get evaluated. Even after learning that he had autism, Mariana still hoped that “it’ll go away.” In time, Mariana began to accept that Benjamin had autism and it was not going away: “It was sinking in, but very slowly, but I learned eventually to accept him as he is.”

Mariana, as with other mothers, described a *process* of coming to acceptance. For mothers, it seemed that the initial response to learning that their child had a disability was to ignore or deny their internal conflicts. Fatima spoke to this when she discussed how, on the one hand, Carlos took a lot of her time, but on the other hand, it was acceptance that was most difficult. Like Mariana, she eventually accepted Carlos was not going to be like other kids in his classes.

Carlos takes a lot of my time. That’s one, but like, I feel like it’s gonna be like that. But the other one, the hardest part is accepting. Accepting things how they were because one thing is doing it, one thing is accepting it. I was not accepting it (Int. 2, 06/20/2018).

Cecelia similarly described a process of acceptance that came about through her self-awareness when she learned that Hector had autism. At first, Cecelia was very concerned that others would judge her as a mother. Her family had often criticized her for being too lenient with Hector, and she also received complaints from the social worker at Hector’s school that she needed to better support Hector’s needs at home. Cecelia described feeling this way: “I was scared, nervous, and I didn’t want to be judged, so I didn’t use the social worker” (Int. 2,

07/12/2018). She then shared how seemingly her growing and changing awareness in part helped her come to a new understanding of Hector's disability through learning more about it.

I managed myself with my phone and going to the library, getting information books. [I learned] that they are so smart. They see the world so different. They're so unique. This has enriched the whole world, this autistic (Int. 2, 07/12/2018).

For Cecelia, autism was not something to be looked at as a pejorative; rather, she saw her son's disability as a gift, something to be cherished and even envied. She elaborated further after I asked her what she meant by autism enriching "the whole world":

'Cause their life is not as damaged as what we live. Their life is so innocent. Even though people judge them by their disability, I feel like they are way smarter than we are. I always treated my son like a regular child. I have never treated [him] like he has a disability. They will give me the helmets, the vest. I would buy them, and try him once or twice and I seen he didn't like it. I would not even insist for him to wear it. I just started buying things that he would like and not get hurt. That's what I started doing. Labeling my house so he would be able to communicate with me. Instead of putting on him, "You have a disability and we put a title on you." I never liked that (Int. 2, 7/12/2018).

Cecelia, through an awareness of her difficulties with accepting Hector's disability, formulated an alternative narrative about autism and what it meant to live with autism. She then went on to describe how she felt after accepting Hector as he was.

It feels great because it feels like I have more resources and I don't have to be in a little ball, just me and my son. I've been wanting to share him. But sharing my son with somebody else feels like less weight on my shoulders. That's how I feel (Int 2, 07/12/2018).

**Confusion about assessment and services.** Perhaps in part, the interrelatedness of difficulty and acceptance of the disability their child had linked to the mothers' awareness of the confusion they faced many times about assessment procedures, diagnostic criteria, and special education services. All of that was part of mothers' work related to supporting their child with a disability. This confusion usually occurred during discussions around the IEP process, but I found it also at various points throughout the interviews. Mothers shared that at times limitations they felt about the related acts of assessment and special education services. Some shared that they had limited prior knowledge about the IEP process. And, mothers discussed at times that their confusion was sometimes mitigated after acquiring additional knowledge and resources.

When reflecting on their early experiences with the IEP process, mothers discussed how they knew very little about IEPs and disability at first. Mariana discussed how she found it difficult to find supports for her 9 year old son Benjamin who had autism. She stated: "It was hard for me to find services at that time. I didn't know where to go. I didn't know nothing" (07/06/2018). Of her first IEP meeting, Mariana said, "At first, I would just go by myself and nod and nod 'cause I did not know what's going on with the IEP." However, Mariana was aware that something was not right. At one point, she said to herself: "Like, no, like come on, this is wrong." That awareness of not seeing the results that she desired for Benjamin seems to have led her to investigate additional resources at the community center to help her better support her son. Similar to Mariana, Amelia was dissatisfied with and confused by the services Abidan was receiving. She once again spoke to her anxiety about dealing with the school by herself before discussing how she realized that she needed support. She explained that she recently realized that she wanted to "know more about what he needs" so that Abidan could be better supported at home and at school.



I was literally gonna go back to the school and be like, “Can I just un-sign there or something and I’ll be there every time you change something?” But then I’m like, okay I gotta let ... that’s why I went to the presentation ‘cause I really wanted to know my rights<sup>2</sup> on that (07/02/2018).

In addition to services, mothers were also confused by their child’s disability characteristics and related assessment procedures about how the disability could be identified. Cecelia, for instance, did not understand why students with Down syndrome and autism at the school Hector attended were seemingly treated the same. She perceived that they were much different disabilities and required much different instructional approaches. At one point she stated: “I thought autism was less dangerous than children with Down syndrome” (07/12/2018). She went on to discuss how she was aware of her own confusion about disability, and how assessment was used to diagnose kids with different disabilities. She then said that she knew she could manage Hector’s disability outside of his speech: “I don’t know what are the steps for autistic children. I don’t have that background of being an autistic teacher or anything. If they would help me with the speech, everything else I know I could manage with.” Similarly, Fatima was confused by the diagnostic criteria used to label students: “No, they cannot label him because they don’t even know what he has. Like, I even thought he had Autism. No, plus, the therapist told me if he would’ve had autism, it would be pointless of them teaching [him]” (Int. 2, 06/20/2018). In a later interview, Fatima stated, “I feel the therapist is wrong by saying, you know, you can’t help the kids with autism. I’m not aware of if it’s true, but I know he’s wrong” (Int. 3, 07/05/2018). By stating she knew the therapist was wrong, Fatima also seemed to reveal

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<sup>2</sup> I facilitated a workshop about the IEP process focused on parental rights and engagement. Amelia came to that and learned about my study.

that she was aware that what she felt interacted with the perceptions of others. She went on to describe how she knew “she needed to learn more about the disabilities” to better support Carlos.

**Summary.** Mothers’ self-awareness seemed to be informed by multiple elements inclusive of their perceptions and emotions related to the interrelatedness of difficulty/acceptance of their child with a disability, and the confusions that could be part of the assessment and services to be offered. Mothers play multiple roles in relation to their children. At various points, they had to interact with the perceptions of family members, teachers, and specialists in order to support their children. Some of these interactions were contentious and unsatisfactory, but through an awareness of their own perceptions and emotions they seem to have guided themselves to gain knowledge and construct new ideas. This awareness was informed by closer examinations of their own beliefs and values about rearing a child. Mothers developed a process of accepting their child as a unique individual.

The theme of self-awareness intersected with the themes of parent knowledge of child (PKoC) and gaining knowledge and/or support from others (GKS). First, mothers’ knowledge of their child often linked to their life histories and knowledge of school-based experiences. These experiences seemed to color the way that mothers saw themselves as caregivers, which became evident in their reflections on how their lived experiences interfaced with their parenting responsibilities. Secondly, as mothers gained more knowledge about the IEP process and their roles within it, they seemed increasingly insightful about how they were an instrumental part of their child’s development. These intersecting experiences, reflections, and insights helped form an awareness of themselves and their children, which often led to new understandings of disability, the IEP process, and their role as mothers. Mothers sometimes reached new understandings through the support of others. Lastly, this ability to perceive their role as parents

was often a part of how they perceived themselves as mothers, which leads to the next theme that emerged from thematic analyses.

### **Mom as Protector**

The theme I am calling mom as protector (MAP) was the fourth theme clearly present during thematic analyses. There were a total of 114 coded statements that formed the theme of MAP, which was 25.7% of the total number of occurrences. While the themes of PKoC and GKS spoke to those instances where mothers discussed their knowledge and where it came from, the MAP theme is a compilation of instances where mothers were active in their support for their children. When discussing their role as a protector, mothers often used words such as talking, speaking, communication, conversation, learn(ing), know(ing), understand(ing), teacher, school, IEP, dad/father, family, gangs, violence, and drugs. Throughout interviewing, mothers often spoke to how they confronted the perspectives of others to ensure that their children were effectively supported and cared for. While these confrontations were often in response to conflicts with the schools where their children were educated, mothers also spoke to conflicts with family and to concerns about the safety of their children. Therefore, the MAP theme is defined as follows: Mothers used their knowledge and available resources, and at times their self-awareness, to advocate for their children and to protect and defend them against the accusations and dangers posed by others. To illustrate MAP, I look at 4 sub-themes: (1) advocacy, (2) conflict with school, (3) conflict with family, and (4) safety concerns in the community.

**Advocacy.** Mothers discussed their role as advocates for their children when they explained comments or actions in which they directly stated their wants and needs for their child. While making judgments about what to report about this capacious amount of data, I looked to

those instances where mothers' advocacy activities were direct, clear, and parts of larger stories that formed a coherent narrative of advocacy. For instance, when discussing why she put Jesus in a certain elementary school, Isabel stated: "I put him in that school because they're more inclusive, so they have a lot of kids with IEPs mixed in with other kids" (Int. 2, 07/02/2018). By stating that she consciously placed Jesus in a school that promoted inclusion, Isabel was discussing her role as Jesus's advocate. Another instance of advocacy was when Fatima used her knowledge about special education, the IEP process, and disability to make informed decisions about how best to support her child. This can be seen, for instance, when Fatima requested that Carlos's teachers use simple one-step directions because "when there are too many instructions for him he gets confused" (Int. 2, 06/20/2018). There were numerous examples of mothers discussing what they wanted for their children, as well as elaborations on why they advocated in a certain way.

Mothers often discussed how and why they advocated for their children. For instance, after Juliana explained her own schooling history, I asked her to reflect on what stories growing up that she would share, or already had shared, with her daughter Natalia. Juliana explained:

Before I actually know what school I'm gonna put them into, I wanna make sure that they have a good academic program, you know? Because I'm gonna tell them, like, "Hey, you know, I know you probably don't care right now, but make sure that you're getting all this information because it's gonna help you out later on" (Int. 1, 06/07/2018).

Juliana wanted to ensure that Natalia would take full advantage of her education, something that she felt she did not do during her own schooling. Juliana went on to explain how this was connected to her own experiences in school: "'Cause I noticed that I didn't really care for elementary school? I thought it was all fun and games. I told you we didn't really do much of the

learning.” Later in the same interview, Juliana discussed some of the knowledge she imparts to Natalia so that her daughter can then speak up for herself.

Just to try to express herself, ‘cause she cries a lot, whenever she’s upset, and I say, “Hey, *mami*, you have to,” I call her *mami*, “you have to tell me what’s going on.” And she would just tell me because ... I need her to speak for herself. I need to know that she speaks for herself so that others don’t hurt her (Int. 1, 06/07/2018).

Juliana continued to elaborate on this need to support Natalia through helping her be more independent. This independence, according to Juliana, would allow her to be more productive in school and not be taken advantage of or hurt by others. This included encouraging Natalia to speak up for herself. But it also included dressing carefully.

I tell her, “Make sure that your pants are the right way, your clothes are on the right way.” Yeah, stuff like that. I mean, I think that it’s their responsibility, ‘cause I feel like, oh, you know, me as a mom, I have to teach them [to] dress up the right way.

Juliana went on to explain that she looked at the different special education programs in schools to determine what was best for Natalia. After Juliana explained how she chose the school to send Natalia to, I asked her how she communicated to her daughter about going to a new school.

Juliana replied:

I just told her, “Hey, *mami*, you’re going to go to another school. You’re going to have new teachers. You’re going to make new friends.” And they were going to take her on the bus from the daycare to the school, so I was letting her know, like, “Hey you’re going to go on a bus, don’t be scared” (Int. 1, 06/07/2018).

Mothers often advocated for their kids by dealing directly with schools. Their efforts seemed to emerge from experiences themselves as a student or experiences as a mother. For

instance, Fatima explained how she helped and supported her son Carlos. Teachers at Carlos's school agreed on a certain LRE placement that Fatima disagreed with. She then explained why she thought Carlos needed to be in an inclusion class to support his social/emotional development.

I wanted that because Carlos would repeat exactly what other kids do. So, if you be in another small room, I don't think he's gonna learn. I'm not saying he's gonna learn bad stuff, but he didn't get the bad habits from nowhere. And he did get some bad habits going through [local public school district] (Int. 2, 06/20/2018).

Fatima went on to discuss how hard it was for her to learn about IEPs because no one sat her down and explained what to expect from the IEP process. She continued to explain what she thought schools could do to better prepare parents for the IEP process.

Yes, that actually [local public school district] should do more information on IEPs. More information what to expect on that. Go in details what to expect about IEPs and what it is. I feel like that's one of the reasons that all the students are called dumb, or stupid, or whatever they want to call it, or slow. Some students, sometimes the parents don't have the right information that they need to help their children (Int. 2, 06/20/2018).

Isabel also was not satisfied with Jesus's services. She wanted an increase in his speech services and had to continually fight to have her requests answered.

I asked for the minutes to be increased and to have individual [as opposed to group services]. It was a little difficult. They just don't [say], "All right, let me add 10 minutes." It's a little difficult to kind of give you a little bit more of those services or the minutes and they try to make it so you cannot ask (Int. 2, 07/02/2018).

In another instance of advocacy by dealing directly with schools, Mariana discussed her dissatisfaction with the services Benjamin was receiving in the autism program at his school. She felt he needed more speech and social work services and the teachers at the school rarely gave her a direct response. Mariana stated, “I don’t see the progress that I wish to see. I didn’t have the opportunity to add minutes to his IEP and everything. Those were my main concerns because they didn’t have the maximum” (Int. 3, 07/12/2018). Mariana continued pushing for extra services, saying that she would “take one more chance in having everybody in the same room,” but also thought a lot about Benjamin’s future and wanting him to be in inclusive environments with students without disabilities. She knew he would have to transition to a new school one day and she wanted to remain proactive. When I asked her about the kinds of things she anticipated in Benjamin’s future, she responded: “I have already seen programs where he can go and do and participate. I even thought about his marriage already. I’m looking at schools for high school and everything.”

Sometimes mothers spoke in terms of advice about how to best advocate for children with disabilities. For instance, Guadalupe stated: “You have to take any opportunities that you have. What the state or the city provides to you, just take everything that you can. Don’t take things for granted” (Int. 3, 09/27/2018). Mothers often framed their advice around their own experiences and how they learned to better support their children. In another example, during the times I spoke with Cecelia, she was about to begin a program for occupational therapy (OT) that she chose to do to better support her son, Hector. Cecelia used that as an example of how mothers can be advocates for their children’s needs.

I kind of know a lot of moms that have kids with a disability and I like to help others. I know there’s a lot of moms out there [and] that we don’t trust people to leave our kids

with. I fall in their categories of not trusting people. So being an OT is kind of like telling them you can be your own son's occupational therapy. You don't have to go and, I don't know, find somewhere to take your child when you can just learn with him (Int. 1, 07/09/2018).

Cecelia continued to elaborate on how mothers could support their children, specifically children with autism. She added another clarifying example: "I do want him to speak. [Since] he's learning sign language, that means that we [the family] have to learn sign language." For Cecelia, it was important that mothers grow with their children. This, in turn, allows mothers to be better advocates for their children.

Mothers advocated for their children's needs in diverse ways. Juliana supported Natalia through building up her confidence and telling her stories that highlighted growth and struggle. Mariana and Fatima voiced their concerns about their children's services. Guadalupe and Cecelia offered advice to other parents, with Cecelia going as far as saying that parents should learn new ways of interacting with their children in order to be more effective in their supportive capacities. These are instances of mothers elaborating on how they protected and advocated for their children. The next 3 sub-themes, however, specifically show how mothers protected their children from others.

**Conflict with school.** Mothers discussed numerous conflicts they had with their child's school that they decided called for advocacy and protection. Sometimes these conflicts were part of larger stories; at other times, they were abrupt admonishments of what they perceived as unfairness on behalf of a school. In the vast majority of these instances, conflict arose from mothers requesting additional information or services related to their child's education. In order to highlight this sub-theme, I did not focus on simple criticisms of a school or school personnel,



reasoning that these criticisms do not necessarily show us how mothers protected and defended their children. These statements were often *ex tempore* and not illustrative of how mothers acted as a protector. Rather, I looked for statements that were part of larger narratives and processes about parents protecting their children from and against various stakeholders and members of a school.

Fatima provided a salient example of a mother engaged in a conflict with a school and how she defended herself and her child. She had been in a disagreement with teachers about her son Carlos. Fatima thought teachers were not doing enough to promote growth in Carlos's skills and explained that she was not being given acceptable answers to her questions. When I asked why that was, she replied: "Because they think I'm stupid and I don't really get involved in Carlos's stuff. It's not that, it's just that I just don't like the school" (Int. 1, 06/13/2018). Fatima perceived that teachers were not giving "100 percent [to] the students with an IEP." This frustrated Fatima, and that seemed exacerbated by the way she believed herself to be perceived. Fatima finally called for a meeting with Carlos's teachers and came to a tentative understanding about how she should be treated in the future, saying, "Now, they say they'll let me know more stuff [about Carlos's progress]."

Similarly, Mariana was frustrated with the lack of communication from the school. Benjamin was coming home crying and teary-eyed and Mariana could not figure out why. "So I don't like when he comes home like that, because I really don't know what happened at school, and when I call the school, nothing happened. I don't hear nothing for my son" (Int. 1, 06/13/2018). Mariana then requested to sit in on Benjamin's classes because she wanted to witness first-hand what was happening to cause his crying. While she was let into the school to speak with the principal and Benjamin's teachers, she was not allowed to sit in on his classes,

which Mariana described as being treated as if she was in jail. “They don’t tell me, they don’t let me in. They don’t let me in to see his classroom or how he works. If I ask questions it’s like, like if I was in jail or something.” In a later interview, I asked how all this felt. Mariana replied, “Like they were shutting doors on us. They didn’t want us to tell them how are we going to make Benjamin do this. Then they didn’t want to do anything” (Int. 2, 07/06/2018).

There were other conflicts with schools that arose from misunderstandings, lack of communication, or power struggles. Cecelia told a story of how Hector would often use sign language to communicate because he was functionally non-verbal. Cecelia was impressed with Hector’s progress with sign language but noticed, rather non-judgmentally, that he would often point with his middle finger. This act, which Cecelia found innocuous, aroused the suspicions of one of Hector’s teachers:

He was pointing with his middle finger and the teacher was like, “Oh, we have to write up Hector because so and so.” And I was like, “Since he was little he pointed like that, so ... There’s nothing I can do with the way he points” (Int. 1, 07/09/2018).

Cecelia was surprised because she had brought this up at an earlier IEP meeting and thought the matter had been resolved. After the teacher threatened to write Hector up, Cecelia sarcastically responded, “Okay, my four year old is swearing already. This is so amazing.” Isabel was similarly frustrated when she asked the case manager at Jesus’s school if her son could receive additional minutes for speech therapy. She then received a response that she found trivializing.

They kind of seemed like they didn’t want to provide those. At some point, they even said that they have a lot of kids and the other kids were receiving the same. Like they said, “Oh, well, your kids are receiving the same as other kids. Why would we give them more?” I didn’t like that kind of attitude (Int. 2, 07/07/2018).

After reminding the school that an IEP meant that “stuff should be personalized,” the case manager capitulated and added 15 minutes per week to Jesus’s overall speech therapy minutes. Isabel was not satisfied; however, she confessed, “I’ll take what I can get.”

**Conflict with family.** Mothers also discussed past and present conflicts they had with family over rearing of their children. These conflicts were often accusatory in nature, with the mother being the object of accusations. Some of these conflicts arose from familial and cultural beliefs about disability and therapy, while others were felt by mothers to be minimizing or shaming. Mothers sometimes defended their children through arguing; however, it seemed that the most common response was ignoring the person who questioned them (e.g., a husband, the mother’s parent). Moreover, in order to protect their children, mothers often had to limit their interactions with a particular person and/or their families. Mothers rationalized that they did what they felt was necessary to support their children’s needs, even if this meant less family contact. In yet other instances, conflicts with family were historical, in that they reflected grievances these mothers had with their own parents. These grievances often manifested and at times it seems re-lived in our interview conversations.

Familial beliefs about disability and therapy sometimes caused conflict in families. In some instances, mothers also referred to culturally-inscribed negative views of seeking outside support.

Especially in our kind of, you know, the Hispanics, they think that, “Oh he’s fine. He doesn’t need all this help.” You know, my son doesn’t have any issues, any problems [stated sarcastically]. So I think that’s the problem. That they don’t want to accept it, or they just don’t want to take the time to get the extra help for their kids and themselves, too (Guadalupe, Int. 2, 09/07/2018).

Guadalupe relayed how this made discussing her children's difficulties uncomfortable, but she continued to attempt to have those conversations with family members. At other times, mothers just learned to avoid the conversations. Isabel, for instance, discussed how she had nieces and nephews that also had speech problems, similar to her son Jesus's developmental delays in speech. She cautioned that it was difficult to give effective advice because some family member's beliefs were demeaning to those who received therapy. Isabel went on to illustrate what this looked like in her family. "It's a little hard because in most of my family they don't kind of believe in therapy. They just say that every kid has these problems and [we] should just let them be" (Int. 2, 07/02/2018). I then asked Isabel what those conversations looked like, to which she replied:

Well, that's why me and my family don't kind of have [that] type of talk. Just sometimes when they ask, because I have an aunt that has this kid that he's three but he doesn't say anything. That's one of the times they ask but then the other family members are like, "Oh no, he will just grow [out of it]" (Int. 2, 07/02/2018).

Isabel would sometimes defend her choice to support Jesus by connecting him with various types of therapy; however, she often avoided these conversations because of the stress that the conflict caused.

Cecelia experienced similar conflicts with her family around the supports she used with her son Hector. Even though Hector had been diagnosed with autism and was non-verbal at the age of four, Cecelia's family continued to believe that she was a contributing factor in Hector's problems. In this excerpt, Cecelia discussed her reaction to learning that Hector needed special education services.

I was scared because my whole family was telling me, “No, he’s just spoiled. He’s this. He’s that.” They were attacking me. For a whole year I stayed away from my family, just for my son. I followed therapies. I took him everywhere. I was consistent [with] what he needed (Int. 2, 07/12/2018).

Cecelia’s dedication to Hector and commitment to his therapies also caused conflict with her partner.

It got to a point that in 2016 I was almost divorced, ‘cause my husband said, “It’s too much, what you’re doing for him. You’re not even paying attention to our relationship.” He would have second thoughts of our relationship. He would tell me, “I will be with somebody else because you [are] putting my son between [us].” I was like, “I’m sorry.”

Cecelia later reflected that her husband did support their other three children but found Hector too difficult to be with on a consistent basis.

And the dad never wants to go. ‘Cause he says he doesn’t have patience for him. I feel like I’m alone. I don’t even [know]. “Are we together?” I tell him. “You don’t help me much.” We’re not on good terms anymore in regards to [Hector]. He’s a good father with the rest of my kids. That’s the only blessing: that he’s able to take care of the other 3 children while I’m with Hector. I have a lot of one-on-one with him. We don’t understand what he’s saying. That’s what I feel. When he does talk, he speaks a totally other language.

Cecelia later reflected on her aloneness with her son. She stated that women “always have to take care of the kids, especially the difficult ones” (Int. 3, 07/24/2018). She, like Isabel, learned to ignore family members’ responses to her and Hector, which, for Cecelia, led to a complete lack of trust: “Because I don’t trust anyone with my son. I don’t even trust my own parents ‘cause

they like to scream and yell and they say, ‘Just hit him. He’ll be feeling better’” (Int. 2, 07/12/2018).

At other times, conflict with families was based on past disappointments with family members, and those disappointments informed mothers’ viewpoints on their role as mothers. Amelia grew up with a father who was often absent, both physically and emotionally, and she came to see men’s roles in child rearing as minimal. “My dad would usually just be working all the time and then he wouldn’t really be there for us. It would be my mom who would do everything” (Int. 1, 06/22/2018). Amelia seemed to repeat this idea of men being absent during childhood by seeing herself as her children’s primary caregiver. “Especially now that I have my kids, that even though their dad is there, I have to be there more for them to make sure that they can always go to me if their dad doesn’t.” Amelia discussed how her conflict with her husband escalated to the point of her having to move in with her mother for three months. As our conversation continued across interviews, Amelia reflected on how she saw their relationship as one-sided.

Right now, I have a lot of problems with his dad. Now that I see it, I feel like Abidan knows his dad is there. He always goes to me. He listens to his dad but he knows my soft spot. Everything he does, he goes towards me [more] than with his dad. I feel like It’s different because even though his dad is there he goes towards me instead of like, “Dad is there. I’ll go with him.” No, he goes towards me. I feel like it affects him because even though his dad is there, it’s like, “Okay I’m gonna do everything with mom instead of both [mom and dad]” (Int. 1, 06/22/2018).

Amelia, early on, linked her past experiences with her parents to her present viewpoints of how she saw her relationship to her sons and husband. She had attended a class with a psychologist at

the community center and openly discussed her issues with her husband in the presence of other mothers. She then summarized what she had learned: “Basically, ‘What did your parents do to you that made you who you are?’ and I’m like, ‘Oh, my mom would do everything.’”

**Safety concerns in the community.** Mothers also discussed the safety concerns they had for their children in the urban areas where they lived. They often discussed the need to keep their children safe from violence and shelter them from negative influences endemic to their urban communities. Juliana was worried about what Natalia saw on the streets and even, at times, out of the window of her apartment.

I don’t wanna expose them to the stuff that’s around there, ‘cause it’s kinda bad, there’s prostitution going on, and drugs and all that. And I don’t want her to see people screaming, ‘cause sometimes people walk around and they’re intoxicated, and they’re screaming stuff, and I don’t want her to see that (Int. 1, 06/07/2018).

Juliana had thought about the future, explaining, “I hope nothing happens when they go out. So that’s why I’m just really working hard to move out of there. So when they get older they don’t see those kinds of things.” Similarly, Mariana discussed how she kept her sons safe by rarely letting them out: “I don’t let my kids out. When we go out, we go out of the city and let them [be] free” (Int. 1, 07/13/2018). She then explained that she would sometimes let them out on their patio but had come to distrust even that: “Yes, it’s fenced. Everything’s fenced. But bullets will flow, they fly everywhere, and you know, I’d rather not risk it.” Cecelia, like Mariana and Juliana, worried about the safety of her children after recently moving to a new neighborhood. “Like gang bangers, I feel like you can’t trust them, because they throw up a sign. Then I tell my husband, ‘What if we’re learning how to sign with [our] son? They’re gonna think we’re throwing up signs or something’” (Int. 1, 07/09/2018). Cecelia had begun learning sign language

to better communicate with Hector but was worried that this could be interpreted as gang activity by local gang members. Like Mariana, Cecelia erred on the side of caution by “never letting the kids out of my sight.”

**Summary.** Parents saw their complex roles as mothers in terms of being an advocate, defender, and protector for their children. Being a mother, for them, was more than just speaking up for their children. Rather, the role seemed comprised of ongoing intentional decisions and actions to do whatever was necessary to support their children’s needs. In many instances, mothers made adjustments to their own parenting methods to dole out this support. These methods were informed by their knowledge, lived experiences, beliefs, and values. In this way, the themes of MAP, PKoC, and GKS crossed each other and often informed the other.

It was often the case that parents felt alone in their role as mothers. This aloneness was often reinforced by familial and cultural beliefs about rearing a child with a disability that were projected upon them by their families. Thus, MAP seemed at times like a defense mechanism to ensure the safety and continued progress of their children. In that way, MAP also intersected with the theme of self-awareness, in that mothers sometimes directly spoke to how they changed in order to be better advocates for and protectors of their children. This self-awareness impacted both their viewpoints and emotional reactions to conflict. It is also within MAP that we begin to see the subtle and not-so-subtle impact of culture on mothers’ beliefs and values, which encompasses the fifth and final theme.

### **Awareness of Cultural Difference**

Mothers’ beliefs and values were shaped in part by the familial and cultural landscapes that surrounded mothers’ lived experiences. Mothers sometimes expressed their perceptions of cultural difference, and how differences delineated particular worldviews. Cultural difference



was often noted by mothers in terms of how their own experiences and perceptions might conflict with dominant culture notions about child rearing, schooling, and family participation. The theme of awareness of cultural difference (AoD) was much smaller than the first four, with 23 coded occurrences, which was 5.2% of the total number of coded occurrences. When speaking about AoD, mothers often used the words race/racism, Mexican/Hispanic, language, English, Spanish, bilingual, different/difference, mom, and school. Therefore, I define AoD as the multiple ways that mothers expressed an awareness of cultural difference related to language, cultural, racial, and/or ethnic difference.

AoD was placed after MAP because mothers' discussions of cultural difference often related to their role as protector. Five of the mothers in this study were first generation immigrants, with their parents emigrating from Mexico before they were born. Two of the parents, Cecelia and Guadalupe, were brought to the United States at the ages of five and three, respectively. These experiences as immigrants and children of immigrants seemed to shape mothers' awareness of the differences they perceived throughout their lives. To account for this, the theme of AoD was formed. The following sub-themes emerged from thematic analyses: (1) language, (2), culture, and (3) race/ethnicity.

**Language.** Mothers often discussed how the native language of their parents, Spanish, had an influence on their own bilingualism and the ways that they perceived language differences. Juliana, for instance, was used to speaking Spanish with her family colloquially but had trouble understanding the formalities of the language when in school:

Well, for my classes, I didn't like my Spanish class. I know it's gonna sound bad, but I didn't like it 'cause when I got raised, my parents they both speak Spanish. They never

taught me about “acentos” [accents], so that was brand new to me, and I’m just like, “Shoot, what the fuck is this?” (Int. 1, 06/07/2018).

Juliana had trouble learning Spanish formally in school but never spoke to any difficulties acquiring the English language. Cecelia, on the other hand, was born in Mexico and experienced great difficulties learning English in school. She was in bilingual classes in elementary school, before having those services discontinued in high school. “They were all in Spanish until I got to high school. [In high school], it was just English, so I had to learn how to speak English because it was hard” (Int. 1, 07/09/2018). Despite Cecelia being placed in special education for a learning disability, she skipped the 7<sup>th</sup> grade because she did so well in her classes. She explained the difficulties that arose from skipping a grade in school.

So that like kind of [put] me off. Because after then it was kind of hard to make friends because [the other students] didn’t speak my language. So in 8th grade, nobody really [spoke] Spanish, so that was a big struggle. I used to cry, like, “I don’t want to come here” (Int. 1, 07/09/2018).

When discussing why teachers put her in a “smaller class” and placed her in the special education program, Cecelia discussed how her shyness was a part of why she struggled in school. However, she had trouble expressing this to her mother or teachers.

I felt like I had to put a foot on the ground and woman up and say something, but I was so shy. I was like, “What if they laugh [at] the way I speak?” It was more of my language than anything else (Int. 1, 07/09/2018).

Amelia, on the other hand, talked about the difficulty of switching between English and Spanish at IEP meetings and feeling “stuck” on certain word choices.

The last time I did [the IEP meeting] with the translator of David. I couldn't say it in English but I could have said it in Spanish and then she translated it right away. Because sometimes if I say something with David that is happening to him and can't really say it, [the translator] will be like, "Oh it's this." I'm like, "Oh, okay." Some words I can say in English and in Spanish, so I'll be stuck. I'll be mixing everything up (Int. 1, 06/22/2018).

Conversely, Guadalupe, who came to the United States with her family when she was 3, did not experience any great difficulties with learning English.

I don't think I had any issues with the language. Because, since I was three years old, I was able to pick up English pretty well. Spanish in my home and English in my house [both of Guadalupe's parents spoke English and Spanish]. So, I was bilingual. Ever since I can remember, I've been bilingual. Regular (Int. 1, 08/24/2018).

**Culture.** In addition to language, mothers spoke about the cultural differences they perceived. Mariana spoke the most about cultural differences because she had attended high school in Mexico and then come back to the United States after graduating. Upon returning, she was confounded by the way her family in America acted.

I didn't like the way my siblings talked to my mother. I didn't like the family of my mother's husband. They didn't respect her either when they'd go to her house. You know, right? I saw a lot of disrespect. You know, I tried to bring back what I learned over there. "No, it's your home. Respect your house." And I was always fighting with the siblings because I tried to like say something (Int. 1, 06/13/2018).

Mariana expanded on these observations when she discussed what she missed about Mexican culture.

I liked it over there because they had principles. How to speak with respect all the time. You don't have to talk to a person with, "You this, you that." You have to say like, "Sir," or "Ma'am." Things like that. I think mostly just manners, [at] the table, in the times, everything. [We] all had schedules and everything like that. So we had to follow everything. And I think that pretty much made me a little bit more ... It helped me a lot (Int. 1, 06/13/2018).

When discussing her children's dependence on technology for entertainment and communication, Mariana said, "The machines. I had no machines over there, right? We had to go to the river to wash [our clothes]." Mariana continued highlighting the differences between living in Mexico and the United States: "Now you have machines to wash for you, to dry for you ... And then the back river. We used to bathe over there." Mariana went on to explain how her family in Mexico would wash their clothes in the river in front of their house and bathe in the river behind their house (i.e. the "back river"). She continued bringing up cultural differences she perceived throughout the interviews and, at one point, reflected:

Sometimes I feel like that, because I don't know how the ways are here sometimes. I try to learn more how they do things around here. The schools and everything are very different than Mexico. Every day, I learn something from the school (Int. 2, 07/06/2018).

Guadalupe, who was born in Mexico, also discussed some of the common perceptions about child rearing in Latino culture. "In our culture, there's a lot of machos that, like, 'Oh, What's the point of going? Now, you're going to be a mom. Then you got to take care of your kids and stay home'" (Int. 1, 08/24/2018).

**Race/ethnicity.** Mothers sometimes discussed how their awareness of race was fostered through attending school. All of the mothers in this study were Mexican American and were

raised in neighborhoods of the city where the majority of denizens shared similar racial, ethnic, and cultural backgrounds. Juliana expressed her surprise at all of the diversity she witnessed in college, and how that diversity differed from her high school experience.

Now that I went to college, what I didn't like is that it was all Hispanics, 'cause when I got to college, I [didn't] know how to interact with other races. It was really hard to me. I didn't know how to interact with other people. I'm just like, "How do I" ... it's gonna seem weird, but I was like, "How do I talk to them? What do I say? What if I say something in the wrong way and they take offense?" You get me? 'Cause I was always going to [elementary and high school] with Hispanics, so when I got to college: African American, Chinese people, all types of races. I'm just like, you know? I don't know. It was all very new to me (Int. 1, 06/07/2018).

Fatima had a similar reaction when she first went to college: "I met different people. Not only Hispanic people, people from different countries. Not only Mexican or Hispanic" (Int. 1, 06/13/2018). Fatima went on to explain how this diversity of people in college challenged her perceptions of who went to college: "And I've learned that ... For example, the math teacher was Indian. I had this concept that only people of certain races will go to college, but then I just realized, I'm like, 'Huh, interesting.'" When I asked Fatima who she thought went to college, she responded, "I just think that White people would just go to college, or they were just the smart ones that go. But then I realized that it was a lie. College opened a little bit of my eyes."

Guadalupe also appreciated being exposed to racial diversity; however, she stated that she witnessed this diversity in high school first, not college like Juliana and Fatima: "My high school was all types. There was Mexicans. There was African Americans. There was a variety of different races and different people" (Int. 1, 08/24/2018).

Juliana and Guadalupe also discussed race/ethnicity along the lines of “legal” versus “illegal” ways of coming to the United States. Juliana differentiated the way that her mother and father came to the United States, saying, “They [her father’s family] actually came over here the right way, with the actual documents; whereas my Mom, she came here illegally” (06/07/2018). Juliana then mentioned how, through marriage, her father was able to “fix her papers” so that her mother was “legal.” Guadalupe also discussed immigrating to the United States using similar terminology. She discussed that, as the oldest sibling, she was the only child of her parents born in Mexico.

I was the only one who was born over there. Then, my parents came over here illegally.

And, then, my dad became a [U.S.] citizen. You could say, [he] fixed our papers. Me and my mom. My papers and my mom’s. Because, we were the ones that were illegal (Int. 1, 08/24/2018).

**Summary.** Mothers often seemed aware of differences in terms of language, culture, race, and ethnicity and how these types of difference interacted with their lived experiences as Latina mothers. These points of overall cultural difference supplied multiple threads in a tapestry of experience encompassing their family’s stories about immigrating to the United States, schooling history, and role as a mother of multiple children. Often times, mothers discussed how they stood at a nexus of multiple worlds; a landscape of diverse familial and cultural histories converging in their own sense of being. These landscapes were dynamic, as can be seen in their evolving ideas and viewpoints, and were colored by new knowledge and skills. Mothers’ musings on and recollections of language, culture, race, and ethnicity also informed their role as a protector and defender of their children. As could be seen in the MAP theme, mothers in this study often had to disrupt cultural notions embedded in their family’s beliefs and values to better

support their child. These disruptions may have been difficult, even unnatural, at first, but mothers appeared to be accepting at some level of what they did, perceiving that they acted in the best interests of their children.

### **Summary of Cross-Case and Thematic Analyses**

To respond to the research questions, I reviewed data about mothers' life histories and conducted thematic analyses that revealed five themes: (1) parent knowledge of child, (2) gaining knowledge and/or supports from others, (3) self-awareness, (4) mom as protector, and (5) awareness of difference. Data collected from these interviews reveal a complex interactionalism between mothers' lived experiences and how they draw on their knowledge, values, and beliefs to support their child. This interaction was often multi-faceted and multi-directional. Mothers supported their child's schooling, social and emotional development, intellectual growth, and familial and cultural understandings in different ways that seemed interdependent with circumstances, mothers' perceived needs of their children, and mothers' abilities to do what they deemed as needed for their children. By offering a dynamic support system, mothers also ipso facto cultivated experiences in accordance with what they deemed best for their child. This was often done through protective capacities that addressed the challenges and struggles their child faced. Throughout interviewing, they portrayed these supports, challenges, and triumphs with a great deal of reflection on their life histories—as well as the family stories that were enmeshed with their personal histories—and an awareness of their role as a crucial thread in an intricate tapestry of experience. Mothers often did not do this work on their own. They were supported by the family members, friends, and professionals that intersected with their lives. At times, also, mothers had to do battle with others as part of supporting their child. Furthermore, despite finding networks of supports for their child, mothers

often expressed the aloneness felt by being a Latina mother of a child with a disability. This aloneness was heard through their narrations of experience, and felt through the poignancy in which they recounted their lived experiences.

The data presented in this chapter also went a long way in understanding the phenomenological question: What is the essence of parents' perspectives about the IEP process and their roles in it? Through thematic analyses, we begin to see how mothers' knowledge, values, and beliefs were constantly evolving to better support their child. This evolution intimated a "process of becoming" and of acting out their role of mother that seemed to engulf multiple roles as advocate, protector, and defender. It is with the weight of the word *mother* that we begin to perceive the essence of the phenomenon in this study. Peeking into the processes through the words that these mothers shared was a privilege.



## V. DISCUSSION

The purpose of this study was to investigate how seven Latina mothers of children with disabilities perceived and constructed their lived experiences related to their child's IEP process in schools. Through three narrative interviews focused on mothers' life histories, their reported interactions and observations of their child, and their reported interactions and participation in the IEP process, I aimed to glean the knowledge, skills, and values parents draw upon and the essence of the meanings they gave to their roles and actions. Specifically, I sought responses to two research questions: (1) What is the essence of parents' perspectives about the IEP process and their roles in it? and (2) In what ways do parents draw on their knowledge, values, and beliefs to support the overall education of their child? Through analyses of the 21 interviews, I identified three major themes: mothers' pivotal knowledge (parent knowledge of child, and gaining knowledge and/or support from others), mothers' wide range of awareness related to their child (self-awareness and awareness of cultural difference), and mothers acting in the role of protector. Mothers' actions, intentions, and thoughts occurred across multiple timescales and locations, which speaks to the complex nature of a mother's lifeworld.

While exploring the multiple meanings I intuited from reflecting on mothers' lived experiences, I used the Moustakas (1994) framework. In Chapter Three, I described use of the first three parts of the framework: *epoche*, phenomenological reduction, and imaginative variation. I now use the final component of his framework, *synthesis*, to integrate the knowledge, beliefs, values, actions, and thoughts present in this study into a final description of the essence (Moustakas, 1994). I do so by first exploring challenges mothers identified and experienced in the IEP process that emerged in part from the 1) dynamics of culture and language, 2) use of technical jargon in IEP meetings, and 3) perceived judgements and critique from others. I then

explore how those dynamics affected mothers' participation choices and practices, which I refer to as "advocacy *in situ*." By examining those challenges and mothers' advocacy *in situ*, I can then move toward discussion of the essence of the phenomenon I aimed to investigate. Lastly, I present implications for practice and research along with study limitations.

### **Challenges in the IEP Process**

Mothers in this study faced numerous challenges to participation in the IEP process as identified in the results, e.g., uncertainty about assessment and diagnostic criteria, conflict with school and family, and lack of supports. They were often frustrated by school practices that impeded their abilities to support their children and participate in the IEP process. At various points, mothers were shut out of decision-making activities at schools, leading some mothers to view their children's schools and personnel as antagonistic and unconcerned with their input. At times, mothers' participation was also discouraged by family members and friends who viewed disability and special education with suspicion.

Those ideas mirror research findings that these challenges are often caused by or at least highly correlated with systemic barriers in schools (Hardin et al., 2009; Hirano, Rowe, Lindstrom, & Chan, 2018; Lo 2008, 2009; Wolfe & Duran, 2013). Challenges are often exacerbated by incongruities between the priorities of schools and families. Those encompass differing perceptions and beliefs about disability as a deficit, views about parenting practices, and overall purposes of schooling (Blue-Banning, Turnbull, & Periera, 2000; Hess, Molina, & Kozleski, 2006). These differences in perspective and belief between schools and families seem regularly quite pronounced in relationships between culturally and linguistically diverse (CLD) communities and schools. The differences are often grounded in systemically ingrained views about culture and language, deficit beliefs about working class people of color, and parenting

practices that might vary from expectations often based on White middle-class norms (Barrera & Liu, 2006; Blanchett, Klingner, & Harry, 2009; Pang, 2011). There seemed to be three main challenges that mothers in this study faced: (1) culture and language that differed from the mainstream, (2) uncertainty and confusion about jargon and IEP processes, and (3) perceptions of judgements and critique from others. This trifecta of challenges often prompted mothers' frustrations with schools, anxieties about child rearing, and a sense of being alone in a struggle to support their children.

**Culture and language.** In several instances, mothers in this study directly attributed challenges they experienced with school personnel to cultural misunderstandings. Their lived experiences as students seemed fused to their lived experiences as parents, and they felt this systemic influence palpably. Often, they linked their current frustrations with schools to their own schooling experiences. Additionally, the mothers indicated that school personnel did not invite their perspectives and perceptions based on observations and insights into conversations, which were often engrained with deep cultural knowledge and norms for action. According to what mothers shared, teachers, case managers, and therapists used their roles as school experts to hinder equity of mothers' voices throughout the IEP process. As a result, mothers felt a sense of despondency, exhibited through comments about how schools "don't care" and "won't let us in."

Cultural differences between schools and CLD families are well-documented in research (Cho & Gannotti, 2005; Harry 2002, 2008; Lo, 2008; Wolfe & Duran, 2013). Kalyanpur, Harry, and Skrtic (2000) suggest that parents' inability to participate in the IEP process is part of an intimidating force in schools, whereby the school or district "experts" exude a self-assurance in knowing what is best for children given their training. This feeling of inadequacy and intimidation is most pronounced in CLD and working class communities, in which persons may

lack the expected social and cultural capital to participate in rich and broad ways in the IEP processes (Trainor 2010b, 2010c). Therefore, to a large degree parents may be dependent on their possessed forms of capital and its transference into acquiring services and resources for their children's education when navigating relationships with and within schools (Cobb, 2013). Conversely, White middle-class parents are more likely to feel parity with school personnel in the IEP process (Fish, 2008; Wolfe & Duran, 2013). This mismatch of capital between school personnel and CLD parents may help to explain the power differential mothers referred to between themselves and schools and school personnel.

Cobb's (2013) extensive review of 20 studies on CLD parental involvement in special education processes may help explain some of the systemic challenges that hinder parent participation. Through parents' narratives, he showed that the concepts of disability, parents' roles, and special education processes differed greatly depending on one's position in the world. He identified three intersecting concepts that he argues contributed to low participation amongst CLD parents: perceptions, people, and systems. Cobb defined "perceptions" as the way that individuals take in the world around them, and how those perceptions differed for school personnel and parents. The second category was "people" and was interrelated to that of perceptions. Simply put, every person has a certain position within a system, such as schools, that shapes interactions. The position of school personnel, for instance, can be quite different than the position of parents. Historical antecedents and differing subjective stances—often based upon possessed capital—can drive a wedge between parents and school personnel. Lastly, Cobb discussed the "systems" of special education as a sometimes monolithic barrier that likely contributes to CLD parents' sense of confusion and intimidation at times.

Cobb's findings from his literature review also coalesce with other scholars' arguments. Special education systems often privilege certain forms of knowledge, modes of communication, and transfers of capital, which act as barriers that exclude CLD parents from decision-making processes (Harry, Klingner, and Hart, 2005; Kozleski, Engelbrecht, Hess, Swart, Eloff, Oswald, & Jain, 2008; Trainor, 2008, 2010a, 2010b, 2010c). Additionally, Van Manen (1990) reminds us that the subjective stances of different individuals can create relational incongruence and make relationship-building strategies, such as empathic listening and reflective dialogue, cumbersome and, sometimes, unbridgeable.

In this study, most of the mothers attended the same school system as their children do now. Their own lived experiences as students seemed fused to their lived experiences as parents, and they felt this systemic influence palpably. Often, they linked their current frustrations with schools to their own schooling experiences. Also, since parents often lacked the technical vocabularies to participate on a similar level as school personnel in the IEP process, this could have been an additional hindrance to participation. Lastly, the normative method of communication that school systems seemed to utilize was often not always robust evidence of parent participation; that is, asking "do you have any questions?" and defining that as participation, show yet another way that the intersections of cultural mismatch may have inhibited participation.

**Uncertainty and confusion about jargon and IEP processes.** The findings from this study revealed that mothers often felt overwhelmed by the use of technical and jargoned language at meetings. Added to that was the myriad amount of information presented at IEP meetings they had not heard before. Those circumstances often led to feelings of intimidation and confusion along with role uncertainty. These dynamics were most salient at the IEP

meetings, which tended to be more formal and have a mandated legalistic component, in part, since the IEP is a legal document.

The historical frameworks and legal mandates endemic to special education and compliance to legalities can sometimes appear as rigid proceduralisms to those not familiar with the system (Skrtic, 1991). With little familiarity and with possible viewpoints about what is best to question (and not question) from authority, mothers may have seen the proceduralistic nature of IEP meetings as antithetical to their normative way of communicating about their child. The fact that mothers became more comfortable in their advocacy as their familiarity with the IEP process grew supports that claim. That comfort often came through mothers' intentional efforts to educate themselves about special education services, the IEP process, technical vocabularies used in the IEP process, and disability. Thus, the acquired vocabularies allowed them to find supports and services for their children. Moreover, that meaning-making came mostly on their own and of their own volition. The mothers shared very little information that demonstrated how school personnel helped them understand and/or be part of the procedural nature of the IEP process and meeting. Thus, the formality of IEP meetings, which was not necessarily an intention in IDEA (2004), can stymie parent participation (Zeitlin & Curic, 2014).

**Perceptions of judgements and critique from others.** Mothers' narratives provided numerous examples of how they often felt pre-judged by school personnel and that personnel saw them as having deficits. Mothers spoke to this deficit lens when they mentioned school personnel who viewed them as "stupid," or schools "not doing enough" for students with disabilities. Mothers were often suspicious of the intentions of school personnel, viewing them as adversarial and antagonistic. These antagonisms led to a mix of reactions and emotions. Mothers sometimes felt angry, anxious, alone, or confused.

Several studies have shown that CLD parents generally experience the special education system as negative and deficit-oriented (Harry, Klingner, & Hart, 2005; Lo, 2008, 2009). This orientation often lies hidden within school structures, spoken of only as necessary procedures in order to involve families (Artiles et al., 2010). As a result, parents may come to be seen as the cause of their child's disability and, according to this embedded perception, may require a form of remediation themselves similar to models used with students (Hess, Molina, & Kozleski, 2006; Turnbull & Turnbull, 2001).

In addition to school personnel, mothers referred to familial and cultural views about disability as a challenge to enhanced participation in the IEP process. In several instances, mothers directly spoke of family members who blamed mothers for a child's disability. Mothers reflected on how their role as a Latina mother of a child with a disability was at times additionally challenging due to beliefs and attitudes of family members. In those instances, family members were suspicious of the therapies and services that mothers utilized to better support their child with a disability. These challenges and conflicts often led mothers to discover and create unique and situated methods of participation with schools to best support their children, e.g., posing certain sorts of questions and carefully telling others about information they had learned.

These actions and views can be seen as part of a larger cultural attitude about disability being inherently wrong and in need of "fixing" (Coomer, 2019; Heshusius, 1986). They are also enmeshed with patriarchal ideas found in our world that includes Latinx communities as well. Some Latinx communities find the notion of a child having a disability as an assault on male virility (Harley, 2018; Salas-Provance, Erickson, & Reed, 2002; Zea, Quezada, & Belgrave, 1994). Commonly referred to as *machismo* (Salas-Provance et al., 2002), this belief had an effect

on the mothers in this study. In many instances, they showed how becoming an advocate for their child with a disability also meant taking a strong stand about an idea or action (e.g., a therapy they wanted to try). Most mothers spoke of how, at times, enacting such a role for their child was met with suspicion or criticism from family and friends.

### **Participation in the IEP process**

Taken together, the dynamics of critique by others, uncertainty and confusion about the IEP jargon and process, and cultural and linguistic mismatches formed a triad of challenges mothers faced in this study. Those challenges affected their participation choices and practices in the IEP process as well. Analyses show how the mothers managed those challenges and were indeed involved in several nuanced and variegated ways. They did not rely on one set of procedures to guide their participation; rather, participation in the IEP process intersected with their lived experiences through their knowledge, beliefs, and values in both implicit and explicit ways. The situated set of participation practices that mothers used to advocate for their children often caused the kind of shifts in power imbalances that Harry (1992b) envisioned for families of color; that is, when school personnel are positioned to honor the culture and family beliefs of parents then IEP meetings become more conducive to parent participation. As a result, there were multiple instances of school personnel capitulating, often reluctantly, to mothers' requests for additional services and more communication from school personnel.

The methods mothers used to position themselves as advocates for their children were indicative of Moll's (1990, 1992) concept of "funds of knowledge" in that mothers' narratives clearly showed how they linked past and present familial and social accounts to their current roles as Latina mothers of a child with a disability. Mothers expressed these funds of knowledge as they described intentionally drawing upon their knowledge and constructing new ideas to find



more supports and services that existed to help their children be successful. These temporal acts aided in mothers' capacities to act as advocates for their children by drawing on knowledge and experience across time as they made sense of present contexts and conditions. I refer to the totality of the intentions, knowledge and knowledge gathering, and actions as *advocacy in situ*.

**Funds of knowledge.** The funds of knowledge approach (Moll, 1992) is foundational to *advocacy in situ*. A funds of knowledge approach is aimed to be intentionally disruptive to the deficit perspectives often cast upon Latinx families (Moll & Gonzalez, 1994). Moll (1992) argues that working class families draw on rich and diverse sets of social and cultural currencies to achieve desired outcomes. The funds of knowledge approach unravels the expansive socio-political structures that govern everyday life; that is, the multiple ways that working class people use their resources to get things done. Furthermore, it provides ways to appreciate the lifeworlds of historically disenfranchised populations (Moll & Gonzalez, 1994). Similarly, mothers in this study provided interconnected micronarratives across time that revealed a complex web of individual, social, familial, and cultural currencies that they intentionally converted into demonstrable action. Often imbued with deep reflection and emotion, and revelatory at times to the mother herself, the stories also show how mothers reached across space and time to gain new knowledge and adapt their circumstances to provide equitable supports for their children. Seen through a funds of knowledge lens, these transformations occurred within sociohistorical milieus that were situated within the lived experiences of individual parents (Esteban-Guitart & Moll, 2014a, 2014b; Moll et al., 1992). Within this process, mothers were also shaping and re-shaping aspects of their identities as deeply knowledgeable advocates and protectors, fiercely standing up for their child's rights to supports and services—both in and, at times, out of school.

Esteban-Guitart & Moll (2014b) argue that humans construct meaning and interpretations through “zooming in and out across multiple places and timescales” (p. 73). That could be a useful lens through which to see mothers in this study. They drew upon multiples funds of knowledge they constructed, and they accessed their knowledge for specific purposes. Those purposes were often clear and remained salient: to acquire additional supports and services for their child through an intentional and sustained advocacy. That finding contradicts conventional assumptions about parents’ lack of knowledge and/or disengagement in the IEP process.

**Supports and services.** Parent learning about how to navigate the IEP process, especially for CLD parent learning, is noticeably missing from the research literature. Harry (1992b, 2002, 2008) has brought attention to this aperture in our knowledge and recommended strategies for practitioners to develop a posture of cultural reciprocity (Harry, Kalyanpur, & Day, 1999). Also missing are the concrete strategies parents use to achieve desired outcomes (Blanchett, Klingner, & Harry, 2009). Mothers in this study often did achieve at least a modicum of success with getting additional supports and services for their children. Importantly, mothers acted with intentionality to expand their knowledge about special education, disability, services and supports, and the IEP process. At times, they looked to advice from school personnel or therapists. At other times they sought out resources online, at libraries, or on social media. Mothers often referred to YouTube and Facebook as valuable resources.

This resourcefulness also speaks to the popular methods of engagement in post-modernity, in addition to highlighting the outmoded thinking about family participation and advocacy still popular in many institutions (Duggan, Lenhart, Lampe, & Ellison, 2015). Increasingly more families use electronic modes of communication (e.g., social media, texting, email) to stay in touch with individuals in their work, home, and school lives (Patrikakou, 2016).

Perhaps an important aspect of the mothers' capacities also comes about from their ages and access. The average age of the mothers was slightly less than 30 years old, and they demonstrated they could use electronic devices and social media to communicate with others for most of their adult lives.

**Advocacy *in situ*.** Advocacy has traditionally been defined as speaking and acting on the behalf of other persons (Burke & Goldman, 2018). However, some scholars talk about a key additional component in *parent* advocacy; that is, sustainability. Parents will always be there for their children and external advocates only provide temporary supports (Burke, 2013; Burke et al., 2016; Trainor 2010a). In fact, parent advocacy groups were an important historical impetus for the drafting of the original IDEA (2004) legislation (Turnbull, Shogren, & Turnbull, 2011). Research has shown that parents want to be informed and feel empowered within the IEP process so that their children can achieve greater academic and social success (Mueller, 2015; Wakelin, 2008). They wish to change the conventional views of parents as peripheral members in decision-making processes (Kalyanpur, Harry, & Skrtic, 2000).

Mothers in this study often spoke about feeling like they were viewed suspiciously when advocating for their children. They observed teachers and therapists disregarding their input and requests, and talked of feeling compelled to make difficult decisions about pushing back or keeping the peace through inaction. And we see that mothers often pushed back. Their advocacy actions were amalgams of past experiences with schooling and knowledge they had gained about disability and the IEP process. Their stories of struggle and triumph, patience and resilience always stemmed from a visceral need to protect their children. The stories revealed varied temporal acts that seemed to ground and enhance mothers' capacities to act as advocates for their

children. They continuously drew upon knowledge and experience across time as they made sense of present contexts and conditions.

I refer to that as “advocacy in situ.” When calling mothers’ actions on behalf of their children “advocacy *in situ*,” I am not stating that the mothers were intractable in what they wanted. Their advocacy was, in fact, dynamic, flexible, and, in many instances, diplomatic. Parents can be viewed as combative and adversarial by teachers when they make requests at schools, even when those requests are reasonable and well-within their legal rights (Rodriguez, Blatz, & Elbaum, 2014a; Salas, 2004). In addition, Salas (2004) found that Mexican American mothers often stayed quiet at IEP meetings due to their respect for authority. Taking the dynamic of cultural norms and mores into account, the sustained and targeted advocacy mothers showed in this study is a salient finding, and one that disrupts traditional notions of power imbalances in schools (Harry, 2008; Heshusius, 1986). However, mothers’ capacities for advocacy did not occur inside a vacuum. They intentionally and continually drew from their lived experiences, knowledge, beliefs, and values to inform their *in situ* actions. When doing so, we saw mothers draw from a repertory of experiences to stand in both an educational and social-cultural relation to their child, intuiting actionable beliefs and values through their role as mother (Van Manen, 2015). When we choose to consciously look to assets-based frameworks, such as a funds of knowledge approach, we choose to consciously recognize the community and cultural wealth that families use to reinterpret their lived experiences (Yosso, 2005). Such experiences are critical actions against hegemonic forces in which non-dominant cultural norms and expectations are seen as inferior and subordinate.

## Essence of the Phenomenon

Exploring the educational and socio-cultural relation of mother and child in this study helps us begin to see what makes the phenomena present in this study *what it is, and without which would not be what it is* (Van Manen, 1990). While exploring the IEP process from Latina mothers' perspectives and actions served as the backdrop and original intent for this study, it becomes clear that it was not the dominant meaning-making activity that occurred in the lives of these seven mothers. Against that backdrop were a host of perceptions, experiences, beliefs, values, and emotions that contributed to the essence of the phenomenon of participating in the IEP process. As Giorgi (1997) and Moustakas (1994) suggest, in a phenomenological study, through interpretation we commonly discover something unforeseen. In fact, Giorgi (1989) illustrates that we only begin to see *what it is* through a personal involvement with those who directly experienced the phenomenon. It is through this prism of personal involvement that more authentic interpretations become possible.

Moreover, two interrelated meanings seemed intimated continuously: (1) the primacy of lived experience and (2) motherhood as resistance. I am conscious that these ideas are my own interpretations. Yet I know they were borne from the interviews and rest upon the stories mothers told in the interviews. The stories are not my interpretations. They belong to the mothers that helped me understand the phenomena I call "primacy of lived experience" and "motherhood as resistance."

**Primacy of lived experience.** Merleau-Ponty (1945) used the phrase "primacy of perception" to describe the fundamental structures of a person's lifeworld. These structures occupy the lived space, lived body, lived time, and lived human relation of persons and are seen as fundamental to a person's lifeworld. Additionally, as Van Manen (1990) shows, these

structures can be productive for the phenomenological acts of questioning, reflecting, and writing. Those concepts are mirrored in this study. Mothers often reached across time to reveal why they had a certain thought, or to demonstrate why they acted in a certain way. Their life actions and decisions and questions did not occur in a vacuum, but were instead fed by numerous tributaries of experience that colored their perceptions. These perceptions were co-creations of past relations with family and friends, as well as the mothers' own experiences in school and knowledge they sought and gained. Those perceptions and beliefs informed mothers' relations with the multiple personnel who now worked with their children. They also informed personal relationships with family and friends. Several diverse experiences come together in varied ways to form, and keep forming, their lived experiences.

I offer this robust example of how the primacy of lived experience reached across timescales. In our second interview, one mother (Cecelia) posed a question to me to illustrate how she felt about the isolation she experienced from having a child with autism: "Have you ever felt like you're in the center of something and there's a lot of people around you, and they're just talking and talking? That's how I felt" (Int. 2, 07/06/2018). When I asked her for clarification, she responded, "Like I was doing it the wrong way. A circle with no doors. There's no way you can step out of it. You're in it forever." Her statement is an abstract, existential, and deeply personal way of expressing a subjective truth she felt viscerally. On a surface level, she was discussing how isolated she felt raising a child with autism. However, when we look across time at the whole of her narrative, it was clear that this also related to Cecelia's personal philosophy: that people cannot be trusted ("I don't even trust my own parents"), trauma and grief were inevitable ("You're in it forever"), and independence was a necessary virtue when confronted with the nature of existence ("I'm just gonna do it on my own").

The idea of primacy of lived experiences reminds me and perhaps partially emerged from existential explorations by Camus (1942). He describes Sisyphus, who is eternally pushing a rock to the top of a summit only to see it plummet to the earth again and again. Perhaps Cecelia, like Sisyphus, saw “the struggle itself toward the heights [as] enough to fill [her] heart” (Camus, 1942, p. 24). She, like the other mothers in the study, seemed to insinuate acceptance and at times deep appreciation for the acceptance of their lives and lived experiences.

**Motherhood as resistance.** The seven Latina mothers in this study had diverse lived experiences quite unique and difficult to essentialize into discrete statements. However, one salient commonality among all of the mothers was a robust resistance to any force—be that from the external world or internal perceptions—that could harm or impede their child’s functioning. Mothers often spoke up for their children when no one else would, pushed back against those who were not treating their children fairly, and educated those who held views that could be harmful to their children. In some instances, mothers created counter-narratives to the dominant deficit-models of disability. One salient example was when Mariana stated that her child with autism is fortunate to see things those without a disability will never see. Such interpretations mothers made often displayed a level of humanism that pushed against traditional descriptions of disability, which defines disability as something inherently problematic (Kiel, 1995). Moreover, mothers’ actions revealed a consciousness that was resistant to what they deemed as oppressive to their children. There is research to support and further inform this notion. Hughes, Valle-Riestra, and Arguelles (2008) found that Latino families often treated their family members with a disability like a “normal child.” This act of seeing and treating a child as “normal,” rather than an abnormality, may help identify the acts of acceptance and resistance that we saw in the mothers in this study.

Simone de Beauvoir (1997) offers helpful ideas about motherhood that shed light on the notion of motherhood as resistance. She wrote of the existential crises that mothers felt after bearing a child. First, there is the realization of having to care for a new being, which is always followed by an awareness of one's own ephemerality. Finally, a mother, "shut up in the home," internalizes the vast responsibility placed upon her and confronts the societal forces placed upon her gender and role as mother (Beauvoir, 1997, p. 541). Despite this, or in spite of this, mothers throughout history have taken up the challenge of rearing a child in an inhospitable and dangerous world. This is more than just an act of protection; *this is an act of resistance*. Yet as Van Manen (2015) writes, "Child rearing is as intrinsic to human life as is feeding, clothing, caring, sex, and sheltering" (p. 19). Additionally, I would like here to point to the universality of the concept of "mother." We are all ushered into existence by a mother. As such, we can all, to some extent, identify with the weight of the word. But only a mother can truly experience and express, in numerous ways, the mixture of thoughts and feelings that define motherhood.

The seven Latina mothers in this study resisted and intervened in a diverse number of ways. Yet key to our understandings of their purposes is this: their interventions and overall actions seemed always enacted with thought about ways to change perceptions and practices they saw as unsupportive of their child's education or well-being. At times, it was hard to determine the extent to which this resistance was intentional. The interventions that mothers enacted were narrated with an ease and intuition that reflected their meaningfulness and essential qualities, but also spoke to the intrinsic nature that intervention may play in the role of being a mother.

The extent of intentionality may be beside the point, however. The findings in this study revealed that mothers resisted forces that were threats to the success and well-being of their children. They were able to clearly articulate this resistance during the course of interviews, and



by doing so, demonstrated a critical consciousness of the people, systems, and structures that were oppressive toward children with disabilities, as well as to themselves as mothers of children with disabilities. The primacy and intentional access they had to examining their experiences (consciously or not), and their sense of advocacy and resistance, when necessary, seem at the core—the essence—of their roles and actions as Latina mothers of children with disabilities.

### **Implications**

Findings from this study yield several implications for practice and research. For practice, I suggest key tools and vehicles through which educators and parents could exchange and build on the knowledge and meaning-making of lived experiences related to supporting students with disabilities. To support the overall education of students with disabilities, we need vehicles for parents and families to co-construct knowledge with educators, imbued authentically with knowledge of cultural mores and expectations. I further argue that doing so could be foundational to community civic engagement. Lastly, I argue that the tact seen in mother/child relations can be an important starting point for rethinking interactions between schools and families. For research implications, I suggest potential valuable follow-up research that can help extend findings from this study. I next discuss the need for research instruments sensitive enough to access and gather family knowledge. Lastly, I demonstrate the value of knowledge about parents gained through using a phenomenological paradigm.

**Implications for practice.** The findings from this study yield a number of implications for practitioners that I will now explore. The goals and aims of this research were to discover the essence of Latinx parents' lived experiences in the IEP process. In addition to the use of a system for gathering knowledge, values, and beliefs, increased parent participation is predicated on equitable structures that invite parent input (Goss, 2017; Salas, 2004; Zeitlin & Curcic, 2014).

Reframing physical and virtual spaces around models of civic engagement could make formal structures, such those seen in the IEP process, more conducive to authentic participation (Hildreth, 2012). Lastly, teachers can mirror the tactful and intuitive pedagogies parents use to rear children to bridge the structural gaps between school and home (Van Manen, 2015).

***Funds of knowledge.*** We have a paucity of concrete methods for gathering parent knowledge generally, and especially throughout the IEP process. One potential method for doing so is through the use of a funds of knowledge approach. Moll's (1992) funds of knowledge approach has been used with a variety of communities in order to better appreciate family knowledge. For instance, Gregg, Rugg, and Stoneman (2011) investigated the funds of knowledge of Latinx families of children enrolled in a Head Start program. They found that families could easily communicate their strengths, aspirations, and knowledge but faced a variety of barriers communicating those to school personnel. Language, culture, and comfort-level were all barriers to more effective communication with school personnel. Additionally, much like many schools and institutions that serve CLD families, Head Start programs do not always have tools present to capture families' funds of knowledge (Gregg, Rugg, & Stoneman, 2011). Approaches for capturing families' funds of knowledge range from ethnographic home visits (Moll et al., 1992; Moll & Greenberg, 1990) to using family-created portfolios (Gregg, Rugg, & Souto-Manning, 2011) or family photographs (Allen et al., 2002) to share with school personnel. We have no agreed-upon standards or methods for accessing families' arrays of knowledge. The aforementioned approaches often happen discretely and have not caught the attention of key stakeholders in schools that could enact practices school- or district-wide.

Within some schools, there are informative tools used in the IEP process, however. For instance, *The IEP-at-a-glance* is sometimes employed by educators in order to provide a one

page form with descriptions of a student's IEP objectives (Horn, Lieber, Sandall, Schwartz, & Wolery, 2002). Sometimes these forms also include information about strategies to address academic, social, and behavioral needs, as well as accommodations and key contact information (e.g., parent, case manager; Hedges, Kirby, Sreckovic, Kucharczyk, Hume, & Pace, 2014). This form is then often given to general educators for a quick reference sheet to be used in the classroom (Hedges et al., 2014). While there are no published examples of IEPs-at-a-glance being used to gather family knowledge, the general idea of providing an overview could offer a starting point for conversations on how to access funds of family knowledge.

The key is to find ways to hear authentically. It is pivotal to value the concept of people having a “fund of knowledge” that is linked in dynamic ways to their individual, familial, and cultural experiences. Individuals have varied beliefs and values on which they draw and compare the present, which also help shape their futures. This study provides results about one group of persons gained through a specific recruitment process and those who accepted to participate. Other studies, and indeed other purposes for studies, will result in different insights. What this study shows, however, is the importance of hearing voices other than Eurocentric voices and ideas that have often guided school structures, content, and actions—including the IEP process.

***The IEP process as civic engagement.*** Much like developing a posture of cultural reciprocity (Harry, Kalyanpur, & Day, 1999), creating spaces for civic activities can have a positive impact on the participation practices of families when interacting with schools (Terriquez, 2011). A key aspect of engaging families is developing a strong and trusting relationship within which values, opinions, and backgrounds of families are taken into consideration (Harry, 2008). Attending to civic engagement principles could be especially important when working with historically marginalized populations, such as individuals with

disabilities and/or those from CLD populations. Those principles include commitments to community service, collective action, political involvement, and social change (Adler & Goggin, 2005). Such ideas could provide an important counter-balance against those persons who have social and cultural capital from dominant groups with explicit and implicit power who might dominate conversations (Bates & Davis, 2004). Certain kinds of social and cultural capital are integral to developing strong partnerships between schools and families (Trainor, 2010a, 2010b, 2010c). The lack of these forms of capital has been found to be a significant barrier to participation for parents and students, especially those with disabilities (Bates & Davis, 2004; Lo, 2009; Rodriguez, Blatz, & Elbaum, 2014; Trainor 2010a, 2010b, 2010c).

One form of civic engagement that has been used in school contexts is World Café's method of structured conversations (Brown & Isaacs, 2005). The format for these structured conversations is predicated upon shared ideas emerging from multiple stakeholders engaged in discussion of a particular idea or question. Brown and Isaacs (2005) offer practical guidelines for engaging people in conversations: (1) set the context, (2) create hospitable space, (3) explore questions that matter, (4) encourage everyone's contribution, (5) connect diverse perspectives, (6) listen together for patterns and insights, and (7) share collective discoveries. The use of such a method within schools could mitigate some of the systemic barriers to participation and create spaces for authentic inclusive dialogue. This could be particularly useful within the context of the IEP process, since formalities embedded within the process often stymie participation (Pang, 2011; Underwood, 2010). This is by no means a curative approach to the systemic barriers that govern partnerships between schools and families; rather, it is an example of a straightforward activity that could lead to development of structural changes that support civic engagement models in schools.

*Tactful pedagogy.* When discussing the complex nature of pedagogy, Van Manen (2015) illustrates the reflective elements and intuitive understandings inferred from caring for children. These reflections and understandings are “primal” and “beyond rational understanding” (Van Manen, 2015, p 15). There is a bi-directionality to engaging in the pedagogic process by being in proximity to the lived space of a child that is cared for. There is also a systemic lived relation between all of the adults that interact within the spheres of influence in which children’s lived experiences occur (Epstein 2001, 2008). These spheres are similar to Brofenbrenner’s (1979) ecological model, in so far as they are vehicles for understanding the dynamic interactions that occur within and across systems. Van Manen (2015) highlights this interactionism vividly when discussing pedagogic relations.

The mother, father, grandparent, teacher, psychologist, nurse, counselor, pediatrician, and those others who care for children learn to understand themselves in new ways as they are prompted to reflect on themselves and their interactions with the children for whom they care (p. 17).

Mothers in this study often relied on their intellectual, emotional, and creative capacities to care for their children. The naturalism behind those lived relationships is what Van Manen (2015) describes as “tactful pedagogy.” The tact endemic to parent-child relations relies on a keenness to know what to do and say in a number of situations. As situations change, parents often respond in novel ways to insulate their children from danger and instruct them on how to remain safe (Smith, Cowie, & Blades, 2015). These are, in fact, intuitive pedagogic relations. They could be transferred to the school instructional setting and incorporated in the IEP meeting. By using a tactful pedagogy in interactions with children, practitioners could begin to remove the physical and mental constructs that isolate schools from homes and communities. Additionally,

positioning practice as tactfully pedagogic can disrupt the deficit-orientations, medical models, and negative attributions informing notions of disability that are also present in schools. In this study, we saw that mothers, in pedagogic relation to their children, were fully capable of coming to new, humanized understandings of disability. Likewise, through pedagogic relations with parents and their children, practitioners could likely do so as well.

**Implications for research.** Several implications for further research emerge from this study. Overall, this study raised important questions about how Latina mothers access their lived experiences and funds of knowledge to advocate for children with disabilities. One key next step could be follow-up interviews with the study participants that could lead to a longitudinal view of participants' work. Another immediate research next step related to the finding about multiple disconnections between the participants and school personnel is adaptation and development of research tools and instruments. We could adapt available instruments around funds of knowledge to access and gather a wide-array of points of view from CLD, Latinx, African American, working class, and other diverse families ("Funds of Knowledge Activity," n.d.). Key in the development is ensuring the domains of questions and the wording of the questions are sensitive and respectful of a person's culture and beliefs. This could help ensure that the instruments do what they are designed to do—namely, capture a cultural and familial wealth of knowledge. The tools would be piloted with diverse families and gender identities to reduce bias and ensure applicability in a diverse array of communities. A related next step would be partnering with mothers in this study as researchers. With them, we could adapt and develop culturally-sensitive tools. Working collaboratively, we could explore lifeworlds intricately related to authentic viewpoints from families.

To explore cultural mismatches linked to misunderstandings and miscommunications, the tools discussed above could help. As seen in this study, those misunderstandings and miscommunications can sometimes be covert and implicit, only appearing through extended conversations. As such, research instruments would need to be structured in ways that could highlight those thoughts and ideas that are not readily apparent. Although not intended as a research instrument, Brown and Isaacs (2005) notion of “World Café” conversations could yield research findings (see Carter & Bumble, 2018) related to creating collaborative educational opportunities with families, community, and school personnel for students with disabilities. Careful analyses of conversations could help researchers understand the nuances and intersections involved with misunderstandings and miscommunications between schools and families.

The results of this study reinforce the value of phenomenological paradigms that allow researchers to view phenomena as they actually exist through the eyes of the participants they seek to understand (Moustakas, 1994; Van Manen, 1990). Although more common in fields such as nursing (see Matua & Van Der Wal, 2015), phenomenological research methods have been used with individuals with disabilities (e.g., Cornett-Devito & Worley) and have been recommended as a way of seeing the field of special education differently than it traditionally has been analyzed (McPhail, 1995). While the last few decades have seen innovative research into the lives of individuals with disabilities and how disability has been constructed through socio-historical and socio-political systems and structures (Ferri, 2008), there is still a dearth of studies in special education that privilege the voices of families of children with disabilities (Coomer, 2019; Cornett-Devito & Worley, 2011). Connor (2019) attributes this to the resistance researchers in special education display toward new perspectives and an overreliance on a certain

kind of “science” positioned as the gold standard to conducting research in the social sciences. Findings from this study indicate the possibilities of gathering research findings about intricacies in the lived experiences of Latina mothers that would be hard to access through research methodologies that did not have a holistic component of capturing life histories and how those relate to the phenomenon under investigation.

Lastly, by situating participants as co-researchers in the investigation of phenomena, phenomenological studies create a space for democratic discourse (Shaw, 2009). Dewey (1935) believed that democratic ways of being enabled authentic ways to resolve conflicts between parties with differing priorities. In so doing, voices are treated equitably in decision-making processes, and that can support the empowerment of a greater number of people involved. Too often, research institutions (like schools), are positioned as hegemonies: top-down bureaucratic organizations where the few make decisions for the many (Apple, 1979; Heshusius, 1986; Skrtic, 1991). By questioning the notion of “participants” as persons “we” seek to study, and instead valuing research in which persons observe and analyze together to shed light on lived experience in their analyses and interpretations, researchers can remove the austere garb of modernity and don an attire more befitting to the 21<sup>st</sup> first century. We can enact the conceptual ideals of democracy, personal freedom, fluidity in gender and identity, and skepticism of traditional institutions—that some argue are increasingly becoming the norm (Hyslop-Margison & Thayer, 2019).

## **Limitations**

Several limitations emerged in this descriptive study of the lived experiences of seven Latina mothers. First, this study consisted of a sample of parents that self-identified as Mexican American mothers. I had originally hoped for a more heterogeneous sample of participants from



different genders and various Latin American countries. Although the purpose of a qualitative study is not to generalize to larger populations (Creswell, 2014), the overall descriptions could have additionally richly layered a wider varied ratio of Latinx cultures and gender identities.

Secondly, and connected, I had a select pool. All participants seemed attuned to gaining support given their choice to participate in interviews or attend a community event(s), which is where I recruited two participants. Also, all participants had a kind of educational capital, in that they all graduated high school and six had at least some college. Additionally, all participants were fluent in English and able to respond in interviews using the English language. Excluding potential Latinx participants not fluent in English and recruiting from a particular pool of persons with shared values may have contributed to a more homogeneous sample for this study. Related to this, it is difficult to determine how findings in this study might transfer to other immigrant communities where persons' social and human capital could be different from the sample reported herein. The participants were also fluent English speakers and that aligned with my language facility. Interviews in which the interviewer and interviewee are not facile in the same language is also a factor to consider. Further research with linguistically diverse populations could further inform both research and teaching practices recommended in this study. Finally, another limitation related to the participant pool is the age of the child of focus. Six of the seven children discussed in the interviews were currently in pre-school or had just recently began kindergarten. Parents of pre-school aged children may discuss participation in the IEP process in a way that is different from parents of older children. Parents in this study also often discussed supports and services that are unique to the education of younger children.

A third limitation is related to the choices I made about what areas and what specific questions to ask the mothers in this study. Though the interviews were semi-structured, which

allowed me to follow up with questions based on the mothers' specific words and stories, their responses and choices were still mitigated by what I asked. Exploring other domains of their lives, and/or asking questions in different way might have yielded different narratives.

A fourth limitation is related to transferability. The extent to which these findings can transfer to other settings is unclear given the sample size ( $n=7$ ) and the design and method of the study. However, as Lincoln and Guba (1985) assert, it is up to the reader's discretion to determine applicability and transferability of findings to another setting.

Threats to reliability and validity include the presence of a researcher who may have biased participant responses (Creswell, 2014). As a White male who does not have a child, my identity contrasted with those of participants in several ways. Although I come from a working class family, work in the field of special education, and was myself identified with a school-aged disability, my lived experiences have been likely very different than the participants in this study. In order to mitigate the biases that color the way I see things, I had numerous conversations about phenomena in this study with other women researchers, mothers, and women of color in order to reflect on what I was not seeing, and why I was not seeing it.

## **Conclusions**

I aimed to provide a picture of the richness of seven mothers' lived experiences related to the IEP process for their children with a disability. I aimed to highlight the knowledge, skills, and values I heard from the interview questions I asked. I wanted to give opportunity for the mothers' perspectives and experiences to emerge, and to show the meanings they made of those. I also wanted to cultivate a posture of reciprocity based on mutuality, empathy, and responsiveness (Harry, Kalyanpur, & Day, 1999). In the end, I also clarified my judgments, preconceived notions, and biases about gender, race, child rearing, and disability. I close with

expressing my gratitude to the mothers. I hope their stories show the strengths they have, and help to show counter-narratives to the entrenched views about Latinx parental participation in the education of their children.

## **APPENDICES**

## Appendix A. Participant Screening Tool



### Participant Screening Tool

**Directions:** For each statement below, please check “yes” if the statement applies to you or “no” if the statement does not apply.

Yes	No	Statement
		1. I identify as Hispanic/Latino/Latina/Latinx.
		2. I currently have guardianship over a child that attends an elementary or high school.
		3. I have attended at least 2 IEP meetings for my child.
		4. I can speak and understand English.
		5. I am 18 years old or older.
		6. My child has an IEP.
		7. My child is currently attending an urban school.
		8. My child receives “free and reduced lunch” at his or her school.

If you checked “yes” to all statements and you are interested in participating, please contact the principal researcher by phone or email. Mr. Passi will setup a time for the first interview.

Joe Passi



Any questions about the research project? Questions can be directed to Joseph Passi or his doctoral advisor at UIC, [REDACTED]

*Thank you for your time!*

## **Appendix B. Interview Protocol**

My interest as a special education teacher also doing research is to improve involvement and communication between schools and families. I believe one way to do that is by understanding parents' backgrounds and the ways in which they support their child's education.

To learn about that I would like to talk with you a total of four times. The first two times will be in person, the third will be in person or via phone and the fourth will be via phone. Today I want to talk with you about those parts of your life that are part of your background and your parenting so I can understand what you value and draw on. Next time we meet we will talk about your experiences with the IEP process.

Everyone has a story to tell, and each story is different and helps people like me to be a better teacher and advocate for kids with IEPs to have successful educational experiences.

### **Domain 1: Focused life history**

1. First I'd like to know about your background in your own growing up. **(10 minutes)**
  - a. Could you tell me about your own schooling experiences?
    - i. In your schooling experience, how many schools did you attend?
    - ii. What did you like best about school?
    - iii. Tell me about your favorite subject in school.
    - iv. Tell me one or two things you didn't like that much.
  - b. Could you tell me about your family?
    - i. EXPLORE: Any siblings? Big family/small family?
    - ii. EXPLORE: What kinds of things did you learn from your family?
2. As you think about your own growing up, can you identify something significant—something important—that you've experienced? Could you tell me about that? **(8 minutes)**
  - a. EXPLORE: What happened? How? Where did it happen? When? What about that seems so important to you?
  - b. How has that, if at all, affected you?
    - i. Is this something you've talked with your child about? Why or why not?
  - c. EXPLORE: Is there some other experience that was significant that you could share?
3. Tell me some stories about growing up that you have shared with your child. **(6 minutes)**
  - a. EXPLORE: What, if any, kinds of things does [child name] know about your schooling, what your family was like growing up, or some of those important experiences you mentioned?

I appreciate learning about your own experiences growing up. Like I said earlier, we all have our stories. Those experiences affect how we operate in the world, too. So I thank you for sharing yours. Now I'd like to talk with you about your child.

## Appendix B (continued)

### **Domain 2: Experiences of and with Child with Disability**

4. Tell me about [son/daughter name]. What is s/he like, what does s/he like to do? What is s/he good at? **(8 minutes)**
  - a. EXPLORE: What are some of the things that [son/daughter name] likes to do? It could be at home, school, a relative's house.
5. [if it hasn't come up:] Tell me about his/her schooling. What do you think your child thinks of school? **(5 minutes)**
  - a. EXPLORE: Talk about a specific thing that [child name] did or said that let you know how s/he thinks about school.
6. What sorts of things do you get to do with [child name]; or what are some of your fondest memories of things you have done together? **(5 minutes)**
  - a. EXPLORE: Tell me about one fun thing you've done with you child recently.
7. Tell me three things to know about the community where you and your child live? **(7 minutes)**
  - a. EXPLORE: You could talk about what it's like to live on the block you live on, or about the neighborhood you live in.
8. What language do you use when talking about school? What language do you use, for example, over dinner, while doing something at home? **(5 minutes)**
  - a. EXPLORE: Besides just the language, think about the way you speak to the school and then the way you speak with your family. How would you describe this?
9. What are some things you have taught [child name] at home as s/he grows up that you think they don't know about in school? This could be stories you have told them, things you have taught him/her to do, things you think are very important for life. **(8 minutes)**
  - a. Do you think that teachers and other people at school would think this is important?
10. [if it hasn't yet come up:] What does [child name] want to do when s/he graduates? How will s/he do this and what do you think about it? **(5 minutes)**

## Appendix B (continued)

### **Second interview / Domain 3: Lived experience in the topic area: The IEP process**

Last time we met we discussed your upbringing and how that impacted you. We also talked about some of the things you learned from your family that you use to support [child name]. Now for this part I want to talk about the IEP process. I use the term “process” because the IEP is more than just a document or a meeting. For instance, teachers sometimes talk with parents throughout the school year about a student’s IEP goals.

1. Let’s talk about special education services and the IEP process. How did you first learn that [child name] needed special education services?
  - a. EXPLORE: Did you see or hear anything that made you think about a need for services?
    - i. Did you know services were available for your child?
  - b. If you didn’t see or hear anything, did teachers raise it? How?
    - ii. What did they say, if you remember?
  - b. EXPLORE: In what ways did the teachers talk about [child name]?
  - c. EXPLORE: In what ways did teachers talk about why [child name] needed special education services?
    - i. EXPLORE: What services did teachers say could help?
    - ii. EXPLORE: Did teachers point out strengths along with what your child needed help with?
  - d. EXPLORE: How did you feel during this time? What were some of your thoughts?
2. Did you talk about this with [child name]? Why or why not?
  - a. How did the conversation go? Did you or [child name] have any questions after?
  - b. Did you talk with any family members or friends about the special services being discussed through or at the school?
  - c. Did you have any specific concerns about having an IEP or special services at school?
3. What did teachers say about the IEP?
  - a. What do you recall was on that first IEP?
  - b. Did teachers/school personnel give a name or label to the disability?
    - i. EXPLORE: Some common labels are learning disability, emotional disturbance, or behavior disability.
4. Tell me about your first IEP meeting and how it went.
  - a. EXPLORE: What do you remember about what was said and who was doing the talking?
  - b. EXPLORE: How did it make you feel?
  - c. EXPLORE: Was [child name] with you? If so, how did she/he react?
    - i. Did you talk about it after the meeting was over? Why or why not?
5. How have more recent IEP meetings been?
  - a. Have they been different? The same?
6. Do you think [child name] is receiving all the services outlined in the IEP?
  - a. What makes you say xxxx or yyyy? What do you see or hear or know that assures you the services are happening?



**Appendix B (continued)**

- b. EXPLORE: What about the services seem good or okay? What more, if anything, would you like to have in terms of services?
  - c. EXPLORE: What other services do you think [child name] needs or could benefit from? Why or why not?
7. Now, a lot of people don't know what an IEP is. If you met someone who didn't know about an IEP how would you describe it to them?
- a. EXPLORE: What else might you say?
  - b. What might you show the person, if anything?
  - c. What might you say or do to advise the person if his or her child needed an IEP?
  - d. How would you describe what parents do in the IEP process?
    - i. What about that seems most important?
    - ii. What about that seems to be missing, if anything?

## Appendix B (continued)

### **Third Interview / Domain 4: Reflection on the meaning**

For this interview I will ask you to reflect on the possible meaning of some of the things we've talked about. We have talked about your family, your child, and the IEP process, among other things. You can keep those in mind when answering some of these questions.

1. Given what you have said about raising your child and your experiences with the IEP process, what does the IEP process mean to you?
  - a. EXPLORE: When you think about the things we talked about with the IEP process, what words/ideas/thoughts come to mind?
2. In our first interview we discussed your own schooling and childhood. How does any of that relate to who you are now?
  - a. How does that, if at all, relate to your child's education and how you see it and understand it?
  - b. What did you learn growing up, or learn about schooling overall, that may have helped you as you try to understand the IEP process and special education?
  - c. What did you learn growing up, or learn about schooling overall, that may have interrupted or gotten in the way as you try to understand the IEP process and special education?
  - d. Are there some additional thoughts you have that you'd like to add?
3. I'm wondering—what do you expect will happen in the next few months and years regarding [child]'s education?
  - a. EXPLORE: This could be in terms of [child name] schooling, future IEP meetings, things you might do to help your child.
4. In what ways, if at all, might you change the ways you relate to and interact with the IEP process and school personnel who participate in it?

**Appendix B (continued)****Member check**

Thank you so much for talking with me these last three times. In order to make sure that what you told me is accurate and what you intended, I am going to read some of the key ideas of what you said in the interviews. You could interrupt me at any time and ask questions, request that I add, modify, or delete something. This will ensure that anything I write will really capture what you intended.

[Read each key idea from the three interviews and allow participant to speak freely about any aspect of what is being read. Ask again if there is anything they would like to add, delete, or modify at the end of reading the key ideas.]

## Appendix C. Codebook

**Overview of study and directions for second coder.** Thank you for agreeing to be the second-coder for my research study. This cover sheet will guide you in the process of coding the transcripts. This qualitative research study investigated the lived experiences of 7 Latinx mothers with children with disabilities with the IEP process. Each participant was interviewed 3 times, for a total of 21 interviews. Four domains were used in the interview protocol for this study: (1) Life history, (2) knowledge of child, (3) experience with the IEP process, and (4) reflection on meaning. After collecting the data, I worked with my doctoral advisor on developing codes. In order to capture the breadth and depth of the interview data, we decided to use a combination of structural-driven and data-driven codes for analysis. We then developed the attached codebook to be used throughout analysis. We coded one-third of the transcripts before finalizing the codebook.

You will be asked to code 9 of the 21 transcripts. The first 3 transcripts will be coded independently by both you and the PI. After finishing the first 3 transcripts, a second meeting will occur to discuss codes. This can be by phone or in-person. To move forward, intercoder agreement must remain at 80% agreement or above. You will then be given 4 more randomly chosen transcripts to be coded independently. The PI's directions for the second coder are provided below. Please refer to these during coding to ensure that the correct procedures are followed.

### Directions for second coder

1. The codebook includes 10 codes with descriptions and examples for each code
2. The process of chunking or "lumping" (Saldana, 2009) will be used to identify chunks of text that share meaning. Each lump will be identified in a participant's responses.
  - a. A lump will occur between an interview protocol question and related probes. Each interview protocol question is highlighted in green.
  - b. Each lump of transcribed text will show particular shared meaning or meanings (e.g., a story or stated belief or view), and it can have any size. The key component of a lump is shared meaning.
  - c. One code or multiple codes in this codebook could be given for every lump. Some lumps may have one of multiple codes contained therein.
  - d. If a lump of text is identified and does not fit any code in this book, please mark it for further discussion.
  - e. Domain 1 contains some narrower questions about participant's schooling and family. Answers to these questions will be put into charts. If a chunk in Domain 1, or anywhere else, cannot be coded write NC ("No Code").
3. One full coded transcript will be reviewed as an example when discussing this book and the overall coding scheme with a second coder.
4. A blank (uncoded) transcript will be coded independently by the PI and second coder.
5. Codes will be compared, and intercoder agreement needs to be at least 80% (Miles & Huberman, 1994) in order to move to next steps.
  - a. If necessary: Additional transcripts will be coded and reviewed until 80% intercoder agreement is reached.
6. Three transcripts will be coded independently by the PI and the second-coder. Coders will then discuss disagreements and make amends to their coding and/or the codebook.
7. Five transcripts will then be given to the second-coder. Intercoder reliability will be met at 80% or higher, or interceding will continue.

Codes	Description	Examples
<b>Advocacy (Adv)</b>	Comments or actions in which the participant directly states their wants/needs for their child.	<p>“So being an OT is kind of like telling them you can be your own son's occupational therapy you don't have to go and I don't know, find somewhere to take your child when you can just learn with him.” (Cecelia, Int 1, p. 13)</p> <p>“Before I was really quiet. I was like ... shy, and then having a son for autism that kind of made me stand up for himself.” (Cecelia, Int 3, p. 4)</p> <p>“I feel that the one speech per week, it's not enough.” (Fatima, Int 2, p. 19)</p> <p>“Maybe ... them providing resources that I could use at home. Maybe like links that I could read and ... so I can help my daughter out.” (Juliana, Int 2, p. 13)</p>
<b>Self-awareness</b>	Participants' knowledge and awareness of their own emotions, thoughts, attitudes, and values in relation to rearing a child.	<p>“I was scared, nervous, and I didn't want to be judged, so I didn't use the social worker. I managed myself with my phone and going to the library, getting information books.” (Cecelia, Int 2, p. 4)</p> <p>“I was like I do need help I don't really know how to like really raise him or nothing 'cause I don't know anything. So I didn't know he was even diagnosed until last year.” (Amelia, Int 2, p. 3)</p> <p>“I was really reluctant about it because he was my first born and I thought it was normal.” (Amelia, Int 2, p. 3)</p> <p>“Cause even parents don't take it good when you say something bad about their kids. Cause that's how I am. It's hard to accept it.” (Juliana, Int 2, p. 13)</p> <p>“I just didn't want my daughter to feel like she was different. I didn't want her to feel weird that she's leaving her friends and stuff like that.” (Juliana, Int 2, p. 7)</p> <p>“In my mind I did not want to receive that because that means accepting that Carlos has a disability.” (Fatima, Int 2, p. 19)</p>

<p>Parent knowledge and observations of child (PKoC)</p>	<p>Parents' detailed knowledge about child based on observations.</p>	<p>"And the reason I realized something different with him was because he wasn't speaking and he skipped crawling to walking. Like, nine months, he started walking." (Cecelia, Int 2, p. 2)</p> <p>"A year and a half he was not walking. He was doing every single thing what a normal kid needs to do, but the walking was just the problem." (Fatima, Int 1, p. 19)</p> <p>I still don't get it because he screams. So I'm like, "If the noise bothers you, why is you yelling?" He doesn't respond to me. That's still in the same spot. (Cecelia, Int 2, p. 3)</p> <p>"I ask him every day, "How was school?" I ask him several short questions. He just walks away on me." (Cecelia, Int 2, p. 7)</p> <p>He is really upset I'll just get on top of him like I'm attacking him and that helps him to relax. He goes like a hog, If I could say, and then I'm like, "Before you start throwing things," I go and I jump on him like, "You need to relax." There's no other way I could. He's really strong. (Cecelia, Int 2, p. 8)</p>
<p>Gaining knowledge and/or support from others (GKS)</p>	<p>Participants gained knowledge and/or support from advocates, school personnel, therapists, family members, and resources.</p>	<p>"It was an organization that used to come into your house and it was completely free. And he would be checking out Carlos, how was he. And she would just leave. So, she would guide me, "Okay, you know, there's this program, there's this this, you can do this with Carlos." (Fatima, Int 2, p. 3)</p> <p>"I kind of Googled it or looked up what kind of programs there were around the community." (Isabela, Int 2, p. 2)</p> <p>"I went on my own, but the person that helped me was my mom because my sister had a special needs." (Fatima, Int 2, p. 10)</p> <p>"Just that he was gonna get more, it was about special services for him. Services that he's gonna, he was gonna receive." (Guadalupe, Int 2, p. 8)</p>

<p><b>Confusion about available services and supports (CAS)</b></p>	<p>Participant confusion about the IEP process, technical jargon, and special education services.</p>	<p>"So, I'm not sure because he's barely starting and they only get shorter every time." (Fatima, Int 2, p. 1)</p> <p>"When they go the first time, they go clueless. They don't know what to expect or they think everything that they say it's okay." (Mariana, Int 2, p. 15)</p> <p>"I don't know what other things he might need because I don't really know much they can offer him." (Amelia, Int 2, p. 19)</p>
<p><b>Confusion about assessment/ diagnosis (CAAD)</b></p>	<p>Participant confusion about assessment and diagnostic procedures.</p>	<p>"I didn't realize, at the moment, he was gonna be in special ed, I just thought he was gonna talk until early intervention came in and then the exam." (Fatima, Int 2, p. 2)</p> <p>"I didn't understand why until at the end that he needed something for his feet." (Fatima, Int 2, p. 2)</p>
<p><b>Conflict with school and/or provided services (CWS)</b></p>	<p>Disagreement with how services, teachers and/or process of support is carried out.</p>	<p>"The teacher said we had to go. They're like, 'We're gonna go to, let's say, the zoo, but you have to go with him, because we're not gonna be able to have, you know, take care of him or whatever.'" (Fatima, Int 2, p. 20)</p> <p>"They let me in but they don't let me in to see his classroom or how he works. If I ask questions it's like, like if I was in jail or something like that, but they had it like, "'Okay, wait for us here, somebody will come and see you.'" (Mariana, Int 1, p. 20)</p> <p>"Yes, they were shutting doors on us, they didn't want us to tell them how are we going to make Benjamin do this. Then they didn't want to do anything." (Mariana, Int 2, p. 5)</p>
<p><b>Conflict with family (CWF)</b></p>	<p>Disagreement with family over rearing a child.</p>	<p>"I felt like I was always being judged because of how I teach Abidan or if I was doing wrong with him or something. That's when I started getting really nervous. I will have problems with his dad because a year ago we separated so I had to live with my mom for three months." (Amelia, Int 3, p. 3)</p> <p>"I was scared because my whole family was telling me, 'No, he's just spoiled. He's this. He's that.' They were attacking me. For a whole year</p>

		I stayed away from my family, just for my son.” (Cecelia, Int 2, p. 3)
Awareness of language, racial, cultural, and/or ethnic difference (AoL)	Participants’ awareness of differences in language, race, culture, and/or ethnicity.	<p>“In our culture, there's a lot of machos that, like, ‘Oh, what's the point of going? Now, you're going to be a mom.’ Then you got to take care of your kids and stay home.” (Guadalupe, Int 1, p. 9)</p> <p>“Yeah. I met different people. Not only Hispanic people, people from different countries. Not only Mexican or Hispanic.” (Fatima, Int 1, p. 17)</p> <p>“I liked it over there because they had principles.” (Mariana, Int 1, p. 9)</p> <p>“I mean, they're like ... the machines. I had no machines over there, right. We had to go to the river to wash.” (Mariana, Int 1, p. 13)</p> <p>“Now that I went to college, what I didn't like is that it was all Hispanics, 'cause when I got to college, I don't know how to interact with other races. It was really hard to me. I didn't know how to interact with other people.” (Juliana, Int 1, p. 5)</p>
Safety concerns in community (SCIC)	Concerns for safety due to violence in communities.	<p>“There is gang bangers at the streets.” (Fatima, Int 1, p. 26)</p> <p>“Yes, it’s fenced. Everything’s fenced. But bullets will flow, they fly everywhere, and you know, I’d rather not risk it.” (Mariana, Int 1, p. 31)</p>



## Appendix D. IRB Approval Letter



### Approval Notice Initial Review (Response To Modifications)

**RE: Protocol # 2018-0284**  
**“Latinx Parents’ Funds of Knowledge: Participation throughout the IEP Process”**

Dear Mr. Passi:

**Please remember to submit a separate Amendment via OPRSLive to request UIC IRB approval to add transcription agency, along with a signed confidentiality agreement prior to utilizing the transcription agency.**

**Please remember to submit a completed Appendix K and written letters of support from each performance/recruitment site before recruiting and/or enrolling subjects and/or collecting any data at the site(s). All submissions must be accompanied by an Amendment form when submitted to the UIC IRB.**

**Please note that if Chicago Public Schools (CPS) or Charter Schools will be involved, a copy of research approval from the CPS Research Review Board (RRB) must be obtained prior to recruiting/enrolling subjects or collecting data from CPS records. Please also note that letters of support from each participating schools’ principal must also be submitted, to the UIC IRB and approved prior to recruiting/enrolling subjects or collecting data from school records. Please remember to submit as a separate Amendment via OPRSLive.**

**Please note that stamped .pdfs of all approved recruitment and consent documents have been uploaded to OPRSLive, and can be accessed under “Approved Documents” tab. Please remember to use only those approved documents to recruit and enroll subjects into this research project. OPRS/IRB no longer issues paper letters or stamped/approved documents.**

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on April 18, 2018. You may now begin your research

Please note the following information about your approved research protocol:

**Protocol Approval Period:** April 18, 2018 - April 17, 2021

**Approved Subject Enrollment #:** 8

**Additional Determinations for Research Involving Minors:** The Board determined that this research satisfies 45CFR46.404, research not involving greater than minimal risk. Therefore, in

UNIVERSITY OF ILLINOIS AT CHICAGO  
Office for the Protection of Research Subjects

201 AOB (MC 672)  
1737 West Polk Street  
Chicago, Illinois 60612

Phone (312) 998-1711



accordance with 45CFR46.408, the IRB determined that only one parent's/legal guardian's permission/signature is needed. Wards of the State may not be enrolled unless the IRB grants specific approval and assures inclusion of additional protections in the research required under 45CFR46.409. If you wish to enroll Wards of the State contact OPRS and refer to the tip sheet.

**Performance Sites:** UIC

**Research Protocol(s):**

- a) IRA: Latinx Parents' Funds of Knowledge: Participation throughout the IEP Process, Version 2, 03/28/2018

**Recruitment Material(s):**

- a) Self-Screening Tool for Parents, Version 2, 03/28/2018
- b) Recruitment Flyer, Version 2, 03/28/2018

**Informed Consent(s):**

- a) Consent: Latinx Parents' Funds of Knowledge, Version 2, 03/28/2018
- b) Verbal Script for Obtaining Verbal Consent, Version 2, 03/28/2018
- c) Verbal (Consent) Script for Subject Enrollment, Version 2, 03/28/2018
- d) A waiver of documentation has been granted only for eligibility screening under 45 CFR 46.117(c)(2) (minimal risk; subject will self-screen by completing a screener; formal written consent will be obtained from potential subjects at enrollment; information from subjects who decline or are ineligible will be destroyed immediately).
- e) A waiver of documentation and an alteration of consent have been granted under 45 CFR 46.117(c)(2) and 45 CFR 46.116(d) for obtaining subjects' contact information prior to written consent (minimum risk; subjects will provide verbal consent to investigator to collect their contact information; a formal and written consent will be obtained at enrollment; contact information will be destroyed at the completion of data collection or following the last interview).

**Assent(s):**

- a) A waiver of assent has been granted under 45 CFR 46.116(d) for children as secondary subjects whose identifiable data may be disclosed by parent subject; minimal risk; impracticable to obtain assent.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

- (6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.



**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
03/06/2018	Initial Review	Expedited	03/16/2018	Modifications Required
04/03/2018	Response To Modifications	Expedited	04/18/2018	Approved

Please remember to:

→ Use your **research protocol number** (2018-0284) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**  
<http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities>).

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 413-1518. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Alma Milat, BS  
 IRB Coordinator, IRB # 2  
 Office for the Protection of Research Subjects

Enclosure(s): Following approved recruitment and consent documents have been uploaded under "approved documents" tab in OPRSLive:

**1. Informed Consent Document(s):**

- a) Consent: Latinx Parents' Funds of Knowledge, Version 2, 03/28/2018
- b) Verbal (Consent) Script for Subject Enrollment, Version 2, 03/28/2018
- c) Verbal Script for Obtaining Verbal Consent, Version 2, 03/28/2018

**2. Recruiting Material(s):**

- a) Self-Screening Tool for Parents, Version 2, 03/28/2018

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b) Recruitment Flyer, Version 2, 03/28/2018

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## Appendix E. Parent Informed Consent



**University of Illinois at Chicago**  
**Research Information and Consent for Participation in Social Behavioral Research**  
**Latinx Parents' Funds of Knowledge: Participation throughout the IEP Process**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

**Principal Investigator Name and Title:** Joseph Passi, Doctoral student at UIC

### Why am I being asked?

You are being asked to be a subject in a research study about the experiences of Latino/a parents and primary caregivers with the Individualized Education Plan (or IEP) process.

You have been asked to participate in the research because you are a parent of a child with a disability, and you have attended at least two IEP meetings for that child in the past. Therefore, a lot might be learned from your unique experiences. No one at the school will know if you choose to participate in this research study or not. You are being asked to participate because after looking at the packet of information you received, you were interested. You also meet the eligibility requirements.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago, the site where this study occurs, or the school where you send your child. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

Between 6 and 8 subjects may be involved in this research at UIC. No more than 8 people will be interviewed in this study.



### **What is the purpose of this research?**

The aim of this study is to explore the perspectives of parents on the IEP process and begin to understand the contributions that parents can make to the IEP process. This study is designed to answer the following question: What is the meaning of the experience of being a Latinx parent involved in the IEP process? The knowledge and skills you have as a parent are valuable, and can help researchers better understand how you support your child. This could help educators to invite parents to contribute all their knowledge to helping their child in school and through the IEP process. There is a lack knowledge about how to do that.

### **What procedures are involved?**

This research will be performed at a place that is **convenient to you**. This could be at a school, community center, public library, or your home. There will be a total of 4 interviews.

You will be asked to engage in the following research activities:

**In-person interviews:** You will be asked to participate in 2 interviews in-person. Each interview will last between 60-90 minutes. The 3<sup>rd</sup> interview could take place in-person or over the phone, based on your preference. The final interview will happen over the phone.

The study procedures will include the following:

- answering questions about your history and your family
- answering questions about your experiences in the IEP process
- reflecting on what was discussed at the interviews
- meeting in-person on 2 separate occasions
- meeting a third time or meeting via phone
- audio recording all of the interviews
- talking on the phone 2-4 weeks after the 3<sup>rd</sup> interview to add or change anything you said

### **What are the potential risks and discomforts?**

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. Although the expected risks to you are small, they may include feeling uncomfortable discussing some of the topics in the interview, or you may feel annoyed or irritated by some of the questions that are asked. **It is important that you keep in mind that at any time you may decline to answer a certain question.** Also, there is a risk of loss of privacy or confidentiality if information collected in this study, including your involvement, were to be spoken about or shown to others who do not have permission to view such information. A risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information).

**Will I be told about new information that may affect my decision to participate?**

During the course of the study, you will be informed of any significant new research information (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation, that might cause you to change your mind about continuing in the research. If new information is provided to you, your consent to continue participating in this research may be re-obtained.

**Are there benefits to taking part in the research?**

Taking part in this research study may not benefit you personally, but the research could help educators, including those working with your child.

**What other options are there?**

You have the option to not participate in this study. You can withdraw from the study at any time and for any reason.

**What about privacy and confidentiality?**

The only person who will know that you are a research participant is the principal investigator, Joseph Passi. Whenever anything is shared, your name will never be used. Information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

Study information which identifies you and the consent form signed by you will be looked at and/or copied for checking up on the research by the UIC OPRS and Illinois State Auditors.

A possible risk of the research is that your participation in the research or information about you might become known to individuals outside the research. We will do everything possible to ensure that does not happen. All consent forms that identify your real name will be kept in a locked cabinet at the researcher's home. All of the audio recordings from the interviews will be stored on a password-protected hard drive. The audio recordings will be later transcribed into writing. If your name is on any of these materials, it will be replaced with a fake name. You can request to listen to the audio recordings after the interviews and edit/change any of the things that you say. After the study is over and Mr. Passi has had a chance to transcribe and look over all of the audio recordings, they will be deleted from the hard drive and any other place they may be stored. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Additionally, all contact information (your name or phone number) will be deleted after all interviews are complete. If you choose to withdraw from this study at any time, then all contact information and audio recordings will be immediately deleted.

**What are the costs for participating in this research?**

There are no costs to you for participating in this research.

**Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will receive a Visa gift card for \$25 at the end of the first and third interviews. Therefore, if you participate in this study then you will receive \$50 worth of gift cards.

**Can I withdraw or be removed from the study?**

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. There are no consequences for withdrawing from this study. Anything that you said during the interviews will not be used in my research and the audio files will be deleted.

The researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interest.

**Who should I contact if I have questions?**

For more information, please contact the researchers at the following email address: [research@university.edu](mailto:research@university.edu)

**What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 1-800-541-4373.

**Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.



**Signature of Subject**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

---

Signature

---

Date

---

Printed Name

---

Signature of Person Obtaining Consent

---

Date (must be same as subject's)

---

Printed Name of Person Obtaining Consent

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## CURRICULUM VITAE

**Joseph R. Passi**

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**OBJECTIVE:** To obtain a research or leadership position in education or an educationally-related field. I am specifically interested in gaining research or leadership experiences to complement my studies and experiences as a recent graduate of a Ph.D. program at University of Illinois at Chicago (UIC).

### EDUCATION

**Doctor of Philosophy, Special Education**, August 2019

University of Illinois at Chicago, Chicago, IL

**Interests:** IEP meetings, parental involvement and engagement, civic engagement, disability studies, socio-cultural theory, critical race theory, systems theory

**Master of Education, Special Education**, May 2007

University of Illinois at Chicago, Chicago, IL

**Bachelor of Arts, Theology; Minor in Music**, May 2005

North Park University, Chicago, IL

### HONORS/AFFILIATIONS

American Federation of Teachers, 2007-present

Chicago Teachers' Union, 2007-present

Council for Exceptional Children: Student Member, 2009-2010, 2015-present

STEP=UP Grant for Special Education Teacher Candidates (UIC), 2005-2007

Most Astounding Young Scholar, North Park University, 2005

Phi Theta Kappa, 2003-2005

Dean's List, 2000-2005

## RESEARCH INTERESTS

Parent engagement in the IEP process.

Civic engagement as a tool to get parents engaged in the IEP process.

Instructional practices used with culturally and linguistically diverse populations.

The social construction of disability.

Inclusive education.

## RELATED EXPERIENCE

### Teaching

August 07-Present     **Benito Juarez Community Academy, Chicago, IL**

*Special Education Teacher*

- Taught range of student populations, including students with mild and moderate disabilities.
- Taught in self-contained and collaborative teaching settings.
- Developed behavioral strategies for students with emotional and behavioral disorders.
- Co-created a Response to Intervention (RTI) program for at-risk freshmen.
- Incorporated new text materials, portfolio assessment system, and literacy strategy instruction.
- Facilitated IEP meetings and maintained full responsibility for completing IEP documentation and data collection.
- As member of instructional support team, co-designed policies and engagement sessions for implementation of competency-based learning.
- Designed, organized, and led after-school club focusing on guitar instrumentation.
- Co-developed training sessions for teachers as part of work on Instructional Support Team (IST).
- Mentored 8 student teachers and 16 teacher candidates, all from UIC.

- Regularly designed and lead department meetings, learning walks, and demo classroom visits.

June '08-August '08 **Hyde Park Day School, Chicago, IL**

*Special Education Teacher*

- Taught mathematics and English to a small group of 5<sup>th</sup> grade students.
- Administered the Wilson Reading Program to students on a daily basis.
- Used interactive whiteboards, PC tablets, and other technology to drive instruction.

March '07-June '07 **Oliver Wendell Elementary School, Chicago, IL**

*Special Education Teacher*

- Taught math, science, reading, and social studies in self-contained and collaborative teaching settings.
- Coordinated lesson plans and teaching strategies with case manager and general education teachers.

September '06- **Benito Juarez Community Academy, Chicago, IL**

April '07 *Intern and Student Teacher*

**Project Soar, Chicago, IL**

May '06–August '06 *Team Leader*

- Led a group of 17 teenagers in teaching literacy activities to Head Start children.
- Worked with Head Start staff and Project Soar administrators.
- Planned activities for teenagers to use with Head Start children.

## **Research**

June '16 - **University of Illinois at Chicago, Chicago, IL**

January '17 *Research Project*

- Submitted research proposal to UIC's IRB and CPS's RRB for a qualitative exploratory study on parental perspectives on IEP meetings.
- Conducted detailed research on involvement and engagement of parents and primary caregivers at IEP meetings.

- Completed research project by writing up introduction, literature review, methodology, results, and discussion to prepare for publication.

April '16

**University of Illinois at Chicago, Chicago, IL**

*Interviews for Urban Educators Grant*

- Interviewed 7 doctoral students on their experiences in the Ph.D. Program.

June '10-August '10

**University of Illinois at Chicago, Chicago, IL**

*Focus Group Research*

- Conducted research on focus groups for transition team

**PRESENTATIONS**

**Passi, J.R.** & Parker-Katz, M. Latinx Parents' Funds of Knowledge. Teacher Education Division of the Council for Exceptional Children in Las Vegas, NV, November 8, 2018. Awarded the TED Kaleidoscope for Best Qualitative Research.

**Passi, J.R.** & Parker-Katz, M. IEP participation: Perspectives of teachers and Latino/a parents. Poster presentation at the Council for Exceptional Children 2017 Special Education Convention & Expo in Boston, MA, April 21, 2017.

Thorkildsen, T. & **Passi, J.R.** *Multiple abilities and adolescent voices*. Part of a larger presentation: "Transnational discourse: Supporting adolescents' participation in personal, civic, and civil engagement." Presented at the 9<sup>th</sup> International Conference on Mental Health in Guadalajara, Jalisco, Mexico, March 6, 2015.

Destigter, T. & **Passi, J.R.** *The dialectical nature of an AP curriculum in a diverse learning environment*. Part of a larger presentation: "With access for all: An urban high school mandates AP composition." Presented at the National Council for Teachers of English Conference in Chicago, IL, November 26, 2011.

**Passi, J.R.** *Quick collaborations between general and special education teachers.* Presented at Benito Juarez Community Academy, Chicago IL, September 2009.

**Passi, J.R.** & Miller, C.L. *Co-teaching: A brief overview and strategies for success.* Presented at Benito Juarez Community Academy, Chicago, IL, January 2009.

*References Available Upon Request*