# Parents as Advocates:

An Investigation of How Spanish-Speaking Parents Navigate the Special Education Legal Processes and Learn to Advocate for the Needs of Their Students



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\* \* \*

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#### <u>Abstract</u>

Due to special education's individualistic and legal nature, increased parent participation is required to achieve the desired outcomes for their students. Parents who do not speak English fluently, do not understand the special education process, or are unfamiliar with the American school culture are disadvantaged when participating in special education processes. Linguistically and culturally diverse parent experiences, such as Spanish-speaking parents, have been studied homogeneously compared to the standard white, English-speaking parent experiences. Research has yet to depict the variability of experiences within the wide category of Spanish-speaking parents. In this paper, I aim to supplement emerging literature by understanding the experiences of Spanish-speaking parents and exploring the heterogeneity within this diverse group. Using qualitative methodology to interview ten Spanish-speaking parents and five school district interpreters, I find that Spanish-speaking parents must become advocates, to differing degrees, to receive desired student outcomes. Specifically, Spanish-speaking parents have varied support systems and conceptions of the school, resulting in distinct types of parent advocacy than the school may consider. Based on these findings, I recommend that local education agencies enforce diverse parent advocacy within individual schools. I argue that schools should promote diverse parent advocacy through culturally responsive practices, creating a bilingual parent liaison position, and encouraging parents to request school staff training. The findings presented here inform how school and district resources should encourage culturally and linguistically diverse parent advocacy in special education processes.

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# I. Introduction

Aura's daughter was diagnosed with multiple disabilities at the time of birth, including Spastic Cerebral Palsy. When her daughter first started kindergarten, Aura had to attend meetings to discuss her daughter's Individualized Education Plan (IEP) with the school and determine how the school should arrange accommodations and provide services to account for her daughter's disabilities. Having immigrated to the United States about 15 years prior, Aura and her husband knew limited English and were unfamiliar with the special education process. As a result, when her daughter was first assigned an IEP due to her disabilities, Aura agreed with everything the school presented to her, even when she wanted a different outcome.

"If you, as her parents, don't speak up for your daughter, no one will." This advice from her daughter's neurologist inspired Aura to overcome her shyness and speak up for her daughter at IEP meetings. As a Spanish-speaking mother unfamiliar with the American school system, Aura had to learn to overcome her fear of contradicting her daughter's school to advocate for her daughter to receive proper accommodations, such as a wheelchair, during certain class activities. "It was difficult, but I learned. If [the school] said something about my daughter that I thought was not right, then, that's when I learned how to say 'no.'"

This paper aims to understand how Spanish-speaking parents like Aura overcome linguistic and cultural barriers to become much-needed advocates for their children in special education. Intending to contribute to the emerging literature about the diverse perspectives of Spanish-speaking parents, this paper seeks to answer the following questions: How do culturally and linguistically diverse parents across various social backgrounds advocate for their children in special education? What does parent advocacy entail for Spanish-speaking parents when navigating the special education processes? The paper will first contextualize this policy problem by providing a historical background on special education. A literature review will follow, beginning broadly with a discussion of research about the disproportionality in special education, then narrows to discuss the parent-teacher relationship in special education, and ultimately presents the emerging literature about diverse parent experiences of the parent-teacher relationship in special education. I will highlight the gap in existing research and identify how my research aims to fill the gap by broadening the understanding of how diverse parents understand their role and engage with the schools during the special education processes. Then, the methods section will ground my research in a diverse, primarily Hispanic county in Southern California and detail the research procedure.

To answer the two aforementioned research questions, I conducted ten semi-structured interviews with parents who have a child who has been assigned an IEP and received special education. As a result of these interviews, five processes emerged that these mothers underwent to overcome linguistic and cultural barriers and ultimately become their child's advocate. The following five processes propel the parents towards advocacy: 1) Forced to Join the Experts, 2) Feelings of Inadequacy, 3) Understanding Confidence as Necessary, 4) Attempting to Better Awareness, and 5) Maintaining Trust in the System. I supplemented the parent perspective with five semi-structured interviews with district interpreters who have interpreted IEP meetings for Spanish-speaking parents. The interpreters' perspective allowed for additional insight into the parent-school relationship during IEP meetings from a neutral third party present at these meetings. From their interviews emerged two major themes: 1) the strategies interpreters employ to remain neutral when the parents look to them for help, and 2) the uncommon outcome of a successful IEP meeting where parents and schools mutually agree.

Drawing from the parents' experiences and interpreters' observations, I propose three policy recommendations to help improve linguistically and culturally diverse parent experiences when navigating the complex special education process. The three policy recommendations for school-level implementation include using Culturally Responsive IEP Practices, creating bilingual parent liaison positions, and increasing staff training. Following the policy recommendations, I discuss research limitations and directions for future research.

By understanding the parent perspective from interviews with both parents and interpreters, this paper reveals the complex challenges diverse parents face when navigating the special education process for their children and how the parents reach varied extents of advocacy to achieve the educational results they desire for their children. Ultimately, schools must provide better support for culturally and linguistically diverse parents who face unique barriers when engaging in the legalized education of their students. The findings suggest that the advocacy of diverse parents is often not the type of advocacy that is heard.

# II. Historical Background

The foundation of today's special education (SPED) policy can be traced back to the Education for All Handicapped Children Act (EHA) of 1975. The EHA was a significant step toward supporting states in providing services and improving outcomes for students with disabilities and their families from birth to adolescence (U.S. Department of Education, 2023). This act was later renamed the Individuals with Disabilities Education Act (IDEA) during its 1990 reauthorization. Since then, IDEA has undergone another reauthorization in 2004 and subsequent revised regulations, each time aiming to further guarantee the rights of students with disabilities and their families. IDEA's scope extends from toddlers aged 3 to adults aged 21, encompassing supplemental early intervention services and post-secondary programs.

The six foundational pillars of the federal statute IDEA are Free Appropriate Public Education, appropriate evaluations and assessments, an Individualized Education Plan/Program (IEP), creating a least restrictive environment for the student's needs, ensuring that parent or guardian participation is supported, and that parent or guardian and student rights are protected.<sup>1</sup> On a state level, there are educational service agencies "authorized by State law to develop, manage, and provide services or programs to LEAs" (Individuals With Disabilities Education Act, 2004). The educational services agencies (ESAs) cover a geographic area larger than a school district. The states with the most ESAs are Illinois with 56, Michigan with 55, Ohio with 53, and California with 49.<sup>2</sup> Each state has distinct names for its ESA.

On a federal level, IDEA outlines a comprehensive support system for students with disabilities. It details what assistance these students are entitled to, including educational support and services to meet their unique needs through specially designed instruction, accommodations, and supplemental services. IDEA establishes 13 categories of disabilities, charging states to create their criteria for each category.<sup>3</sup> It authorizes grants to state-local education programs to aid local education agencies (LEA) in supporting students under the 13 disability categories.<sup>4</sup> Through Child Find, another requirement under IDEA, an LEA must locate, identify, and assess students with disabilities.<sup>5</sup> An assessment evaluates, determines, and aids in forming decisions

<sup>&</sup>lt;sup>1</sup> Hereinafter, use of "parent" will also include guardian.

<sup>&</sup>lt;sup>2</sup> Information on other states can be found at *Educational Service Agencies: Review of selected/related literature*. AESA. (2023). <u>https://www.aesa.us/2021/06/02/educational-service-agencies-review-of-selected-related-literature/</u>.

<sup>&</sup>lt;sup>3</sup> The 13 categories of disabilities that IDEA outlines are Autism, Deaf-Blindness, Deafness, Emotional Disturbance, Hearing Impairment, Intellectual Disabilities, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment, Specific Learning Disability, Speech or Language Impairment, Traumatic Brain Injury, and Visual Impairment Including Blindness. Per IDEA Sec. 300.322 Parent Participation. Individuals with Disabilities Education Act. (2017). https://sites.ed.gov/idea/regs/b/d/300.322.

<sup>&</sup>lt;sup>4</sup> A local education agency (LEA) is another term for a school district.

<sup>&</sup>lt;sup>5</sup> An official medical diagnosis is not required for a student to be placed in special education.

about special education services to accommodate students' particular needs. Special education is a broad program encompassing a variety of student needs, whereas placement in the program is on an individual basis and affords students specific services.

A crucial part of IDEA is the Individualized Education Program (IEP), assigned to every student identified and placed in special education. This program is not a one-size-fits-all approach but a tailored plan that considers each student's unique needs. An IEP is a confidential, legal document that defines what a Free Appropriate Public Education should be for every student based on their needs. It is reviewed in an IEP team meeting, which occurs annually, triannually, or by special request by either the school, the district, or the parent. The IEP team consists of the student's general education teachers (if the student is still in general education), special education teachers, an LEA representative who is knowledgeable of and can approve services and resources for the student, an expert to relay the student's assessment results,<sup>6</sup> and the parent or guardian of the student. IDEA ensures that the IEP team attends every IEP meeting.<sup>7</sup>

Developing an IEP document involves the IEP team engaging in discussions during the meetings, considering various factors. These include the assessment results of the student, parent concerns, the student's strengths and weaknesses, academic and functional needs, and appropriate services to aid the student. Additional special factors – such as the student's behaviors, modes of communication, and language levels – may also be discussed. The completed document, tailored to the individual student's needs, may specify the following in detail: transition services, accommodations and modifications, the student's present assessment levels, goals for the academic year, and the duration and location of services provided. Once the IEP team reaches an

<sup>&</sup>lt;sup>6</sup> Typically, an expert includes therapists or teachers.

<sup>&</sup>lt;sup>7</sup> However, IEP team members can wear multiple hats, meaning that if a teacher can relay information about the assessments results, then the teacher can also be the expert in the meeting. Otherwise, an expert is typically a speech pathologist or occupational therapist, distinct from a classroom teacher.

agreement, a certain section of the IEP document is signed by all parties and retained in the student's educational record, with a hard copy provided to the parent for their records.<sup>8</sup>

IDEA not only ensures parents the right to be part of the decision-making process regarding their child's special education, but it also provides procedural safeguards to protect their rights and those of their child. These safeguards empower parents, giving them an active role in their child's education. The safeguards include an explanation of parental rights, access to interpreters for the IEP meeting if necessary, an IEP document in their native language, the right to participate in meetings, the ability to give and deny their consent about certain procedures or actions offered by the school, and a due process hearing if the parent disagrees with the school.

# III. Literature Review

Numerous studies have investigated various aspects of the special education process. In this section, I focus on the existing research that has investigated diverse student and parent experiences within special education. Firstly, I present literature exploring the causes of the disproportionality of diverse groups in SPED and efforts that have attempted to address this. Secondly, I describe studies highlighting the significance and prevalence of English-speaking parental involvement in their children's SPED education and the role of teachers in facilitating such involvement. Thirdly, I will discuss more recent research that has explored diverse parents' involvement in SPED and how this involvement fares differently than English-speaking parent involvement. Finally, I will explain how this paper aims to build on this existing literature by investigating the heterogeneity of diverse parents and not comparing them to a standard.

<sup>&</sup>lt;sup>8</sup> The Attendance Page is part of the IEP document that all the IEP Team members who attended the meeting sign. The Student/Parent Agreement Page is part of the IEP document that only the parent signs depending on whether they agree or disagree. More information at IDEA Sec. 300.322 Parent Participation. Individuals with Disabilities Education Act. (2017). <u>https://sites.ed.gov/idea/regs/b/d/300.322</u>.

### **Disproportionality in SPED**

Several studies have explored the effects and causes of disproportionality in special education. Disproportionality is the overrepresentation or underrepresentation of a specific race, ethnicity, or other group of students who are identified and placed in special education. Research has ultimately found that since there are no established and well-defined measures to assess disability and determine placement, referrals to SPED are often based on teacher referrals that take into account student demographics including gender, race, and socioeconomic status rather than the disability itself (Dever et al. 2016; Kramar, 2022). Minority groups, including black and Latinx students and low-income students, are the affected groups that are overrepresented in SPED. Kramarczuk et al. (2017) identify these minority groups to possess certain factors that are a 'cultural mismatch' from the middle-class, white teachers and school administrators, who may have practitioner beliefs against low-income, minority students that lead to disproportionality when these school staff engage in discriminatory behavior. For example, a study by Gilliam et al. (2016) found that when teachers are told to identify students engaging in challenging behavior, white teachers were more likely to look to black students to find the challenging behavior, even when no challenging behavior was present. Additionally, the same study described that what may appear to be 'back-talk' to a white teacher may be understood as the appropriate response by a black student. The practitioner's beliefs are identified as an underlying reason leading to disproportionality of minority students being identified and placed in SPED.

As highlighted by Barrio (2017) and Artiles et al. (2005), English language learners (students whose native language is not English) are the most overrepresented in SPED. English learner students tend to be placed in special education due to reading-related learning disabilities. Artiles et al. (2005) posit that a cause of this is the lack of culturally and linguistically responsive assessment materials, leading to lower academic achievement and an increased probability of English learners being placed in special education.

Whereas unfair, predisposed beliefs of students from white, middle-class teachers may lead to the overrepresentation of minority students in SPED, other studies have also identified how the same factors can lead to the underrepresentation of minority students. Due to the previously mentioned practitioner beliefs, white teachers may hold lower standards for minority students, leading to overlooking their needs in identifying them for special education and thereby having an underrepresentation of minority groups in SPED. Fish (2019) investigates how teachers of color are associated with minority students' increased likelihood of receiving SPED across various categories of disabilities, which may be attributed to the higher expectations the teachers of color hold over students whom they may identify with. Specific categories of disabilities, such as students with behavioral and emotional risks, are also underrepresented in SPED, which is attributed to lack of proper assessments to identify these behaviors (Dever et al., 2016).

As a result of identifying disproportionality as exacerbating inequality in public education, research has aimed to analyze the efficacy of solutions to disproportionality, including Response to Intervention (RtI) and Multi-Tiered Systems of Support (MTSS) (Kramarczuk et al., 2017; Barrio (2017). RtI has been identified as providing a more holistic approach to identifying learning disabilities than standardized test results (Liu et al. 2008), especially since standardized tests do not accurately determine disabilities from cultural and linguistic differences (Liu et al. 2008; Bryen, 1974). Dever et al (2016) find that a more data-driven approach reduces the disproportionality of students of color and males in special education, though widespread use of this approach has yet to be fulfilled. MTSS is a direct and prompt response to students' needs as they arise, that is based on evidence-based data before forming decisions, which provides an apt intervention that accounts for language and social skills differences (Hebbeler and Spiker 2016).

A recent study of disproportionality – describing it as a misalignment of sociodemographic factors and educators' practice – identifies a shared framework to connect researchers' different approaches to disproportionality. Ahram et al. (2021) proposed a shared framework for researchers to connect to broader conceptual frameworks that relate both micro and macro social variables when considering certain categories of students, while also engaging in a dialogue of these variables across disciplines; in other words, a holistic approach when understanding disproportionality and considering solutions. An especially relevant and emerging framework that describes a potential source of disproportionality is DisCrit, or disability critical race theory, which is an intersectional approach through the analysis of racism and ableism (Annamma et al., 2018).

#### Parent and Teacher Relationships in SPED

Another area of studies related to special education has identified and studied the increased parent involvement compared to parents of children in general education. Womack and Johnson (2022) found a relationship between the parents' race, income, satisfaction with the school, interaction with the school, and parent expectations with the likelihood of the parent's involvement in helping their special needs child with their homework. Taking into account parent involvement within microsystems, mesosystems, and overarching macrosystems, Kirksey et al. (2022) find that parents increased home-based involvement and school-based involvement following their child getting an IEP assignment.

IDEA provides a general framework for schools and districts to promote parent participation, such as setting mutual times to meet for IEP meetings or providing a hard copy of the IEP document. However, Phillips (2008) asserts that parents need additional assistance in identifying and reaching optimal outcomes for their child in SPED due to the complexity of the disability itself, and the IEP process. Though IDEA establishes provisions for parent involvement – including parent training and information centers to provide resources to parents –, these provisions should be combined with teacher and faculty development to promote and encourage parent collaboration (Strassfield, 2019). Bettini et al. (2017) assert that district-level leadership is necessary to cultivate effective SPED teachers, which can be achieved through the described theoretical model: selection, enculturation, support, evaluation, and retention. Studies have yet to study the effectiveness of these supposedly well-trained teachers and how their presence has improved, or not, parents' experiences.

Even with available resources and information for parents, the struggle in navigating IEP meetings and feeling confused leads them to turn to advocates. Burke and Goldman (2017) conclude from their 33 SPED advocate interviews that there are five main stages to effective advocacy: developing rapport with the parents, learning about the child, creating baseline expectations of their child's IEP, educating and empowering the parents, and participating in IEP meetings.

# **Diverse Parent Involvement in SPED**

Recently, diverse parent involvement in special education has been an area of interest in special education research – specifically, parents with culturally and linguistically diverse backgrounds, or diverse parents. Studies have reported tensions between diverse parents and

their participation and engagement in IEP meetings, due to these diverse parents not being fluent in English and holding the necessary cultural and social capital (Cioè-Peña, 2020; Burke et al., 2021; Montoya et al., 2022). Larios and Zetlin (2022) use a Critical Race Theory perspective, finding that social capital (e.g. being from a higher socioeconomic background) is the underlying factor in better navigating IEP meetings and facilitating better responsiveness with school actors. Alba et al.'s (2022) study during the COVID-19 pandemic found that language was significantly associated with whether their child was receiving special education services during the pandemic, more so than household income or parental education. Parent experiences, who are from diverse and minority backgrounds, have also been a subject of study. In Chang et al.'s (2023) investigation of focus groups with diverse parents regarding the SPED process, the following parent experiences were identified: a sense of isolation, various misunderstandings, an overall lack of knowledge, feeling restricted to certain choices, and a discontinuity of school faculty during the student's transition periods.

Within the diverse parent perspective literature, there are specific studies regarding the experiences of Latino immigrant parents with the SPED system. From parent focus groups, Burke et al. (2021) establish the prevalent systematic barriers, such as language differences, that lead to Spanish-speaking parents being less likely to participate in educational settings, thereby exacerbating the negative experiences and communication barriers for Spanish-speaking families, compared to English speaking families. When investigating Latino mother experiences, Cioe-Peña (2020) finds three major themes that define how these mothers engage during IEP meetings: the mother's intentions, the mother's actual experiences, and how they negotiate the two, which often led to their impeded participation during the meeting. Similarly, Montoya et al.'s (2023) study found that Latino immigrant parents identified similar experiences related to

IEP meetings, including difficult terminology during the meetings, feelings of discrimination or misconceptions, lack of knowledge amongst the staff, and parents desiring a more active role during the process.

In addition to parent experiences, emerging research has identified the implementation of federal and state policies related to special education to play a role in exacerbating racial inequalities. Cowhy et al. (2024) recently published a study that studies SPED implementation and establishes parents as policy agents due to the legal responsibility of the structure of the SPED policy. Parents who may not have resources, such as time, money, or knowledge, to access the services available leads to additional "administrative burdens" on the parents for a process meant to provide equitable education to their children (Cowhy et al., 2024).

### Intended Contribution

Recent research has made significant efforts to understand culturally and linguistically diverse parent perspectives when navigating the SPED system and to investigate how the implementation of SPED law has upheld inequalities amongst parents. The gap in this existing research is that diverse parents are compared to white, middle-class parents. Studying diverse parents as one homogenous group leads to the loss of individual perspectives within the group due to stereotyping and overrepresentation of one point of view. There remains a gap in understanding how diverse parents navigate the special education system. Due to these limitations in research, this paper aims to investigate a subgroup within culturally and linguistically diverse parents. Therefore, I will study the diverse experiences of Spanish-speaking parents, a subgroup of the diverse parent category. Understanding the full extent of Spanish-speaking experiences and exploring the similarities and differences within the group of

Spanish-speaking parents is important. By considering the demographic backgrounds of parents, and putting that into conversation with how parents understand and participate in the school system, this paper will contribute to the growing knowledge of diverse parent participation in special education processes.

## IV. <u>Methods</u>

The following research questions guide this paper: How do culturally and linguistically diverse parents across various social backgrounds advocate for their children in special education? What does parent advocacy entail for Spanish-speaking parents when engaging with their child's SPED processes? To answer these questions, I conducted ten semi-structured interviews with Spanish-speaking parents and five semi-structured interviews with interpreters, which were analyzed. The methodology section that follows outlines the approaches taken for this investigation.

# Setting

Though IDEA is a federal statute, each state has discretion in how they supply special education through their education service agencies (ESAs). California has the fourth highest number of ESAs, with 49 agencies called the County Office of Education. Given that California is one of the most racially diverse states that houses almost one-fourth of the foreign-born population in the nation and the state has several County Offices of Education that support special education in each school district, I decided to focus my investigation on California.<sup>9</sup>

I chose a culturally, linguistically, and socioeconomically diverse county – approximately half of the county is Hispanic, and about one-fourth of the students are classified as "English

<sup>&</sup>lt;sup>9</sup> This data is as of 2022. More information at Person, Mejia, M. C., Perez, C. A., & Johnson, H. (2024). *Immigrants in California*. Public Policy Institute of California. <u>https://www.ppic.org/publication/immigrants-in-california/</u>.

Learners" or speak a language other than English at home.<sup>10</sup> Of these English Learner students, an overwhelming majority, over 90%, have Spanish as their dominant language at home, spoken by their parents. Additionally, the county provides several types of special education programs that range in age and severity of disability across schools. There are county-wide programs, district-wide resources, and several schools only composed of special education classes, with the opportunity to learn and access this information in Spanish. Of the students identified as English Learners, about 15% of them receive special education services.

There also persists a cultural and socioeconomic diversity amongst Hispanic parents of English learner students in special education. These parents have been in the United States for varying numbers of years, they have differing knowledge and mastery of English, and they have a diversity of educational backgrounds and types of jobs. In this county, in particular, there is a large population of migrant workers, and Migrant Education is afforded to migratory children.<sup>11</sup>

For the above reasons, I chose a county in Southern California, which I will leave nameless and reference as 'County' to maintain the privacy of the parents, their children, and the district where the interpreters have worked. These aforementioned characteristics of the County and its location in California allow for unique insight into the intersectionality of culture, language, and class effects on parents and school interactions.

### Access and Recruitment of Participants

#### Parents

In choosing the ten parent interviews for this study, I limited the selection of parents to those with at least one child in special education who were assigned an IEP for at least two

 <sup>&</sup>lt;sup>10</sup> As of 2022-2023, documented by Dataquest (CA Dept of Education). (2023). <u>https://dq.cde.ca.gov/dataquest/</u>.
 <sup>11</sup> More information at Overview of Migrant Education in California - Migrant (CA Dept of Education). (2024).

https://www.cde.ca.gov/sp/me/mt/overview.asp.

academic years. I aimed for at least two years of experience with the IEP process to have an opportunity to ask parents to reflect on how, if at all, the process has changed over the two (or more) years. Parents also had to consider Spanish as their first language. I purposefully sought parents with various demographics, such as time in the U.S., knowledge of English, educational background, and types of jobs. Potential interviewees were screened for these characteristics by directly asking them about the mentioned characteristics over messaging before scheduling their interview (Appendix A). I chose parents with varied responses to these demographic questions to ensure a diverse parent group.

Recruitment of the parents occurred through a combination of purposeful sampling and snowball sampling.<sup>12</sup> By posting on three different Facebook parent support groups for parents of children with disabilities, I got seven responses from parents on Facebook. I interviewed four of these parents who fit the above criteria. I supplemented these parent interviews through my connections from various parent affinity groups at churches throughout the county. I contacted families I knew had special needs children, were Spanish-speaking, and had different demographic backgrounds. Then, I used snowball sampling to request contact information from other families they knew that fit the criteria and may have been interested in interviewing. I interviewed three parents with connections to the parent affinity groups, and then another three parents I recruited through snowball sampling. A total of ten interviews were conducted, with 30.5 minutes as the average interview time. Prioritizing the parents' preferences, I conducted four in-person interviews at a location of their choice.<sup>13</sup> The remaining six were conducted over the phone or via the Facebook Messenger audio call feature.

<sup>&</sup>lt;sup>12</sup> More about the effectiveness of purposeful sampling here: Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2013). Purposeful sampling for qualitative data collection and analysis in Mixed Method Implementation Research. Administration and Policy in Mental Health and Mental Health Services Research, 42(5), 533–544. <u>https://doi.org/10.1007/s10488-013-0528-y</u>.

<sup>&</sup>lt;sup>13</sup> Three parents were interviewed in their home. One parent was interviewed at a local coffee shop.

All of the parents had initially reached out for an interview – and all of those interviewed – were mothers. Though only interviewing mothers was not an intention of the recruitment process, this was not necessarily shocking in the recruitment process. In Blum's (2015) research on mothers raising their children with "invisible disabilities",<sup>14</sup> Blum opens in the first chapter with a discussion explaining why motherhood and childrearing continue being highly gendered, especially with practical responsibilities related to the children, such as school. However, a distinction from Blum's research is that I analyze and make policy recommendations for all parents, not only mothers. I did not solely consider the participants' role of a mother when analyzing the interviews. Instead, I approached their position as a parent involved in their child's special education process. Therefore, when referring to the participants, I will interchangeably refer to them as 'mothers' or 'parents'.<sup>15</sup>

The variance amongst the cohort of chosen parents to interview is crucial to gaining insight into the diversity of Spanish-speaking parents' experience with their child's education. Table 1A highlights the demographics related to the parents interviewed. The names listed of the parents are assigned pseudonyms specially chosen to convey a Latinx name. The mothers' occupations vary, which was an intention in recruitment to understand how different parents navigate their different daily schedules. Next listed is the level of education the mothers have attained, whether in the U.S. or outside of the U.S. The level of education listed for those who attended school outside the U.S. – five were born in Mexico, one in Guatemala, and one in

<sup>&</sup>lt;sup>14</sup> Blum (2015) uses the term "invisible disabilities" to describe diagnoses such as ADHD, mood and conduct disorders, and autism spectrum disorders.

<sup>&</sup>lt;sup>15</sup> The sections of this paper most related to the participants' experiences and responses typically are referenced with 'mothers', while policy recommendations and more general sections about the parent experiences are referenced with 'parents'.

<sup>&</sup>lt;sup>16</sup> Some participants only remembered how old they were when they stopped going to school, so an approximate grade was given based on the age they remembered.

Honduras. The three born in the U.S. were all first-generation U.S.-born citizens who have spent chunks of their childhood and adolescence outside of the U.S. and have partners who are not completely bilingual. Though most of the participants have been in the U.S. for over two decades, only the U.S.-born participants are confident in their bilingualism, while the other participants state that they have trouble understanding and speaking. All participants were asked, "¿Qué tan bien hablas y entiendes el inglés?" which translates to "How well do you speak and understand English?" Curiously, all participants who were not "bilingual" answered in percentages, even though the question was meant to elicit descriptive answers about their degree of knowledge of English proficiency. Though the percentages cannot be compared directly to each other given that there is no standardized reasoning into the percentage provided, the percentages are useful in understanding the confidence level each parent feels about their English abilities.

# Table 1A

Parent Demographic Information

Parent	Occupation	Education	Country of Birth	Years in the U.S.	English Knowledge <sup>1</sup>
Aura	Child care, Bakery	Middle School*	Mexico	24	70%
Betty	None	Middle School*	Mexico	26	75%
Carla	Agriculture	Middle School*	Mexico	9	30%
Dalia	Cook	College*	Mexico	16	90%
Luz	None	Middle School*	Mexico	25	Over 50%
Manuela	Pharmacy	High School*	Guatemala	20	80%
Nora	Retired	College	U.S.	60**	Bilingual
Paola	Office	College*	U.S.	51**	Bilingual
Raquel	Teacher	College	U.S.	46**	Bilingual
Susana	Agriculture	Middle School*	Honduras	23	30%

*Note*. Adapted from "Experiences of Latinx Immigrant Parents of Children with Developmental Disabilities in the IEP Process" by C. Montoya, C. Gilson, & V. Yllades, 2023, Education and Training in Autism and Developmental Disabilities, 57, 404-416.

N=10. All of the participants were mothers.

<sup>1</sup> No official assessment was given to evaluate their knowledge of English. These responses are provided by the parents themselves.

\* Education outside the U.S.

\*\* Parent was born in the United States. The parent may have spent a certain number of years outside of the United States.

Table 1B depicts the demographic information of the parents' families and their children with special needs. All of the mothers stated that their partner, or the father of their special needs child, was actively involved in their child's special education. Whether or not their family receives government assistance was included as one indicator of income level. There was not too much variation in the child disabilities, given that half are diagnosed with autism. However, Dalia was the only mother whose child had no medical diagnosis—more on how Dalia's experience differed from the rest of the participants in the Findings section. The average age of their children in special education was 13 years old, while one child was an outlier at 30 years old and already completed their special education. The total number of children of the participants ranged from two to four. As a note, referring to the participants' child implies that I am referencing their child who receives special education. I purposefully leave their children's names out of the Findings so as not to introduce additional names but instead focus on the parents' experiences.

# Table 1B

Parent	Marital Status	Total Number of Children	Government Assistance?	Child Diagnosis <sup>1</sup> ; Age of Diagnosis <sup>2</sup>	Child Gender, Child Age <sup>1</sup>
Aura	Married	3	Yes	Spastic Cerebral Palsy, Multiple Disabilities; Birth	F, 8
Betty	Divorced	3	Yes	Autism; 3	M, 19
Carla	Married	2	Yes	Down Syndrome; Birth	M, 7
Dalia	Married	2	No	None	М, б
Luz	Married	3	Yes	ADHD, Learning Disabilities; 5	M, 15
Manuela	Married	3	No	Autism; 3	M, 18
Nora	Married	4	Yes	Cerebral Palsy; Birth	M, 30
Paola	Married	2	Yes	Autism; 3	M, 21
Raquel	Separated	4	Yes	Autism; 3	F, 6
Susana	Married	3	Yes	Autism; 4	M, 17

Demographic Information of the Parents' Families and Their Child with Special Needs

*Note*. Adapted from "Experiences of Latinx Immigrant Parents of Children with Developmental Disabilities in the IEP Process" by C. Montoya, C. Gilson, & V. Yllades, 2023, Education and Training in Autism and Developmental Disabilities, 57, 404-416.

N=10. All of the participants were mothers.

<sup>1</sup> The child who receives special education services and was the subject of the interview.

<sup>2</sup> Age in years.

### Interpreters

I conducted five semi-structured interviews with participants who have experience working in a local district as the district translator and interpreter of the special education department and who specifically have experience interpreting at IEP meetings between English and Spanish. Three interpreters have been co-workers in the same district at some point in their careers. Using my connection with one interpreter, I used snowballing to network and recruit four additional interpreters. The only criterion for interviewing these interpreters was that they have at least one year of experience interpreting for IEP meetings at a district. As depicted in Table 2, the average years of experience in their position as district translator and interpreter in their district's special education department is 7.6 years, with the shortest experience being two years and the longest being 14 years. Their interviews were, on average, 26.8 minutes long, two of which were in person,<sup>17</sup> one via Zoom, and two via phone call. Pseudonyms were assigned to the interpreter participants at random.

# Table 2

Interpreter	Pam	Nate	Frank	John	Ellis
Years of Experience	14	7	2	5	10

The Interpreters' Years of Experience

*Note.* The years of experience is specifically the amount of time they have worked in a school district as an interpreter for IEP meetings.

<sup>&</sup>lt;sup>17</sup> Both at a local coffee shop.

#### **Data Collection and Analysis**

All ten interviews with the parents were conducted and recorded in Spanish. The audio file was uploaded to Sonix to produce an automated transcription; then I revised that transcription. Parent quotes included in this paper were translated into English from Spanish and verified across multiple online translation websites.<sup>18</sup> I used an interview guide to interview the parents (Appendix B), which I developed from previous knowledge about special education and concepts learned from the literature review. To ensure the identification of key ideas and themes in the parents' original wording and meaning, I completed the coding and analysis of the transcripts in Spanish. As a result of wanting to maintain the meaning of the interlocutors' responses, In Vivo and Axial coding methods were used to analyze the interviews (Saldaña, 2016).<sup>19</sup>

Given that parents discuss their child's special needs, how they have processed their child's needs throughout their special education, and their negative and positive experiences related to their child's education, I reassured the parents that they have a right to deny any questions, stop the interview altogether, or ask me questions. Though I provided them a copy of the Verbal Consent Form in Spanish (Appendix B) and reviewed it with them at the beginning of the interview, given that this process may appear to be a daunting legal process to the parents, I assured them throughout the process that they can exercise their participant rights at any time and were not bound the interview because they had already agreed to participate. I took these precautions to protect the vulnerability of this non-English-speaking population.

<sup>&</sup>lt;sup>18</sup> The two translating websites used were *English to French, Italian, German & spanish dictionary* - *wordreference.com.* English to French, Italian, German & Spanish Dictionary - WordReference.com. (n.d.). <u>https://www.wordreference.com/</u> and *Linguee: Dictionary for German, French, Spanish, and more.* Linguee.com. (n.d.). <u>https://www.linguee.com/</u>.

<sup>&</sup>lt;sup>19</sup> In Vivo coding was used to maintain the participant's voice and choice of words in their native language, to allow for deeper understanding into their worldview and culture. Axial coding was subsequently used to divide the experiences of the mothers into categories based on similar characteristics and attributes described by the parents.

All five interviews with the interpreters were conducted and recorded in English. The audio file was uploaded to Sonix to produce an automated transcription; then I revised that transcription. A Verbal Consent Form in English was provided and reviewed with the interpreters (Appendix E). I treated the interpreters like experts, asking for their opinions and observations about the school-parent relationship during IEP meetings. I used an interview guide to interview the interpreters (Appendix D). The transcripts were analyzed using versus and theoretical coding (Saldaña, 2016).<sup>20</sup>

This study was approved by The University of Chicago's Institutional Review Board under the Social and Behavioral Sciences Division (IRB 23-1786). All volunteers whose participation was crucial to this study were compensated with \$30 cash. Participants' compensation, travel expenses, and transcription subscription expenses were covered through funding received from Public Policy Research Funds and The Committee on Education Research Funds, both at the University of Chicago.

### **Positionality**

Through my positionality – knowing Spanish as a first-generation Mexican-American and being familiar with the IEP and SPED processes through the experiences of my younger brother – I was able to build a quick and effective rapport with the parents by engaging in mutual disclosure briefly at the beginning of the interview (Chaudoir & Fisher, 2010). Mutual disclosure made participants feel more comfortable speaking with me about vulnerable topics.

<sup>&</sup>lt;sup>20</sup> Versus coding was employed because of the distinctions interpreters were making between certain types of school workers and parents that are part of IEP meetings. Theoretical coding was employed to advance the coding process towards policy implications by linking concepts from the interpreters with concepts that emerged with the parent interviews.

## V. Findings

### Parents

Based on the ten parent interviews, I argue that the parents must attain a certain level of advocacy to share their opinions and be heard by their child's schools. To illustrate the growth parents take in establishing themselves in the role of an advocate for their child, I have developed five stages that these mothers' undergo to overcome linguistic and cultural barriers. The five stages are as follows: Forced to Join the Experts, Feelings of Inadequacy, Developing Confidence, Attempting to Better Awareness, and– despite facing adversity– Maintaining Trust in the System. As will be distinguished in each section, not all of the participants had experiences pertaining to each stage.

### Forced to Join the Experts

All the interviews began in the same way: by asking about the first time their child was diagnosed (if applicable) and when they were assigned an IEP.<sup>21</sup>

Of the ten parents interviewed, only one mother stated that her son does not have a diagnosis, Dalia. Dalia's educational journey with her son is shorter than that of the other mothers, given that her son is the youngest of the group at six years old.<sup>22</sup> Her journey of becoming an expert is distinct from the other mothers' journeys. Dalia views her son's IEP as a brief service that will help improve her son's behavior and speech delay for a couple of years and will eventually end. Dalia describes the IEP meetings as indifferent, unlike other mothers who displayed strong sentiments toward these meetings. Dalia's indifference is due to her

<sup>&</sup>lt;sup>21</sup> Ensuring to not assume their child has a diagnosis, I first asked if their child has received a diagnosis before inquiring more about the diagnosis. Reference Appendix B.

<sup>&</sup>lt;sup>22</sup> Her interview was also the shortest interview: 18 minutes.

unquestionable agreement with the expertise of the teachers and therapists' opinions. Not all mothers find the need to advocate for their child's needs, especially when they always agree with the school. Nevertheless, it may be the case that Dalia does not understand the explanations given to her about her son's needs, and by putting full trust in the school, she is not actively seeking other options for her son's education.

As for the remaining nine mothers, upon receiving the diagnosis of their child, the common sentiment across the mothers' experiences can be described as "just trying to understand" the diagnosis. As described by Paola's following narrative of the time she first read her son's diagnosis:

"It was, I don't know, eight pages long and I had no idea what [the psychologist] was talking about. And at the end where it said diagnosis it said *Autism*. I sat there on the living room floor, just trying to understand. "What does this mean?", I thought to myself. I had never heard that word. I had no clue what that was."

Though Paola considers herself bilingual, she describes a medical language barrier, in which she was overwhelmed with paperwork related to her son's development. Paola, along with seven other mothers interviewed, had never heard of their child's diagnosis before. Paola and the other mothers describe their early experiences when learning about the diagnosis similarly: they were confused and upset by the diagnosis, before taking the steps to learn and help their child's needs. Manuela, who has a more limited knowledge of English, recalls asking the doctor if there is a cure for her son's autism diagnosis: "I thought there would be some medication, or supplement, that my son could take to help him. [...] It took me a while to understand that autism is something that he'll have to live with." Seeking remedies was Manuela's initial step towards understanding the extent of her son's needs. Similarly the other seven mothers' first steps were asking questions to who they deemed as 'experts' – doctors.

The one mother who had heard of her daughter's autism diagnosis before was Raquel. As a teacher, Raquel had heard of the diagnosis in passing but had never had a student with autism or epilepsy or a student assigned with an IEP in her class before. Instead of turning towards the doctors or teachers for further clarification, like the other mothers, Raquel states that she turned towards friends who had children with autism. Raquel describes that these parents were an integral part of helping her cope with her daughter's diagnosis and understand the next steps she should take to help her daughter. For parents like Raquel, who know of other people with children with similar diagnoses, inquiring with other parents about their experiences is preferable to engaging with a doctor in a formal setting, especially when the doctors may not be bilingual.

Finding bilingual experts was an issue for the majority of the mothers, given that the majority do not consider themselves bilingual<sup>23</sup>. Not knowing sufficient English turned the aforementioned medical language barrier into an English language barrier. Some mothers expressed that they had to find out the meaning of the diagnosis on their own, whether through reading books, finding sources online, or asking at their child's school. When the medical experts did not answer the questions about their confusions, the mothers turned to other sources for help. This shift in attempting to find information first from the experts, then to research on their own or asking their child's school directly, illustrates how the mothers' idea of who is an 'expert,' or who can help them understand their child's diagnosis, was redefined. Parents began considering teachers as experts that were sought out, and eventually became experts themselves as they grew more familiar with their child's needs.

<sup>&</sup>lt;sup>23</sup> Seven of the ten participants did not state they were bilingual in Spanish and English and instead stated they had a limited English proficiency. See Table 1A.

Yet, some mothers had Spanish-speaking experts help them from the beginning. Aura describes herself as "afortunada"<sup>24</sup> when describing her daughter's bilingual neurologist. According to Aura, this neurologist would explain to her the complexity of the diagnosis in a way that it "abría tu panorama",<sup>25</sup> making it easy for her to understand the diagnosis. By breaking down the terms and defining each part of Spastic Cerebral Palsy, Aura describes feeling less overwhelmed after having appointments with that neurologist. There is less cognitive overload for the parents when the medical experts speak Spanish since it saves them the stress of finding a definition that works on their level (Xu et al., 2018). Defining and understanding their child's diagnosis on the mothers' terms allowed the parents to become an expert themselves and feel more confident in anticipating the needs of their child.

These various methods of becoming experts of their child's diagnosis were successful, given that the mothers were knowledgeable in the medical terminology, could define their child's diagnosis clearly, and could explain how the diagnosis has evolved in their child over the years. The diagnosis marked the start of the long journey ahead of these mothers, in which they would constantly seek support for their child's special needs. Part of their child's educational journey was how the diagnosis and their needs kept "evolucionando",<sup>26</sup> over time, leading the mothers to be generally more present in the education of the child with a diagnosis compared to the general education of their other children. For Luz, it became clear to her from early on that she would need to be very present in her child's schooling. This became more evident as time went on and her son kept falling behind in reading. Luz's son has attention deficit/hyperactivity disorder (ADHD) and learning disabilities. When describing her son's reading struggles, Luz shares:

<sup>&</sup>lt;sup>24</sup> English translation: lucky, fortunate.

<sup>&</sup>lt;sup>25</sup> English translation: opened your mind, gave insight.

<sup>&</sup>lt;sup>26</sup> English translation: evolving, changing, developing.

"At the moment, he doesn't grasp [reading], but rather he has to process it for a long time, or read it many times. That's what doesn't allow him to advance. [...] Then they evaluated him again and [...] gave him another diagnosis which was very difficult for me. But I say, whatever it may be, there has to be help."

As Luz and her son were getting acclimated to the help they were receiving from one school, her son was soon moved and placed into a different school where he received the additional diagnosis. In addition to the abrupt change of schools, the compilation of diagnosis after diagnosis and the changes of her child's behavior made it difficult for Luz to maintain an expert status on her child. It becomes more difficult for mothers, such as Luz, to create new relationships with the teachers and therapists when their child transitions from schools. On top of managing new relationships with a new IEP team, the development of their child's needs presents new areas where both the school and parent must collaborate to create the appropriate plan for the student.The education journey of their child for parents includes creating and managing relationships with various IEP team members, while being continuously knowledgeable in their child's evolving needs.

As a consequence of constantly having to learn about their developing child's needs, some mothers viewed this undertaking as a job, as Luz recalls:

"First, [my son] was diagnosed with ADHD, because he wouldn't stay still in his [class]. So from there I started, well, *really working* and always seeking help for him."<sup>27</sup>

Luz goes on to explain that only her husband works while she does not. Instead of working, Luz explains, her main priority is ensuring that she can attend her son's appointments and school meetings. Unlike Luz, not all mothers can afford staying home. The majority of the mothers (n=8) have worked full time jobs since their children were born (Table 1A), but did not report

<sup>&</sup>lt;sup>27</sup> Italics indicate the speaker's emphasis.

any difficulty attending school IEP meetings or making time for their child's appointments. Yet, these mothers who do work demonstrated how they still ensure to carve out time in their schedules to attend school meetings and doctor appointments. Multiple mentioned that they would attend school meetings during their lunch breaks, for example.

Now having become more knowledgeable of their child's evolving needs and the meaning of the medical diagnosis, the mothers were next faced with becoming knowledgeable in the special education system. For mothers who were not born in the U.S. (n=8), they had to learn about the American education system in addition to the legal special education process. Accounting for the time when their child was first diagnosed to when they were expected to participate in IEP meetings, these mothers had a couple of years between learning about the diagnosis and then participating in meetings where they are expected to contribute about their child's school performance. After enduring their own educational journey of learning about their child's diagnosis, these parents were forced into meetings where their child's limited strengths and abundant weaknesses are constantly reiterated, with explicit detail. In the following array of quotes, the common negative emotions mothers had towards the IEP meetings are depicted:

Manuela: "Yes, I felt a bit sad to be aware of all the limitations that my son had and well yes, during the entire IEP they shared every detail."

Nora: "They were very helpful, but it quickly got to the point where there was not much they could do during his early stages. I didn't have too many good feelings about [the IEP meetings] after that; I was just going through the process."

Aura: "First I would say, 'Wow, these take so much time, are very lengthy and they take such a long time'. Sometimes, the people, the ones who would speak, would say things that would make me think to myself, 'No, [my daughter] is not like that, she does not have that anymore'"

Manuela was one of six of the mothers who explicitly stated that she had cried after leaving an IEP meeting. This may be that technical terminology is often used by those who evaluate the student to describe the students' capacities, which is often under a negative connotation of what the student has failed to achieve.<sup>28</sup> The technical jargon may allow the school staff to distance themselves from the personhood of the student and from empathizing with the parent by speaking at their level (Montoya et al., 2023). Nora's quote encompasses her feelings of indifference towards the school, since it got to a point where they told her options were limited due to her son's extreme needs. Aura characterizes the meetings as being long and an environment where she was constantly hearing things she disagreed with about her daughter. Though the aim of IEP meetings is for the parents to join the school as one IEP team to reach a mutual agreement of steps to help the student, these mother's reveal how disconnected and othered they felt in the way their children and the child's needs were being discussed and characterized.

Dalia, who was the mother of the son who was not diagnosed, was indifferent towards the IEP meetings in general. She understood that the IEP document will serve its purpose in helping her son, and will eventually not be needed by her son anymore. However, one mother describes her IEP experiences positively. Luz shares,

"In the first IEP held, [my son's] teacher – a very polite and very loving teacher, who [my son] still remembers a lot. That teacher helped him a lot and my son was so happy because there was a person that helped him, and she did help him during the meetings."

Out of all the mothers interviewed, Luz's son was diagnosed at 5, the oldest age to be diagnosed (Table 1B). This means that Luz's son transitioned from general education classes to more

<sup>&</sup>lt;sup>28</sup> In the interview with Ellis, an interpreter, she suggests that all IEPs should start with what the student has succeeded in; start the meeting off on a good note as opposed to setting the tone discussing the student's limitations. More on this in the 'Interpreters' subsection of the 'Findings'.

specialized classes, given that his special education began after he started school. Prior to having a more personalized education, Luz's son had a hard time focusing in the classroom and was reported as a misbehaving student by his prior teachers. Upon moving to special education classes and working with special education teachers, Luz's son's behavior improved and his attitude about school improved. Since Luz's son can express his feelings to her, Luz's perspective of the IEP meeting was influenced by how her son felt and how he expressed it verbally to her. As a result, Luz's initial attitude toward the IEP meetings was overall positive. For other mothers with nonverbal children who may not explicitly express how they feel about school, their feelings about the IEP was solely based on their own experiences, likely resulting in the overall sentiment towards the IEPs to be negative.

By being required to attend legal meetings to discuss primarily their child's deficienciesin rhetoric that felt impersonal, confusing, and stressful- these mothers were forced to join the school experts. The school actors part of an IEP team (teachers, therapists, principals, etc.) are experts in a twofold sense: these actors are professionals in the education field and have participated in various IEP meetings before, therefore familiar with the process and their role in the process. As described in this section, parents of students with IEPs must join the school experts to become part of the IEP team. However, these parents are inherently at a disadvantage for being unfamiliar with not only the legal process of an IEP, but also with the language and the culture of education. Consequently, when seated in front of who they perceive to be the experts, these mothers have doubts in their own positionality within the meeting. These parent doubts are the subject of the following subsection.

### Feelings of Inadequacy

Feelings of inadequacy was a common theme throughout the mothers' responses. This sentiment of inadequacy was expressed across the following three domains: 1) towards themselves as parents, 2) towards the school, and 3) towards their positionality during IEP meetings. These three areas of inadequacy influence one another and are what made the mothers doubt the efficacy of their student's education, their abilities as a parent, and their role as a parent in an IEP meeting.

#### 1) Inadequate Parenting

Some mothers expressed feelings that they had not done enough to help their children, which I describe to be feelings of inadequate parenting. Before beginning the interview, I stressed to the parents that my questions and topic of conversation was not meant to make them feel that they were not doing enough for their children. I made my goal explicit: to hear about their experiences and their feelings, positive and/or negative, throughout the course of their child's education. I reminded the mothers that at any point of the interview we could take a break, they can ask me questions, or we can skip a question or topic altogether.

Regardless, I commonly observed certain mothers express throughout their interviews that in hindsight, they could have been better parents had they tried to better learn the IEP process earlier, had known their rights as parents since the beginning, and had been knowledgeable in managing the resources available to help their child. Luz was very expressive in highlighting how much she does not know. At two separate points in her interview, Luz stated the following: "Maybe if I knew more or had more in-depth information that was more feasible related to my son's problems, I think it would have been different, right?"

"We can say that [my son not being able to read] has always upset me that I have not been able to resolve that. That I have not been able to get help for my son."

Luz believes she was missing the necessary knowledge and abilities to help her son. According to her, had she possessed the adequate skills she assumes that her son would have learned how to read. Instead of believing that the school system failed her son, Luz becomes convinced over the course of the interview that she failed her son. Diverse parents may place more pressure on their own abilities due to misunderstanding the extent that schools are responsible for accommodating and helping their child's needs.

Another point of contention for some mothers was discovering details about their child from school meetings, instead of learning the details on their own and leading them to doubt their agency as a 'good parent'. As Manuela (who has an autistic son) recalls:

"I didn't find out until after, over the years that passed since then, when [my son] would tell me about that bad teacher. But I did not know at that moment because he never told me. Well, in this journey of his autism, there will always be good people and people not so good, but, oh-well, that's how it is."

Similar to Luz, here Manuela shifts the blame to herself. Instead of pointing out the lack of communication from the school, Manuela understands the lack of communication between her and her son. In remembering this discovery about her son's bad teacher, she reacts by placing the blame on her as a parent, and sharing what she should have done differently: "I think that we as parents also have to be more active, be more aware of our children." What these parents may have been misunderstanding is the lack of communication between them as parents and their child's schools; instead of holding a continuous line of communication with their child's teacher, for example, some mother's only engaged with the teachers during planned IEP meetings. The lack of communication between parents and schools may be due to parents being unaware of the option to ask teachers about their child's day at school, or simply not having the time to reach out to the teachers outside of pre-scheduled meetings.

However, what Manuela and Luz have in common is that their sons are both verbal and very expressive. Their sons have the verbal capacity to describe their negative school experiences – Luz's son complaining about being bullied for not being able to read and Manuela's son telling her about a past bad teacher. Hearing from their children leads these mothers to believe they were inadequate parents, leading to a reflection on different approaches they should have taken to help their sons. Still, not all mothers expressed feelings of inadequacy as a parent. For mothers of non-verbal children, it becomes difficult to find the truth of what their children have experienced and how their children feel. This leads to mothers believing that the school is at fault for not being transparent in their education practices instead of blaming themselves. This relationship is described in the next subsection.

#### 2) Inadequate Schools

Many of the parents felt the school provided inadequate services for their child, with the root of concern being the lack of communication they had with the school. Raquel (a school teacher with a daughter that is nonverbal) reveals:

"There needs to be more communication. I never hear from the speech therapist, *like ever*, or I never hear from the occupational therapist. I don't know how it's going [with my daughter]. I don't know how [my daughter] is doing working with them. I don't really know what's going on. I mean, [my daughter] just tells me what she does in class, but I don't really know what's going on when they pull her for [therapy] sessions. There needs to be more communication, or at least some type of report."

Especially with non-verbal children, it can be difficult for parents to rely on their child to describe their school day, what they did in class, or how it went when they get pulled out from class for specialized instruction. Without knowing how the school day is going for their child, and whether or not their child is progressing, parents remain clueless for most of the school year about their child's academic progress until discussed at an IEP meeting. Though parents do reserve the right to request a meeting, that option is not always feasible since the meetings are commonly described to be run for too long and be very tiring. Or, mothers simply are not familiar with their right to request a meeting.

Some mothers identified that their child's schools are missing a constant line of communication between parent and school, that is, separate from an IEP meeting. Though they have the right to request an IEP meeting, mothers seek communication distinct from the negative environment of an IEP meeting. Whether it be through text, through a notebook that the teacher and parents write in and place in the student's backpack, or by talking in person during school pick-up time, these mothers express a desire to know more about their children at school. What complicates this desire is that the teachers and school staff do not know Spanish. As Betty (stay-at-home mother whose child was diagnosed with autism) shares:

"What's missing is a bit more resources. In other words, there should be a person in the schools, available every day to speak [with parents]. Of course with these children one always has questions, and sometimes in the school, well, there's only the person from the office and many times they don't speak Spanish or know all the information that I am requesting."

Betty found it difficult to find someone at the school who: 1) was available, 2) spoke Spanish, and 3) were knowledgeable about the progress of her son to be able to answer her questions. The root of Betty's problem appears to be: lack of school resources and helpful personnel. As a result, parent concerns and questions remained unanswered. The mothers who are not bilingual rely on school staff that know Spanish, or the parents attempt to communicate in English. In this context, mutual communication is when the both parties can both fully articulate their opinions and fully comprehend what the other is saying. When the Spanish-speaking mothers are told something in English without an interpreter, full comprehension is not attained until they ask their spouse, their other children, or a friend what was said. Consequently, conversations between a school staff speaking to a Spanish-speaking parent in English is not a successful, mutual communication. Even with the presence of an interpreter, if school staff do not break down technical jargon, there is still a communication gap between the school and the parent.

The self-described bilingual mothers have been able to achieve communication, yet they struggle to feel truly heard. Paola (bilingual mother whose son was diagnosed with autism) has tried various forms of communication with school staff at her son's school: from emailing the teacher, to writing notes in a notebook, to having to resort to calling the office. Throughout her interview, Paola often expressed that she felt that she was being "fastidiosa", "molestosa", and "pesada"<sup>29</sup> when attempting to find out about her son's school day. According to Paola, the reason she incessantly tries to understand how her son is doing at school is because when her son was in the first grade, she found out well into the school year that his teacher would place him in a box for hours when he was misbehaving. Paola's son is autistic and non-verbal, so her son could not express this upsetting experience. Additionally, the teacher did not reveal this information during their annual IEP meeting. Paola found out from a family friend who worked at the school and saw her son inside of a cardboard box. From then on Paola forced a line of communication between herself and the school, and she has continuously exercised her parental right of scheduling IEP meetings when she deems necessary. Though she feels like a bother to

<sup>&</sup>lt;sup>29</sup> Translation: annoying, bothersome/irritating, tiresome

the school staff when contacting them, she is motivated by her son's well-being to overcome the mindset that she is pestering the school.

Parents who do not feel confident in their knowledge of English find it more difficult to manage these types of communication networks with the school. Even so, parents who do not have an inside perspective of their child's day at school may never truly know what their child does at school unless it is revealed to them. Transparency from the schools is evidently lacking, and this communication gap remains when the parent is unsure of how to express themselves to the school in their native language.

Linguistically diverse barriers aside, there still remains a cultural barrier. For Luz, the inaccurate notion that her actions may negatively affect her son at school refrained her from communicating with his school. After Luz had shared about how her son complains about school bullying,<sup>30</sup> I asked what she had done to help her son. Instead of reporting the bullying to the school, Luz tells her son the following: "Don't pay attention to the bullying. Let it go. People are like that. Don't pay attention to it." Luz views the pre-scheduled IEP meetings as necessary, and any other attempt of contact on her part as confrontational.<sup>31</sup> Therefore, she altogether avoids unnecessary communication with the school, even in regards to this bullying situation. Luz's idea of when she *should* and *should not* communicate with the school, and the fact that she does not initiate the communication, highlights how she perceives unsolicited contact with the school as confrontational, which she actively avoids. Though she does not reach out to the school on her own terms, Luz still demonstrates feelings of inadequacy regarding the services offered to her

<sup>&</sup>lt;sup>30</sup> For context, Luz' son was diagnosed with ADHD and learning disabilities, and is behind various grades in reading level. Her son was in highschool.

<sup>&</sup>lt;sup>31</sup> Another instance that demonstrated Luz did not understand her rights as a parent is when she corrected me when I asked if she had ever recorded an IEP meeting. She stated that it is illegal for parents to record IEP meetings, which is not correct. Parent's can record IEP meetings, as long as they advise the school prior to the meeting.

son. She expresses vehemently throughout the interview that her son does not know how to read and she has tried tirelessly to find programs for him, as she admits: "It is my biggest upset, to not find the help that I know my son needs."

### 3) Inadequate as a Member of the IEP Meeting

Beyond feeling inadequate as a parent or insufficient communication on behalf of the schools, the mothers felt inadequately prepared as members of the IEP meeting. A major part of an IEP meeting is reviewing the student's assessment scores and evaluations that teachers and therapists conducted with the student. Though this information is translated to the mothers with an assigned district interpreter, the technical jargon used to review assessments and evaluations is often not broken down for the parent. It was a common experience for all mothers to describe school actors as not speaking to them at a comprehensible level, even with interpreters. Many mothers explicitly made an "us versus them" distinction when describing how the school would inundate them with information and terms. As Manuela describes:

"It is difficult to understand the entire process because thank God that they are professionals, the ones who are caring for our children, because [we as parents] we are not [professionals]. When [the professionals] would tell me about certain terms like 'occupational therapy', but I never really... they would always tell me that it was therapy, but maybe it was my mistake, that I never asked, "But what is it that you are teaching my son [in occupational therapy]?""

Manuela expresses gratitude towards the school staff, highly valuing their work as professionals who hold the capacity to help her son. She then goes on to reference her and her husband, who are not professionals, are at a disadvantage when trying to understand the school workers. Occupational therapy was a service afforded to Manuela's son that pulled him out of class for a set amount of time each week to teach him fine motor skills. Given that the school suggested this therapy, and Manuela values the school team as the experts, she agreed to the therapy without completely understanding what it entailed. It took months for her to investigate what exactly the therapy meant for her son. When reflecting on the time it took her to find out what the therapy was, she realizes that she should have spoken up during the IEP meetings to ask questions. Manuela, like other mothers, was afraid to speak up during IEP meetings to ask questions about knowledge that appeared to be common. "I guess I was afraid to ask, because I was the only one to ask", she mentions when recalling her early IEP meeting experiences.

A factor that makes it difficult for parents to attempt to speak up is the unwelcoming environment of an IEP meeting itself. Based on the participants' experiences, the meetings were not always formatted to elicit parent participation or to inform parents about their role as a member of an IEP. Across all of the mothers' experiences, they all shared feeling "pressured" and "tired" following an IEP meeting. Several mothers shared that they sometimes left the IEP meeting crying because of the amount of information they received and the steps they felt they had to figure out to help their child. Luz expresses this sentiment the clearest when she shares: "There's some times when, honestly, I leave [the IEP meeting] crying because, well it isn't easy, right? But I try. [...] Well, I come from Mexico and I don't know a lot of things. I do what I can for [my son]." This quote expresses how difficult it is for Luz, who came from Mexico and is unfamiliar with the U.S. school system and school culture, to keep track of and understand everything related to her son's education. Instead of the IEP meeting being a place where the mothers can get clarification about their child's progress, they were inundated with information and left the meeting unclear about the next steps they could take to help their child.

Manuela expresses how she felt like a bad mother when she would attend IEP meetings and the school could point out her son's "strengths and weaknesses", which were observations she had never noticed in her son before. Learning about her son in IEP meetings, whether his good or bad behavior, made her feel inadequate as a mother for not having seen that in her son. Further than the role of a mother, she expressed feeling as though she could not participate in the IEP because the school workers appeared to know more about her son than she did. What was amiss in Manuela's thinking is that these school staff do spend all day with her son, doing tasks with him and purposefully observing him to track his progress methodologically; it is the professional job of the school to be able to articulate in a certain way about the students they observe. However, instead of feeling comforted by the expertise of the parents, they were often intimidated. Parents felt pressured to be better parents due to their high respect and regard for the school staff as professionals, compared to themselves as "just the parents".

### Developing Confidence Through Experience

As my conversations with the mothers moved towards their more recent experiences with IEP meetings, it became clear that it was "conforme a los años"<sup>32</sup> that the mothers learned the IEP process and not through the school's attempt to promote parent participation as mandated by IDEA. All the mothers, except one,<sup>33</sup> grew in participation during IEP meetings. This participation increased for two reasons: 1) gaining confidence from a third party and/or 2) realizing the necessity of emitting confidence to defend their child. As will be discussed in this section, a growth in participation is when the parent no longer sits through an IEP and leaves the meeting with doubts and unanswered questions. Instead, a growth of participation is when the parent can express what they believe is best for their child, ask questions, and keep the school accountable.

<sup>&</sup>lt;sup>32</sup> Translation: throughout the years, over the time.

<sup>&</sup>lt;sup>33</sup> Dalia, who maintained a generally stagnant participation level throughout the two years of her son's IEP. She describes going to IEP meetings to merely listen and sign paperwork.

Having the motivation of a third party person was the starting off point towards confidence for many of the mothers. Aura shares how her daughter's neurologist inspired her to speak up for her daughter's needs by telling her:

"The neurologist always told us, 'If you (as her parents) don't speak up for your daughter, no one will. If you are her voice, you need to demand her rights, because if you don't do so, no one will.' So in that way maybe I was more timid and quiet. It was difficult, but I learned. If [the school] said something about my daughter that I thought was not right, then, that's when I learned how to say 'no'."

From the doctor's encouragement to Aura and her husband to speak up on behalf of their daughter, Aura overcame her timidness to advocate for her daughter. Aura would disagree with the IEP team when they made inaccurate conclusions about her daughter's behavior, and inserted her opinion when she believed they were wrong and advocated for services that would better serve her daughter. The neurologist did not make Aura feel pressured into speaking up for her daughter. Rather, the neurologist propelled Aura's confidence by bringing to light how necessary Aura's voice is for advocating for her daughter's needs.

Also, gaining the confidence to speak up for their child was inspired by other parents that the mothers came into contact with over the years of knowing other parents at their child's schools. Luz, for example, invited a friend to sit in at her son's IEP meeting. This friend was another parent more familiar with IEPs, given that her son was older in the special education process. Luz describes having learned about her rights as a parent from her friend instead of the explanations from the school or online resources. The mere presence of another person at Luz's son's IEP team had the IEP team appear to take the meeting and Luz's requests more seriously. After Luz's friend attended an IEP meeting with her, she excitedly shared how she had learned to address the IEP team and what questions she should ask them afterward. From the knowledge passed down from her friend, Luz's confidence to advocate during an IEP meeting grew. Learning from a fellow parent is more accessible for parents without an extensive education background, such as Luz, Susana, Betty, and Aura.

Other parents developed courage over time by reaching out to advocates who would also sit in during their child's IEP meetings. Notably, the mothers who contacted advocates were typically bilingual and knew how to access an advocate. Nora had an advocate for many years who greatly helped her with her son's needs and had a large impact on other parents with special needs children at their local church community.<sup>34</sup> Nora describes the advocate as "amazing" and having helped her with her son and his needs at school "tremendously." Paola had an advocate who wrote a letter to the district to get Paola's son the services she requested. The letter worked, and from then on, Paola learned that letters to the district were a viable tool to advocate for her son.

When asking the other mothers who were not fluent in English if they had requested an advocate before, the general reaction was that, luckily, their situation had never gotten dire enough to need an advocate. With these mothers, a misunderstanding emerges regarding the role of an advocate. The parents who speak less English were all under the same impression that an advocate was for more 'serious' disputes and that their complaints about the schools had yet to get to be that serious. For instance, Luz's situation, where her son has not learned how to read and is currently in high school, where he is being bullied for not being able to read, is not enough in her eyes to request an advocate. When asked if she knew how to request an advocate, it became clear that Luz had not considered it before. These Spanish-speaking mothers may not consider certain paths to solicit help for their child when that path is not accessible to them; these

<sup>&</sup>lt;sup>34</sup> More on Nora's local church's parent group in the subsection: *Attempting to Better Awareness*.

mothers believe their situation does not require an advocate because they do not know how to obtain an advocate and, therefore, do not know when they would need an advocate.

Receiving support—whether moral or practical—from medical professionals, other parents, or advocates, these mothers' experiences depict how becoming more knowledgeable in the IEP process helped boost their confidence in participating in the meetings or reaching out to the district to request services.

Lamentably, even when valiantly speaking up in the intimidating environment of an IEP meeting, the mothers' confidence in making their opinions known or making requests was often shut down with excuses from the schools. For example, the following requests were brought up by the mothers at an IEP and were denied due to the following reasons: tutoring was denied to Luz's son because they do not have enough personnel; Aura's daughter had to move schools, against Aura's and the school psychologist's wishes, because the principal had decided moving schools would be best; and Paola's son was denied speech therapy because he did not talk, which Paolahad argued was because he did not have speech therapy. In the above examples, the mothers were not satisfied with the 'excuses' given by the school. However, some mothers continued requesting a different outcome, while others did not proceed with their request and took the school's opinion as the final decision. There is no distinct pattern as to why certain mothers were successful or not in eventually getting services since there are several factors that could affect the outcome, such as how receptive the school was during an IEP meeting, the type of request made by the parent, or the number of resources available at each school that made certain services more feasible.

What is clear, however, is that the mothers who face language and cultural barriers, and hold misconceptions about the school system, often hesitate to speak up in IEP meetings. Susana's experience is a poignant example of this. She recalls a time when she refrained from asking questions, fearing that it would prolong the meeting: "During [the IEP meeting,] one does have a ton of questions. But I was there for like three hours, and I just wanted to go home. I looked at the faces of those from the school and it was like [*shaking her head*] 'that's it'. Like the time was up."<sup>35</sup> Susana's fear of inconveniencing the school workers with her questions led her to withhold her input, even when she was given the opportunity to ask at the end of the meeting.

### Attempting to Better Awareness

As a result of becoming their child's parent advocate, the actions taken by some of the mothers to improve their child's development at school inadvertently improved the preparedness of the staff by raising awareness of their child's special needs. Paola, Raquel, and Nora shared stories of how their actions bettered the actions of the professionals working with their children or how they have helped other parents. Once again, it is important to reiterate that these three mothers self-identify as fluent in English. Following the analysis of the stories of these three mothers, speculation as to why these stories are prevalent amongst strong English-speaking parents will be discussed.

Despite Paola's feeling that she "bothers" the school staff due to her seemingly constant communication with them, Paola's actions have led to better behavioral outcomes for her son and a better school environment. By contacting her son's teacher and the school nurse, Paola warned the school staff about behaviors that her son may demonstrate before his behavior escalates, which are signs that notify the nurse to administer his medication. The nurse has the medication

<sup>&</sup>lt;sup>35</sup> Italics depicting a gesture that the speaker did at that moment in stating the quote.

and information about how to administer the medication, but without Paola's input, the nurse would not know when to administer the medication. Including the teacher becomes important since the teacher spends the most time with Paola's son. The teacher must be included in the conversation about Paola's son's behaviors and when the nurse should administer medication. By advocating for her son's behavioral and medical needs, Paola helped facilitate communication between the teacher and the school nurse to better her son's school experience. Being an expert on her son and knowing when his behavior may escalate, Paola imparted her expertise to the other experts – the teacher and the school nurse.

Unlike how most of the mothers had never heard of their child's diagnosis prior to the diagnosis, Raquel had. Nevertheless, Raquel was not an expert in the beginning. Over time, Raquel learned from doctors and therapists how to proceed when her daughter would get seizures. To Raquel's surprise, when her daughter changed schools and returned to the third grade after being homeschooled for two years due to COVID-19, the school staff were not familiar with working with students diagnosed with epilepsy. To ensure her daughter was safe at school, she had to teach the school staff about her daughter's needs, as outlined in her following explanation:

"[The staff] definitely need more training. Because when I first took her back to school, not a lot of staff knew about epilepsy. They didn't know what to do. So we had to go through a training together, all of us, for them to learn what to do. Definitely more training on not just autism, but different [...] disabilities that they have – different needs."

Similar to Paola's situation, due to a medical necessity, Raquel had to reach out to the school staff and request for them to be trained and develop the necessary skills to help her daughter during seizures. In the latter part of the quote, Raquel also points out that she perceives teachers as more well-trained and knowledgeable in certain disabilities than others. Raquel advocates for

a better-trained school staff to help her daughter and other students with similar needs. Awareness about the diverse needs of the student body is raised by ensuring the staff is trained in different students' needs.

Outside the school, Nora is part of a parent group at her local church where parents of children with special needs can get together. Though this group is just in English, Nora is bilingual and has interacted with English and Spanish-speaking parents. As an older mother whose child with special needs is 30 years old, Nora has become more knowledgeable about available disability services for families over the years. As part of this parent group, she has advised parents of resources that they can access to improve their child's experience at school, learn more about the IEP process, or receive additional family support. Nora uses her experience and connections in the community to raise awareness, not about her child's needs necessarily, but about programs and services that could aid other parents, both English and Spanish-speaking.

The other mothers who were less comfortable with English did not have similar stories in attempting to raise awareness about their child's needs or special education resources. Raising awareness in either aspect, as described through the experiences of Paola, Raquel, and Nora, is a higher level of advocacy that these mothers have achieved in that it leaves a more lasting impact on the schools and other parents. What enables them to spread awareness is their mastery of English and knowledge of their rights as a parent. The Spanish-speaking mothers, though they had adverse experiences during IEP meetings or when attempting to communicate with the school, did not engage further with the school or learn about available county resources. The following subsection discusses how Spanish-speaking mothers, despite negative experiences, still value special education and the IEP process.

Although all the mothers, except one<sup>36</sup>, retell experiences where they felt they failed their child or the school failed them, some mothers still maintain their trust in the system. In this context, I employ the term 'system' to encompass special education and specifically, the IEP process.

Mothers who had previously depicted how highly they valued the school staff as experts were the mothers who maintained trust in the system. Manuela recalls a time when, following a three-hour IEP meeting, she had many questions but was mentally done and was not encouraged by the school staff to ask questions. The reason for this drawn-out meeting and her desire to ask questions, she explained, was because the speech therapists went into too much detail without actually explaining the terminology and numbers she was referring to. However, when I asked a follow-up question about the environment of that IEP meeting,<sup>37</sup> Manuela had a contradictory outlook:

"Everything seemed good to me. I think that everyone was there to help my son. Once and a while I noticed that the principals– I don't know if it's because they have a lot of work to do– but there was one time when the principal [...] was saying 'hurry up, hurry up' when we were introducing ourselves to one another. I stayed like [offended face]. I said to myself, "Well, if [the principal] does not want to be here, well she shouldn't be here. She can leave. She is not important for this meeting because she knows nothing about my kid.' That principal made me feel bad. But the majority– generally all of the therapists and the teachers and everything was really good."

Manuela went on to say that this principal made Manuela feel negatively during the several IEP meetings she had throughout the years at that school. However, Manuela gives the principal the benefit of the doubt for acting inconsiderately, creating the excuse that the principal likely has

<sup>&</sup>lt;sup>36</sup> Dalia, who maintained a generally stagnant participation level throughout the two years of her son's IEP. She describes going to IEP meetings to merely listen and sign paperwork.

<sup>&</sup>lt;sup>37</sup> From Appendix B: "¿Cómo te pareció el ambiente durante esa junta del IEP?"

much work to do. Manuela then states that she sees the IEP meetings as a place where all the school staff are there to help her son and that everything goes smoothly for her as a parent, for the most part. Regardless of the negative experiences Manuela, as a mother, and her son, as a student, have endured due to school staff in IEP meetings or the classroom, Manuela maintains a positive attitude toward the IEP meetings in general. Manuela went as far as to say she would recommend schools make more required IEP meetings throughout the academic year, though she also stated at a different point that she has never requested an IEP meeting herself. This trend was similar for other mothers (including Luz, Aura, Betty, Susana, and Carla) who said at the end of their interview that they found IEP meetings helpful, which appears to contradict their earlier sentiments toward IEP meetings, in which they felt the meetings to be overwhelming, emotionally draining, and intimidating environments that limited their participation.

This list of mothers mentioned above had more limited knowledge of English, which may have contributed to cultural barriers that led to wanting to respect the school staff as the experts they perceive them to be. The mothers with the youngest children are also in this category,<sup>38</sup> suggesting they *must* maintain trust in the system since their children have many years of education left. Of the six mothers who maintained trust in the system, three (Aura, Raquel, and Carla) had children still in elementary school, with at least a decade of education ahead. The average age of their children was 6.75 years old. The other mothers who maintained trust in the system (Luz, Manuela, and Betty) had children in high school or post-secondary education. Mothers with children at least a couple of years younger than 21 maintain trust in the education system because they remain hopeful that their child will receive a better education.<sup>39</sup>

<sup>&</sup>lt;sup>38</sup> Dalia, though she did not depict many of the other sentiments or experiences as the other mothers to belong in the previous subsections, she did maintain trust in the system by believing that after her son achieves his current IEP goals, he will no longer need an IEP. <sup>39</sup> According to IDEA, once past the age of 21, students are no longer able to receive SPED and related services.

Consequently, the mothers form a paradoxical opinion that future school interactions will be more promising than previous negative school interactions.

Conversely, the mothers with children who are close to aging out or have already aged out are well beyond maintaining trust in the system. Paola and Nora outwardly expressed their distrust of the system, which could be the reaction to their children being in the education system for nearly a decade longer than the children of most of the other mothers or because Paola and Nora were bilingual. I define 'distrust' in the system as parents who do not take for granted the outcomes given by the school at the end of an IEP meeting but instead exercise their parental rights to request the services they deem appropriate for their child. For instance, both sought an advocate to assist them during their son's IEP process instead of unquestioningly trusting that the school system would eventually benefit their son.

#### **Interpreters**

Five interviews were conducted with school district interpreters who have retired, changed jobs, or are still working as interpreters. The participants currently are or have been district translators and interpreters in the special education department of a district within my county of interest. From sharing their understanding of their role as an interpreter during IEP meetings, how the parents and the schools understand their role as interpreters, and offering their conclusions about miscommunication between parents and schools, interviews with these interpreters provided insight into an IEP meeting from an impartial perspective. The following section discusses the two strategies these interpreters deploy to maintain their position as an impartial third party when managing communication between two languages and cultures: 1) Establishing and Maintaining Professionalism and 2) In Through One Language, Out Through

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Another. These strategies were necessary since the Spanish-speaking parents they worked with often sought out their professional opinion. In addition to these strategies, the interpreters had several recommendations and ideas of what makes an IEP meeting successful in their experience. I divide their responses into two main categories: 1) Parents Maintaining their Agency and 2) Preparing Parents to be Their Child's Advocate.

### Interpreters as Neutral Third Parties

### 1) Establishing and Maintaining Professionalism

To understand the interpreter's role within the IEP meeting, I started their interviews by asking if their job requires their impartiality and what strategies they use to remain impartial. Though employed by the districts and working closely with the schools, interpreters shared similar techniques of maintaining a neutral position during IEP meetings. What made neutrality difficult for the interpreters was the parents' attempts to communicate with the interpreter as a person to help them make decisions in IEP meetings since they felt comfortable being with another Spanish-speaking worker.

Establishing professionalism with the parents since the first introductions, before the IEP meeting, helped set the tone for their interactions. The five interpreters explained that they meet the parents in the school lobby, often engaging in small talk with the parents. John sums up the initial interaction when meeting the parents in the lobby, walking them to the meeting room, and his inner thoughts as an interpreter in the following excerpt:

"Sometimes they would want to talk a little bit. And, you know, you would talk with them. But if they ask questions like, 'What's the purpose of this? They sent me a letter and it said this, what is this?' That's where you would really set the tone for the rest of the interaction, or the rest of the meeting, where you [as an interpreter] would say 'Those are really good questions, and you can ask the team all those questions during the meeting.' I strictly believe in setting that boundary, so they [don't] see me as someone that was part of the [IEP] team, but more [as someone] who is just there strictly to interpret."

John, along with the other four interpreters, demonstrated a high level of professionalism in their interactions with parents. This deliberate approach was crucial, as parents, often relieved to finally communicate with a district worker in their native language, would naturally gravitate towards the interpreter. In this context, John's role was akin to a guide, directing parents to the appropriate person to address their concerns, and a voice that was always ready to interpret when needed.

Some interpreters recalled extreme circumstances when parents looked to them as more than interpreters but, instead, as knowledgeable Spanish-speaking professionals who could help them make decisions. Ellis had a couple of experiences where parents would be very grateful for her interpretation and wanted to express their gratitude through a small gift or by buying her lunch. Alternatively, when a parent would turn to her during a meeting to ask Ellis if she should accept or decline the services offered by the school. In both scenarios, whether outside or during an IEP meeting, Ellis maintained professionalism by reminding the parents, "I'm only here to relay a message." Ellis and the other interpreters agreed that sometimes certain parents needed a reminder that their role as an interpreter is to relay information from English to Spanish and Spanish to English and not provide either the parent or the school with any new information. John suggests that setting the tone at the beginning makes it easier for the parents to understand the role of an interpreter and not to pass their boundaries, though the interpreters often give reminders.

### 2) In Through One Language, Out Through Another

IEP meetings typically follow the same procedure: the district reviews the Parent Rights, teachers and therapists go over the student's assessments results and evaluations, the school team creates a set of goals for the student to complete in the upcoming school year, and then the meeting ends with the parent signing in agreement with the goals. As a result of being present in several hundred IEP meetings, the interpreters are familiar with the process and have grown to understand the rights and responsibilities of the parents, the school, and the students. However, each meeting is still unique, and much of the information presented is unique to the student, and therefore varies from IEP to IEP.

Therefore, another strategy interpreters use to maintain partiality is what I term as In Through One Language, Out Through Another.<sup>40</sup> The interpreters do not retain specific information that was discussed in the IEP meetings, which may be due to the abundance of information discussed and the several IEP meetings they interpret. Pam shared that sometimes the IEP team would ask for her opinion about a parent, or a parent would ask about something that occurred in the meeting, to which Pam shares:

"[...] as an interpreter, there's some information that, at that moment, you forget. You're not a recorder, there's plenty of information that you forget. So the best approach is to relay a parent's question to the team or remind the team that you were only focusing on facilitating the communication, not the content."

Pam maintains her neutral position as an interpreter when faced with these speculative questions from one side of the IEP team (parents or school/district workers) by simply not actively recalling the information after the meeting is over.

<sup>&</sup>lt;sup>40</sup>A play on the traditional saying "in through one ear, and out the other".

Though not retaining all the details from a meeting can be seen as part of a subconscious act, there is also a conscious aspect of leaving behind the information from the meeting. As previously mentioned, the interpreters not only are experts and relaying the necessary information, but they also become knowledgeable in the subject matter they are actively translating or interpreting. All of the interpreters brought up moments when they had hoped the parent would decline an offer made by the school, but maintained their composure by not revealing their opinions. John shares how many parents would come with their work uniform, thinking that the meeting would be a quick ten minutes. John would realize that the school did not communicate with the parent to explain what an IEP meeting entailed, resulting in John concluding by "the end of the meeting, that [the parents] had no idea what they had signed or even what the purpose of the whole [IEP meeting] was". The interpreters expressed feeling frustrated when the school lacked clear communication with the parents such as this, or other instances when the school/district staff would talk over parents, the school staff would use too much technical jargon, or when the school staff would have side-bar conversations in English and not include the parents. Yet throughout these emotions, the interpreters maintained an impartial position as required by their position.

### Successful IEPs, According to Interpreters

Having now established these interpreters as impartial, third party actors who are present during IEP meetings, their perspective about the parent-school interaction can be understood. Of course, their perspectives are still their opinion, however it is not a professional opinion that is part of their decisions as interpreters for Spanish speaking parents nor as district employees. In the latter part of the interview with these interpreters, I inquired about how they would define a 'successful' IEP meeting, if there is such a meeting. The following two categories are two major camps that their responses landed within.

#### 1) Parents Maintaining Their Agency

Though parents become advocates themselves, they can also request a free advocate<sup>41</sup> or hire one of their own to attend their child's IEP meetings with them. The opinion of parent-hired advocates, and the impact they had on the meeting, was split amongst the interpreters. Pam, Ellis, and Nat did not have many strong opinions about them. Ellis describes hiring an advocate as a way that parents try to participate more in IEPs, while Nat says that advocates can guide parents through the process – both keeping their answers short. On the other end of the spectrum, John and Frank were adamant to highlight two different types of advocates that parents hire: good advocates and bad advocates.

According to John and Frank, a good advocate was rare. Most advocates, Frank explains, take over the role of the parent:

"In reality, the parent is not given the opportunity to understand what's going on, and to actually decide. From what I've seen, the advocate decides for them and will speak for them and then later explain what was said [in the meeting]. In my opinion, I don't see this as the best option, because parents should really know and be the ones deciding."

Instead of being the parent's support and helping the parent to articulate what they want for their child, advocates were described by these two interpreters to be overbearing.

John also maintains that most advocates make decisions for the parent. He also adds how a bad advocate can change the environment of the meeting:

<sup>&</sup>lt;sup>41</sup> In California, this is achieved through contacting their local County Offices of Education.

"Because depending on how the advocate presents himself, it can create a kind of a tense meeting because now everybody on the team is acting defensive. You could feel that tension as soon as the advocate introduces themselves and comes across aggressively, you know. When someone brings an advocate, the team might feel like 'the parent thinks we're not doing enough' or that the parent thinks 'we're not doing what we're supposed to be doing'."

He goes on to describe a tense meeting usually means longer meetings in which the opinion of the parent is drowned out by the school staff trying to overcompensate in defense against the advocate who is seeking more services for the sake of seeking services. John describes a difference between a good and bad advocate to be that the good advocate listens and takes into account the school and the parents, while a bad advocate seeks services just for the sake of getting as many services as possible for the student. When an advocate acts on their own accord –coming into the meeting with their own agenda and seeking services they alone deem necessary for the student – then the advocate does not assume the role of being the voice of the parent. Instead, with a bad advocate who acts on their own agenda, the parents' opinion is still unheard regardless of the help they tried seeking.

# 2) Preparing Parents to be their Child's Advocates

The following characteristics of an IEP meeting summarizes what a successful meeting means to the interpreters: an IEP team-the school, district, and parent- who listen to each other and arrive at a mutual agreement, achieved through a mutual understanding of all content matters discussed in the meeting. I would also advance that an impartial interpreter is needed, since they not only relay the message but can allow parents to feel more comfortable during the meeting. To obtain a mutual understanding between all parties, the interpreters' highlighted that slowing down the meeting was necessary to open up opportunities for parents to ask questions and offer

opinions throughout the meeting, and not just within a small window at the end where it is asked if the parents have any questions before having to sign the IEP documents.

The interpreters agree that meetings that tend to run smoothly and for a shorter, more digestible time are ones where the school was already in communication with the parents. As Pam describes:

"There are some easier meetings to interpret, [...] like when [the] parent has been previously informed about the goals. In other words, when the case manager [or] the teacher has reached out to the parent. So when the IEP meeting time comes, [the parents] have already reviewed previously some of the information. Once we get to the meeting, they're summarizing to the parent, but also asking them, 'Do you have any questions about what was reviewed?' And then there's more time [for] the parent to think about it. Sometimes [the parents] do come in with their questions ready. Sometimes they just say, 'No, I have no questions.' [...] A meeting flows faster when they've already reached out to the parent before."

As mentioned by the parents and by the interpreters interviewed, there is a lot of technical jargon

and terminology riddled in the IEP meeting – especially by particular actors, such as the

therapists. It helps when these school actors make the effort of reaching out to the parents prior

to the meeting to give time for the parents to review, understand, and formulate their questions in

preparation for the IEP meeting. Parents cannot prepare for the meeting without the school first

offering them the relevant information. As John succinctly summarizes:

"For me, I felt like when an IEP meeting was successful, both the [school] team and the parents were prepared. [Both] had all the information, [the school] allowed parents to speak, and parents took the opportunity to speak and to ask questions. And then at the end, they were both on the same page of what the meeting was supposed to accomplish."

Preparing parents is a good intention, but there is no simple solution given the diversity

of Spanish-speaking parents the schools work with. From speaking with the interpreters, it

became clear that there are a range of types of Spanish-speaking parents who are part of IEP

meetings. Ellis summarizes this distinction aptly:

"We work with a range of parents. From the parents [who] do not read or write, or do not even speak our language. [...] Some parents just take everything that is fed to them. They just nod and say, 'okay.' Other parents have a notebook, [and] writing everything down."

Given there are different levels of education, language levels, and time in the U.S. of the parents that these interpreters have worked with, they had different types of experiences over their years of work. Yet, the interpreters noted that the schools or district workers do not try different approaches in an attempt to make connections with the parents.

It becomes complicated for schools to bridge the communication with parents when the parent is not mutually willing to be engaged in the IEP process. Frank describes the spectrum of uninterested parents as follows:

"It's hard to know if it's really that [the parents] are not informed [about their children] or that they're not educated in the IEP itself. I wouldn't want to say that they're not interested, because these are their children. But they do seem uninterested. We see that lack of interest. I've seen situations where parents are in a rush [to end] the meeting. That to me, or to anyone, would equal [a] lack of interest. If a parent is rushing, asking how much time more they have to be here or how much longer, that's really a bad scenario."

Meanwhile, Pam counters that it is up to the schools to ensure that the parent has the appropriate means to engage properly with the IEP material. In response to asking about the preparedness (or lack thereof) of parents that she has observed, Pam responds that "it's the responsibility of [the school] to find a solution, a suggestion, or provide a new intervention for both the parent and the student– whatever needs to be taking place to help should be done". The school's responsibility may include having smaller meetings over time to accommodate parents with strict work schedules or slowing meetings down by discussing and explaining technical jargon more descriptively.

# VI. Policy Recommendations

From interviewing the parents and interpreters, I found that navigating the special education process is akin to a legal process, making it difficult for culturally and linguistically diverse parents to attain desired outcomes for their child. This investigation highlighted what has been helpful and what has hindered Spanish-speaking parents from communicating with their child's school and engaging during IEP meetings. From the findings of this study, I highlight one area of policy improvement and propose two new policies for schools and districts to continue providing support and bridge gaps in communication and understanding with culturally and linguistically diverse parents. These policy recommendations are drawn primarily from the mothers' experiences and proposed solutions while supplemented by the interpreters' knowledge and observations.

First, the main area of policy improvement would be to support an already existing regulation of IDEA further, Parent Participation.<sup>42</sup> The general requirements proposed to increase parent participation are a mere starting point for increasing parent participation among diverse parents. IDEA requires local education agencies (schools and districts) to create opportunities for parents to participate,<sup>43</sup> yet does not account for parents who may need help understanding when it is their opportunity to participate or how they can participate. Therefore, I propose that included in IDEA, there is a subsection outlining that schools should take a culturally responsive approach when working with diverse families. Culturally responsive teaching, a growing practice in education that emphasizes student equity by teachers employing a culturally relevant

<sup>&</sup>lt;sup>42</sup> See *IDEA Sec. 300.322 Parent Participation*. Individuals with Disabilities Education Act. (2017, July 12). https://sites.ed.gov/idea/regs/b/d/300.322

<sup>&</sup>lt;sup>43</sup> See *IDEA Sec. 300.322 Parent Participation*. Individuals with Disabilities Education Act. (2017, July 12). https://sites.ed.gov/idea/regs/b/d/300.322

curriculum that accounts for the students' cultures and identities,<sup>44</sup> ought to be extended to treating students' parents and families by school and district staff. IDEA can include 'Culturally Responsive IEP Practices' as an additional responsibility for the local education agencies to account for the diverse cultures of the parents and promote their participation.

Culturally Responsive IEP Practices can highlight the importance of communication before the IEP meeting, during the IEP meeting, and after the IEP meeting. Increasing parent-school communication around IEP meetings ensures the promotion of valuable parent participation, given that these are legal meetings establishing the curriculum and services afforded to the student. The interpreters observed that those they deemed as 'prepared parents' had a copy of their child's IEP document and came prepared with their questions because of previous conversations with their child's teachers or therapists. Therefore, before the IEP meeting, schools must establish communication by ensuring the parents are clear about how long the meeting is and what the content of the meeting will discuss, as well as by providing a Spanish copy of the meeting. Interpreters also recalled how some schools had intimidating seating arrangements and pre-meeting conversations in English that hindered the creation of a welcoming environment an IEP meeting should have. IDEA can include clear guidelines for how to conduct meetings for diverse parents, such as having the IEP case manager greet the parent in the lobby with the interpreter instead of the interpreter by themselves, refrain from pre-meeting conversations that the parent cannot understand, or include the parent in pre-meeting and side-conversations that an English-speaking parent would otherwise understand; create less-intimidating seating arrangements by not having the parents on their side of the room, but

<sup>&</sup>lt;sup>44</sup> There is various literature on culturally responsive practices. See Parkhouse, H., Lyn, R., Severson-Irby, E., Drulis, E., Senechal, J., & Lozada, F. (2023). Mapping How Teachers Become Culturally Responsive. Journal of Teacher Education, 74(4), 383-397. https://doi-org.proxy.uchicago.edu/10.1177/00224871231168076

instead join the school staff in an inviting seating arrangement. Suggestions for school staff to be culturally responsive to the parents' needs during the meetings include breaking apart technical jargon and not assuming that acronyms, medical terms, and short-hands are easily interpreted; pausing often for questions and gauging if the parent is following along; and starting the meeting with a good tone by reviewing the student's strengths first. Suggestions for post-meeting engagement with the parent include school staff continuously sustaining communication by providing updates about the child's progress and making themselves available to answer the parents' questions when necessary.

Outside of IEP meetings themselves, parent empowerment can be fostered by utilizing behavioral tools that are relatively low cost to the schools and can target psychological factors, such as cultural barriers, that may hinder parents' engagement outside of IEP meetings.<sup>45</sup> The use of text messages is a powerful and cost-effective tool that schools can implement to empower parents to communicate continuously with the schools in a format that may be more accessible. School staff can send parents who opt-in text message reminders about upcoming IEP meetings, updates about their child's progress, answer brief questions the parents may have, or schedule brief times to meet with the parents to discuss more elaborate questions. Teachers who do not have access to Spanish can utilize copy-and-paste features to communicate with the parents through Google Translate, helping bridge communication until the help of a translator or interpreter can be accessed.

<sup>&</sup>lt;sup>45</sup> Research on behavioral insights into the participation of low-income parents with their child's school has found suggestive evidence that personalized messaging and engagement from the school helped increase participation. See the following two studies: Gennetian, L. A., Marti, M., Kennedy, J. L., Kim, J. H., & Duch, H. (2019). Supporting parent engagement in a school readiness program: Experimental evidence applying insights from behavioral economics. Journal of Applied Developmental Psychology, 62, 1–10. <u>https://doi.org/10.1016/j.appdev.2018.12.006.</u>; Kalil, A., Mayer, S. E., & Gallegos, S. (2021). Using behavioral insights to increase attendance at subsidized preschool programs: The Show Up to Grow Up intervention. Organizational Behavior and Human Decision Processes, 163, 65–79. <u>https://doi.org/10.1016/j.obhdp.2019.11.002</u>.; Mayer, S. E., Kalil, A., Oreopoulos, P., & Gallegos, S. (2019). Using Behavioral Insights to Increase Parental Engagement: The Parents and Children Together Intervention. Journal of Human Resources, 54(4), 900–925. https://doi.org/10.3368/jhr.54.4.0617.8835R

Secondly, I propose creating and adding a bilingual parent liaison position at each school site. This person would act as a street-level bureaucrat; the middleman that is less than an advocate (in that they do not participate in IEP meetings) but more than an interpreter (in that they can engage with the parents on a more personal, need-based level). The liaison would specialize in information related to special education-including the IEP process, services offered by the school districts, and services provided by other agencies in the local county. In addition to knowing special education services that aid the student, the liaison would also be knowledgeable in other systems of support for the families. For instance, the liaison would be able to point parents to local parent support groups or to where parents can receive help for certain legal processes related to the disabilities of their child.<sup>46</sup> The parent liaison can be the main contact for Spanish-speaking parents to connect with when they have questions or concerns and may not know who or how to reach out to the schools. Otherwise, these parents may wait until the next IEP meeting. Given the parent liaison's responsibilities, they would have to know Spanish, especially since the interviews demonstrated how comfortable and at ease the mothers were when they worked with an interpreter or someone from the school who spoke Spanish.

Parent liaisons can encourage parents to use each other as resources through parent support groups hosted by the schools. These support groups would be a space where parents can meet to discuss the IEP process, their feelings about the process, and any questions or advice they may have in an informal environment. Parent groups have been studied and identified as positive networks for parents with children who have disabilities, which could help parents cope

<sup>&</sup>lt;sup>46</sup> In California, parents or guardians can become 'conservators' of their child who is 'developmentally disabled'. This is an additional legal process that may be difficult to navigate, and is not often told to parents with children who are developmentally disabled in special education. See Conservatorship of persons with disabilities. Disability Rights California. (2017).

https://www.disabilityrightsca.org/legislation/principles-conservatorship-of-persons-with-disabilities.

with their emotions and stresses concerning their child, as many of the interviewed mothers felt.<sup>47</sup>

Third, I propose increasing school staff training by creating a process in which parents can request training for teachers or other school staff who work with their children. A common parent complaint was that the staff often treated their kids without compassion and were not properly trained to accommodate their needs.<sup>48</sup> As discussed in the Findings section, several mothers had to teach the staff how to engage with their child's special needs properly. Creating a formal way for the parent to request for the staff to receive additional training can help increase school staff awareness of the diverse needs of the students and decrease the need for mothers to engage with the school under negative circumstances. This formal process can be facilitated through the aforementioned bilingual parent liaison, who would collect parent complaints, present them to the school administration, and propose the training staff should undergo in a timely manner.

# VII. <u>Limitations and Future Research</u>

This research contributes to the total understanding of the diverse group of culturally and linguistically diverse parents. However, it is important to acknowledge the three main limitations. The first limitation is the small sample size and recruitment of the parents. Given that most parents in this study were from Mexico, further research could expand to include diverse parents from other Hispanic countries or who speak another language altogether.<sup>49</sup> Also, n=6 of

<sup>&</sup>lt;sup>47</sup> See Kazak, A. E., & Marvin, R. S. (1984). Differences, Difficulties and Adaptation: Stress and Social Networks in Families with a Handicapped Child. Family Relations, 33(1), 67. https://doi-org.proxy.uchicago.edu/10.2307/584591.

<sup>&</sup>lt;sup>48</sup> As Nora stated, "I would like to have seen the teachers be more caring, more compassionate towards us as parents."

<sup>&</sup>lt;sup>49</sup> Data biases group together indigenous people from Latin America as Hispanic/Latino, and include their indigenous language or dialects under Spanish. As a result, these groups are understudied and overlooked in education research. For more information about the advancement of the Language Justice movement for Latin

the parents were recruited via snowball sampling, meaning that many of their responses may be similar to and influenced by the other parents with whom they have a connection. Selection bias is present in this recruitment style: personal networks exclude parents outside the network, and recruitment through Facebook excludes parents who are not on Facebook or part of the relevant Facebook groups. Future research could utilize a recruitment method to find parents who may be less active in parent affinity groups and understand how they navigate the SPED process without the support of such groups.

The second limitation is the small sample size of the interpreters interviewed. However, future research can expand the scope to include interpreters of other languages, especially since indigenous language interpreters are becoming increasingly necessary in the United States for other legal processes, such as immigration.<sup>50</sup> Due to the increasing use of virtual IEP meetings via Zoom, research that aims to understand and differentiate between the types of meetings that can provide insight into how the school engages with parents virtually compared to in-person, providing data for further policy improvement.

The third limitation is the containment of this study within a county in Southern California. Though the diversity and amount of SPED resources were driving factors for focusing data collection within this county, future research can broaden the scale to include more districts in California or nationwide. This expansion will not only mitigate the previous two

American indigenous languages, see Promise Institute for Human Rights, UCLA Bunche Center. (2022, January 31). We are Here. ArcGIS StoryMaps. https://storymaps.arcgis.com/stories/618560a29f2a402faa2f5dd9ded0cc65 <sup>50</sup> Indigenous language speakers in U.S. immigration proceedings create unique problems for scheduling and finding indigenous language interpreters. See TRAC Immigration. (2021, April 26). *40 Languages Spoken Among Asylum Seekers with Pending MPP Cases.* 40 languages spoken among asylum seekers with pending MPP cases. https://trac.syr.edu/immigration/reports/644/

limitations but also provide more comprehensive insights into the experiences of diverse parents and interpreters.

# VIII. <u>Conclusion</u>

Regardless of the intentions of the special education federal law IDEA to promote parent participation and engagement in their student's education, culturally and linguistically diverse parents are at a disadvantage when navigating this complex legal process. By interviewing Spanish-speaking parents as a subgroup of diverse parents, this study established similar ways parents navigate the process and differences in how they understood their role in relation to the school. Still, a commonality across the experiences of these parents was their evolution towards advocacy to attain the desired outcomes for their students. It is up to the schools to develop more culturally responsive practices and re-organize structurally to include actors that can bridge the gap between diverse parents and the schools. Diverse parents desire to be heard as the advocates they are. Parents' diversities must be accounted for in the implementation of special education policies at the school level.

"Nunca nadie me había preguntado todas estas cosas [...] y estoy muy sorprendida. Gracias por dejarme contarte mi historia."<sup>51</sup> - *Aura* 

<sup>&</sup>lt;sup>51</sup> "Never has anyone asked me all of these things [...] and I am very surprised. Thank you for letting me tell you my story." - *Aura* 

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### Appendix A

Screening Questions asked to Potential Parent Participants

[English]

Thank you for your interest in participating in this study! Before scheduling an interview, I would like to ask you a few questions. What do you consider to be your first language? What is your highest level of education? What is your current occupation?

[Spanish]

¡Gracias por su interés en participar en mi estudio! Antes de programar una entrevista, me gustaría hacerle algunas preguntas. ¿Cuál consideras que es tu primer idioma? ¿Cuál es tu nivel más alto de educación? ¿Cuál es su ocupación o a que se dedica?

#### Appendix B

### Parent Interview Guide (English)

In no way are these questions meant to be judgemental or cause you to feel pressured. Please feel free to answer the questions any way you like, to ask me questions, or to say skip. If you realize you don't want an answer included, or no longer feel comfortable to finish the interview, there is no problem in letting me know.

#### Introduction

In this portion of the interview, I would like to get to know your child briefly, which can help me ask questions in the rest of the interview, especially since all children with special needs are different.

- Tell me about your special needs child:
  - Do they have a medical diagnosis?
  - When did he/she first get diagnosed?
  - What led up to their diagnosis?
  - Had you ever heard about the diagnosis before then?
  - What was the early process like? Therapies? Appointments?
- After the diagnosis, did you do anything to learn more about it?

### Education

Now we will move on to the school years, specifically when they were in special education. Most of all, I would like to know about *your* experiences of being part of your child's IEP meetings and interacting with the school. Your perspective is important – all your feelings and confusions about the process is what I would like to hear about.

- When did your child join special education?

- Was it full time or were they pulled out of class?
- Did the school recommend it, or did you ask the school for help?

Try to recall the first IEP you attended. Or at least the earliest meetings you can remember.

- How did you feel attending the IEPs then?
- Was someone there to support you?
- What did you want for your child at that time?
- What was the outcome of the IEP?
- Did you understand what the process involved/ your role in such a process?
- Are you more familiar with the process now? What has helped you become more knowledgeable?

I would like to hear about your experiences with an interpreter:

- Did you feel more comfortable?
- Tell me about some stand out experiences you have had with an interpreter.
- Is interpretation enough for you to understand the process?

Thinking about your general experiences with IEP meetings:

- Who is the hardest person to understand in an IEP meeting? Why? Do you do something to try to understand?
- How do you participate in IEP meetings?
  - Do you take notes, have you recorded the meetings/ requests, do you ask questions?
- How would you describe a typical IEP meeting environment?
- Do you think IEP meetings are helpful? How/why?

- Have you ever reached out to an advocate/ attorney for help? Or anyone else for help during an IEP?
  - When other people come to support you and your child at the IEP meetings, how does that make you feel?

As your child grew older – from elementary, to middle school, to high school:

- How was the IEP transition between each school? Was it the same teachers/therapists/staff? Were there any difficulties?
- Did the meetings change with each transition? How?

Thinking about outside the IEP meeting:

- How often do you communicate with the teachers/therapists?
- How did you feel interacting with them?
  - Was it easy? Were you able to tell them what you wanted?

Any last things you would like to add?

### **Demographics**

The following questions are to establish a context of who I am speaking with. All the information will remain anonymous. It is meant to help me understand and describe the group I am speaking to.

- How would you describe your knowledge of the English language?
- Married?
- What are your (and your spouse's) occupations?
- How many children do you have?
- Does your family receive any benefits from the government?

#### Parent Interview Guide (Spanish)

Quiero aclarar que no es mi intención que estas preguntas te hagan sentir presionada o culpable. Siéntase libre de responder las preguntas como desee, de hacerme preguntas o indicarme si en algún momento no quiere participar. Si te das cuenta que no quieres incluir una respuesta, o ya no te sientes cómoda para terminar la entrevista, no hay problema en avisarme.

### Introducción

En esta primera parte de la entrevista, me gustaría conocer brevemente a su hijo para tener un contexto general de sus necesidades. Especialmente porque todos los niños con necesidades especiales son diferentes.

- ¿Tiene un diagnóstico su hijo?
  - Cuénteme ¿Cuándo diagnosticaron a su hijo?
  - ¿Quién recomendó que le hagan una evaluación?
  - ¿Cuántos años tenía su hijo?
  - ¿Habías escuchado alguna vez sobre el diagnóstico?
  - ¿Cómo fue el proceso inicial? ¿Tenía citas? ¿Lo llevaba a Terapias?
- Después del diagnóstico, ¿hiciste algo más para investigar sobre ello?

### Educación

Ahora pasaremos a los años escolares, específicamente cuando estaban en educación especial. Sobre todo, me gustaría conocer tus experiencias al ser parte de las reuniones del IEP de su hijo, e interacciones con la escuela. Por ejemplo, si hablabas con la maestra, si comunicabas con la escuela sobre el teléfono, si mandas un correo electrónico, o una carta escrita. Su perspectiva es importante: todos sus sentimientos y emociones sobre el proceso es lo que me gustaría saber.

- ¿Cuándo empezó su hijo a recibir educación especial?
  - ¿Fueron clases a tiempo completo o lo llevaban a otra clase?

Intente recordar el primer IEP al que asistió. O al menos las primeras reuniones que puedas recordar.

- ¿Cómo te sentiste entonces?
- ¿Había alguien contigo para apoyarte?
- ¿Qué ayuda deseabas para tu hijo en ese momento?
- ¿Cuál fue el resultado? ¿Qué ayuda recibió?
- ¿Entendiste lo que implicaba el proceso?
- ¿Cuál era tu papel (rol, derecho) en ese proceso?
- ¿Qué te ha ayudado a adquirir más conocimiento sobre el proceso del IEP?

Quiero conocer sobre tus experiencias con un intérprete:

- ¿Cómo te sentiste? ¿Te sentiste más cómoda?
- Cuéntame sobre experiencias significativas que hayas tenido con un intérprete, ya sean buenas o malas.
- ¿Crees que la interpretación es suficiente para entender (comprender) el proceso del IEP?
   ¿Por qué?

Pensando en sus experiencias generales con las reuniones del IEP:

- ¿Quién es la persona más difícil de entender en un IEP?

- ¿Por qué?
- ¿Cómo participa usted en las reuniones del IEP?
- ¿Estás más familiarizada con el proceso ahora?
- ¿Cómo te pareció el ambiente durante las reuniones del IEP? Te sentiste nerviosa o intimidada, te sentiste cómoda y crees que te escuchaban?
  - ¿Cómo te sientes cuando otras personas vienen a apoyarte a ti y a tu hijo en las reuniones del IEP?
- ¿Alguna vez ha pedido ayuda a un defensor/abogado? ¿O alguien más que le ayude durante un IEP?

A medida que su hijo fue creciendo y avanzando de la primaria a la secundaria y a la prepa, etcétera:

- ¿Cómo fue la transición del IEP entre cada escuela?
- ¿Las reuniones del IEP cambiaron de alguna manera?
- ¿Tuviste dificultades con el cambio de maestros y terapeutas?
- ¿Las escuelas hicieron un buen trabajo en comunicarte la información necesaria relacionada con su hijo y sus necesidades?

Ahora quiero preguntarte sobre cosas no relacionadas con el IEP

- ¿Qué frecuentemente te comunicas con los maestros/terapeutas?
  - ¿Cómo te sentiste al interactuar con ellos?

¿Algo más que deseas agregar?

### Demografía

Las siguientes preguntas son para establecer un contexto de con quién estoy hablando. Esto me ayudará a tener una mayor comprensión del grupo para mi proyecto. Toda tu información personal que compartas permanecerá anónima.

- ¿Qué tan bien hablas y entiendes el inglés?
- ¿Casado/a?
- ¿Cuáles son sus ocupaciones o a que se dedica (y su cónyuge)?
- ¿Cuántos hijos tienes?
- ¿Recibe su familia algún beneficio del gobierno?

### Appendix C

#### Verbal Consent Form (Spanish)

### **Consentimiento verbal**

**Título del estudio:** Comprendiendo la relación entre los padres con diversidades culturales y lingüísticas y la escuela de sus hijos; y cómo los padres navegan a través el proceso del IEP (Programa de Educación Individualizada)

### Investigadora: Gloria Parra

**Propósito:** El motivo de este estudio es para ofrecer más literatura sobre las perspectivas de los padres cuando su hijo está en educación especial, ya que la Ley de Educación para Individuos con Discapacidades (IDEA) requerida por el gobierno federal exige que las escuelas fomenten la abogacía y la participación de los padres durante la educación de sus hijo. Las perspectivas de los padres son menos investigadas y a menudo ignoradas en investigaciones relativas. Mi investigación incluirá las perspectivas de los padres, particularmente en los subgrupos de padres inmigrantes y de trasfondos socioeconómicos más bajos.

**Procedimientos y tiempo requerido:** Se le pedirá que participe en una entrevista de 1 hora en el lugar que usted elija. Con su consentimiento, las entrevistas serán grabadas en audio.

**Información financiera:** Su participación en este estudio no incluirá ningún costo. Es completamente voluntario. Se le pagará \$30 por su participación en este estudio. Esta cantidad se le entregará después de completar la entrevista. Si en el transcurso de la entrevista usted decide que ya no desea participar, aún así se le pagará los \$30 por su participación.

**Riesgos y Beneficios:** Su participación en este estudio no implica ningún riesgo para usted más allá del de la vida cotidiana. Es posible que participando en esta investigación no le beneficie personalmente, pero podemos aprender cosas nuevas que pueden ayudar a los demás.

**Confidencialidad**: Con su consentimiento, la entrevista será grabada. Si no desea que se grabe, tomaré notas escritas a mano y las transcribiré a un documento personal en mi computadora portátil. No incluiré su nombre, el nombre de su hijo/a ni ninguna otra información de identificación personal en la versión final de mi investigación. Analizaré su entrevista y probablemente use porciones de su entrevista como evidencia de apoyo al construir un argumento en mi investigación. Aunque puedo utilizar porciones de su entrevista en el ensavo final de la investigación, no incluiré ninguna información de identificación personal. Si en cualquier momento usted decide retirarse de este estudio, borraré de inmediato la información recopilada sobre usted y ya no se utilizará. Los detalles de la entrevista estarán guardados en mi computadora portátil; yo seré la única persona que tendrá acceso a la información identificable y no la compartiré con nadie más. La información recopilada como parte de esta investigación se puede utilizar o compartir para futuros estudios de investigación, aunque se eliminarían todos los identificadores. Inmediatamente después de la presentación y aceptación de mi trabajo de investigación final, borraré apropiadamente toda la información relacionada con su entrevista. Contactos y preguntas: Si tiene preguntas o inquietudes sobre el estudio, puede comunicarse con la investigadora Gloria Parra o al IRB utilizando la tarjeta de contacto proporcionada. Consentimiento: La participación es voluntaria. Negarse a participar o retirarse de la investigación no implicará ninguna sanción ni pérdida de beneficios a los que de otro modo podría tener derecho. Si en algún momento durante la entrevista o después de la entrevista decide retirarse, aún conservará la compensación de \$30.

**Consentimiento verbal con grabación de audio:** "¿Estás de acuerdo en participar y en que se le grabe?"

## Elementos opcionales: Consentimiento verbal con grabación de audio: "¿Puedo

comunicarme con usted después de la entrevista si tengo preguntas adicionales?"

Número de estudio: IRB23-1786

### Información de contacto del investigador (para preguntas sobre la investigación):

Gloria Parra, (805) 574-9382, parrag@uchicago.edu, gloriapar1719@gmail.com

Información de contacto del IRB (para preguntas sobre sus derechos como participante de

la investigación): University of Chicago Social & Behavioral Sciences Institutional Review

Board (IRB): teléfono +1 (773) 702-2915, correo electrónico sbs-irb@uchicago.edu.

# Appendix D

# Interpreter Interview Guide

# Introduction

- How long have you worked as an interpreter?
- Describe your responsibilities as a district interpreter during IEP meetings.
- Describe your positionality as a district interpreter during IEP meetings.

# **Observations about the School Workers**

- Describe the relationship/rapport that you have with the school staff of an IEP meeting?
- Have you observed how the school staff treats the IEP meeting? Describe it.
  - How do they treat the parents before, during, and after the meeting?
- Do you see the school and the parents as equal partners within an IEP meeting, or is there an obvious distinction between the two?

# **Observations about the Parents**

- Describe the relationship or rapport that you typically develop with the parents during an IEP meeting.
- How do you believe parents have previously understood your role as interpreter during IEP meetings?
  - Do parents try to make more contact with you rather than the teacher or other school staff?
- How would you describe a prepared parent during an IEP meeting?

# General

- Who sets the tone in a meeting?
- What would you define as a successful IEP meeting?
- Do you believe advocates are helpful?
- Would you say that being an interpreter also includes understanding and helping connect cultural differences? Why or why not?

#### <u>Appendix E</u>

#### Verbal Consent Form (English)

#### **Verbal Consent Form**

**Study Title:** Understanding The Relationship between Culturally and Linguistically Diverse Parents and their Child's School, and How Parents Navigate the IEP (Individualized Education Program) Meeting

#### Researcher: Gloria Parra

**Purpose**: The reason for this study is to offer more literature on parent perspectives when their child is in special education, since the federally mandated Individuals with Disabilities Education Act (IDEA) requires schools to encourage parent advocacy and engagement during their child's education. Parent perspectives are less studied and often overlooked in related research. My research will add parent perspectives, particularly from subgroups of parents who are immigrants, from lower socioeconomic backgrounds, and/or culturally and linguistically diverse. In addition to interviewing parents, I will supplement the general knowledge of Spanish-speaking parent participation within the IEP meeting by interviewing interpreters.

**Procedures and Time Required:** You will be asked to participate in a single, 1-hour long interview at a location of your choosing or over the phone. With your permission, the interviews will be audio recorded.

**Financial Information:** Participation in this study will involve no cost to you. It is completely voluntary. You will be paid \$30 for your participation in this study. This amount will be given to you after the completed interview. If partway through the interview you decide you no longer want to participate, you will still be paid the \$30 for your participation.

Risks and Benefits: Your participation in this study does not involve any risk to you beyond that

of everyday life. Taking part in this research may not benefit you personally, but we may learn new things that can help others.

**Confidentiality**: With your permission, the interview will be recorded. If you do not want to be recorded, I will write handwritten notes and transcribe the notes onto a personal document on my laptop. I will not use your name, your child's name, or any other identifying information in the final version of the research. I will analyze your interview and may use portions of your interview as supporting evidence when building an argument in my research. Though I may use excerpts from your interview in the final research paper, no identifying information will be included. If you decide to withdraw from this study at any point, I will promptly erase the information collected from you and it will no longer be used. The interview details will be secured on my laptop — I will be the only person who will have access to identifiable information and will not share it with anyone else. The information collected as part of this research may be used or shared for future research studies, though all identifiers will be removed. Promptly after the submission and acceptance of my final research paper will I properly erase all information regarding your interview. Post-interview follow-up of a brief email, text, or phone call will likely take precedence instead of scheduling another long interview session.

**Contacts & Questions:** If you have questions or concerns about the study, you can contact the researcher, Gloria Parra, or the IRB using the contact card provided.

**Consent**: Participation is voluntary. Refusal to participate or withdraw from the research will involve no penalty or loss of benefits to which you might otherwise be entitled. If at any time during the interview or after the interview you decide to withdraw, you will still keep the \$30 compensation. Verbal consent with audio recording: "Do you agree to participate?" "Do you

agree to be recorded?" Optional Elements: Verbal consent with audio recording: "Can I contact you following the interview with additional questions I may have?"

# Study Number: IRB23-1786

# Researcher Contact Information (for questions about the research): Gloria Parra

(805) 574-9382, parrag@uchicago.edu, gloriapar1719@gmail.com

# IRB Contact Information (for questions about your rights as a research participant):

University of Chicago Social & Behavioral Sciences Institutional Review Board (IRB):

phone +1(773) 702-2915, email sbs-irb@uchicago.edu.