SOCIO-CULTURAL AND SCHOOL BARRIERS THAT LATINO SPANISH-SPEAKING AND MIXTECO-SPEAKING FAMILIES WITH A PRESCHOOL CHILD WITH AUTISM SPECTRUM DISORDER FACE IN THE SPECIAL EDUCATION REFERRAL PROCESS IN SANTA BARBARA COUNTY, CALIFORNIA

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by
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SOCIO-CULTURAL AND SCHOOL BARRIERS FOR LATINO STUDENTS

The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled:

SOCIO-CULTURAL AND SCHOOL BARRIERS THAT LATINO SPANISH-SPEAKING AND MIXTECO-SPEAKING FAMILIES WITH A PRESCHOOL CHILD WITH AUTISM SPECTRUM DISORDER FACE IN THE SPECIAL EDUCATION REFERRAL PROCESS IN SANTA BARBARA COUNTY, CALIFORNIA

presented by Ivan DeJesus Alvarez

a candidate for the degree of Doctor of Education

and hereby certify that, in their opinion, it is worthy of acceptance

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Dr. Ray Avila
DEDICATION

I would like to dedicate my dissertation to my parents, Jesus and Ana-Bertha Alvarez for their encouragement and guidance throughout my education, from K-12, College of Sequoias, UCLA, Fresno Pacific University and the University of Missouri-Columbia! Thank you for being my first teachers and for instilling my love for learning. You always believed that I could achieve my dreams as a first-generation college graduate, including being the first in my family to earn a Bachelor’s degree, Master’s degree and Doctorate degree. I also would like to thank you for teaching me to be biliterate and bilingual in Spanish and English. It has enhanced my work with students and families due to my cultural proficiency and bilingual communication skills. Although you are fluent in both languages, I wanted to include my dedication in Spanish below:

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I would also like to dedicate my dissertation to my brother Osvaldo Alvarez. You are the best younger brother and I am very proud of your accomplishments! Keep realizing your dreams.
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According to multiple studies, a referral process bias exists in the early identification of autism for children of color, in particular Latino children. Sociocultural, economic, educational, and health care barriers have significantly impacted Latino children. For example, Latino children are less likely to receive access to early intervention services, are at increased risk for delays in the diagnosis of autism spectrum disorder, and are significantly older at the time of diagnosis. In addition, the delays in autism diagnosis for Latino children are poorly understood among medical and school personnel.

The purpose of the study was to gather qualitative and quantitative data regarding the experiences of Spanish-speaking and Mixteco-speaking Latino families in Santa Barbara County, California, who have a child with autism. The study examined the school referral process for special education services and diagnosis of autism for students and families. The study examined how sociocultural, economic, educational, and health care barriers affected Latino students in preschool during the special education referral process while also investigating Latino families’ experiences with their child who have received a clinical diagnosis of autism and/or eligibility of Autism for special education services. Ultimately, the intent of the study results is to propose possible changes for practitioners and school teams in the preschool special education referral process and for pediatricians in the diagnosis of autism from the parents’ perspective in Santa Barbara County. Recommendations are also provided for test publishers for improving the assessments for Latino students with the identification of autism as well as for SBCSELPA, schools and community agencies for improving the support for parents.
CHAPTER ONE: INTRODUCTION TO THE BACKGROUND OF THE STUDY
CHAPTER ONE: Introduction to the Background of the Study

Early identification of autism in children is associated with positive outcomes, including improved long-term prognosis, early intervention, and improved family acceptance of autism (Zuckerman et al., 2013). Early identification also reduces intellectual, behavioral, and functional impairments in students with disabilities (Fountain et al., 2008). Children who receive high-quality early intervention services have improved short- and long-term outcomes in relation to language and socio-emotional skills, cognitive functioning, adaptive functioning, peer relationships, educational performance, vocational training, and employment (Vismara & Rogers, 2010).

Diagnostic Process

The diagnostic process can be affected by barriers that parents experience when attempting to receive a referral for an assessment and, ultimately, obtain services (Jimenez et al., 2014). Families having a child with a disability can receive early intervention services, if eligible, from birth to age 2, in accordance with Part C of the federal law Individuals with Disabilities Education Act (IDEA), and special education services, if eligible, from age 3 to 21, under Part B of the IDEA (Individuals with Disabilities Education Act, 2021).

Children are typically diagnosed with autism by clinicians using autism screening and diagnostic instruments starting at age 2 (Nowell et al., 2015; Elder et al., 2017). Research suggests that sociological factors, including race, ethnicity, socioeconomic status, and parental education level, influence the diagnosis of autism for children (Nowell et al., 2015).
Fundamental Cause Theory

The age when a child is diagnosed with autism is consistent with the fundamental cause theory (FCT) because medical services are influenced by a family’s socioeconomic status and race/ethnicity (Magaña et al., 2013). The fundamental cause theory proposes that social-economic inequalities persist for individuals over time, impacting health care access and services (Clouston & Link, 2021). Community resources such as screening practices, availability of intervention and health services, school-based health centers, and the number of pediatricians can impact autism identification rates (King & Bearman, 2011).

Research indicates that obtaining an autism diagnosis can be extremely difficult for children. For example, multiple studies have demonstrated that Latino children have experienced the greatest delays in receiving a diagnosis of autism and early intervention services from birth to 3 years old. Latino children have also received fewer services when compared to non-Latino White children when they qualified for early intervention services (Magaña et al., 2013).

Impact of Diagnostic Delays for Latino Families

Diagnostic delays can significantly affect children’s access to diagnosis, early intervention, and special education services and can have significant ramifications. Studies have suggested that parents report delays in receiving diagnoses and referrals even when parents have been proactive and have expressed concerns to their pediatricians (Magaña et al., 2013). Latino families have encountered additional challenges that impact autism interventions and services, including delays in diagnosis, early intervention, and special education services (Magaña et al., 2013; Begeer et al., 2009).
Delays and Barriers in the Diagnostic and Referral Process

Children of color have faced more significant barriers during the diagnostic and referral process related to autism. Communication deficits and social skill concerns may be attributed to language acquisition or acculturation factors rather than autism by pediatricians and early intervention service providers (Begeer et al., 2009). Limited parental knowledge related to disabilities can delay the identification of children of color with autism (Blacher et al., 2014).

Statement of the Problem

According to Zuckerman et al. (2014), a referral process bias has existed in the early identification of autism for children of color, particularly Latino children. This referral bias can prevent children from receiving referrals in a timely manner for the assessment and diagnosis of autism and early intervention services (Blacher et al., 2019).

Sociocultural, Economic, Educational, and Health Care Barriers for Latino Children

Sociocultural, economic, educational, and health care barriers have significantly impacted Latino children. For example, Latino children were less likely to receive access to early intervention services, were at increased risk for delays in the diagnosis of autism, and were significantly older at the time of diagnosis (Magaña et al., 2013; Pederson et al., 2012; Ratto et al., 2016). Latino children have been underdiagnosed with autism compared to children of White or African American backgrounds (Begeer et al., 2009). In addition, the fact that there have been delays in the autism diagnosis of Latino children is
poorly understood among medical professionals and school personnel (Zuckerman et al., 2013).

**Delays for Latino Children with Receiving Autism Screenings or Early Intervention**

One of the factors contributing to the diagnostic delays for children of color is that they do not receive routine developmental or autism screenings from a pediatrician in their primary language, even when they have adequate access to health insurance and primary care (Janvier et al., 2016). Most children (90%) do not receive early intervention services, even when they demonstrate developmental concerns (Jimenez et al., 2014).

**Bias in the Assessment Process for Latino Children with Bilingual Backgrounds**

During the diagnostic process, Latino children with bilingual backgrounds (Spanish as the primary language) have been more susceptible than White students to being identified with an incorrect area of eligibility for special education services (Magaña & Venegas, 2017). For example, Latino students with Spanish as their primary language have been most often identified by school personnel as having an intellectual disability (ID) or a speech or language impairment rather than autism (Magaña & Venegas, 2017).

Research has suggested that diagnostic assessment tools may not reliably identify Latino children from Spanish-speaking households with symptoms of autism due to lower rates of sensitivity and specificity and fewer symptoms being reported by Latino parents (Blacher et al., 2014; Venegas et al., 2016). Children from immigrant and bilingual backgrounds may have experienced test bias during the assessment process or diagnostic bias from clinicians. Due to cultural test bias, children who speak a primary
language other than English were more likely to perform lower on cognitive assessments and were more likely to be misdiagnosed with an intellectual disability (Nowell et al., 2015).

**Diagnostic Delays for Latino Families**

Diagnostic delays may predominantly have occurred due to Latino families’ lack of access to early intervention or diagnostic services and limited health insurance (Hidalgo et al., 2015; Zuckerman et al., 2013). In addition, delays may have occurred due to parents’ limited knowledge and to cultural beliefs related to autism and developmental delays (Zuckerman et al., 2014).

As a result of these barriers, Latino children were significantly less likely to receive access to early intervention services and have experienced delays in being diagnosed with autism. They were also considerably older when they received such a diagnosis (Magaña et al., 2013; Ratto et al., 2016).

**Purpose of the Study**

The researcher will conduct a mixed-methods study to examine the special education referral process and barriers experienced by Spanish-speaking and Mixteco-speaking Latino students and families, specifically in receiving a diagnosis of autism and eligibility for special education services in preschool. Quantitative and qualitative data were collected via interviews and surveys with Spanish-speaking and Mixteco-speaking Latino families in Santa Barbara County, California. The parent interviews and surveys will assist the researcher with understanding the barriers that exist for Latino families and
children with autism during the referral and diagnostic process for receiving early start services, special education services, and a clinical diagnosis of autism.

The study aims to understand the experiences of parents and include specific supports that helped and propose parent recommendations for practitioners, clinicians, school teams, and other parents to the diagnostic or preschool referral process from the parental perspective for students with autism in Santa Barbara County. The study results will also be presented at a special education meeting or forum within the Santa Barbara County Special Education Local Area Plan (SBCSELPA). According to the literature review, this was the first study to examine the barriers and disparities experienced by parents during the diagnostic and referral process for students with autism in Santa Barbara County.

**Research Questions and Definitions**

**Research Questions**

The research questions guiding this study include the following:

1. How has the special education referral process addressed the needs of Spanish-speaking and Mixteco-speaking Latino preschool students with autism by the Santa Barbara County Education Office?

2. What, if any, barriers have delayed assessments, diagnosis, and eligibility for special education services for Latino students with autism from Spanish-speaking and Mixteco-speaking families in Santa Barbara County from 2014-2021?

3. How do community, medical, school, or parent networking resources contribute to positive outcomes or serve as barriers during the assessment, diagnosis, and eligibility
process for Spanish-speaking and Mixteco-speaking Latino families with a student with autism in Santa Barbara County?

**Definition of Terms**

**Individualized Family Service Plan (IFSP).** An initial Individualized Family Service Plan (IFSP) meeting is held to review the assessment results and determine eligibility for infants or toddlers referred for Early Start services (State of California Department of Developmental Services, 2021). An IFSP is developed for infants or toddlers who are eligible for services (State of California Department of Developmental Services, 2021).

**California Early Intervention Services Act.** The state legislature approved the California Early Intervention Services Act for infants and toddlers from birth to two years of age who are at risk of having disabilities or who have disabilities to “enhance their development and minimize the potential for developmental delays” (State of California Department of Developmental Services, 2021, para. 1). The act indicates that resources invested in early intervention services improve families’ ability to care for their child’s special needs and minimize the need for special education and related services during the child’s education (State of California Department of Developmental Services, 2021). The act also states that infants and toddlers referred should receive a multidisciplinary assessment to determine their eligibility for Early Start services (State of California Department of Developmental Services, 2021).

**Transition/referral from Early Start to preschool special education services.** Special education is defined by the education code (i.e., California laws related to
education) as specially designed instruction to meet the unique needs of the child who has been identified with a disability that significantly impacts their educational performance (SBCSELPA, 2020). The Individualized Education Program (IEP) is a legal document that includes the student’s present levels of educational performance (from assessments or observations), goals/objectives, how progress was measured, specific instruction/services, and participation in state and district tests. The IEP includes individualized goals and services for eligible students based on areas of need determined from assessment(s) or observation(s) (SBCSELPA, 2018).

The transition from Early Start to preschool special education services. As part of the transition process from Early Start to preschool-related services, students aged 30 months are referred from the local, regional center to the local education agency (LEA) for an assessment (SBCSELPA, 2020). California’s Education Code 34 CFR 300.304 states that students must be assessed in all suspected areas of disability by the LEA as part of their transition from Early Start to special education services (before their 3rd birthday) (SBCSELPA, 2021a).

Timeline for initial special education assessments. A referral for a special education assessment may be completed by the student’s parent/guardian, school personnel, agency, or physician. The school or LEA has 15 days from receiving the referral to offer an assessment plan or to complete a prior written notice declining the assessment. The assessment team has 60 calendar days from when the assessment plan is signed by the parent/guardian to hold an IEP meeting to determine eligibility for special education services and develop an IEP if the student is eligible (SBCSELPA, 2021a).
Requirements for psycho-educational assessments. To evaluate intellectual and socio-emotional functioning, psycho-educational assessments must be administered in the student’s primary language by a trained professional, such as a credentialed school psychologist (Education Code 20, 2015). According to Education Code, the student should be assessed in all areas of suspected disability, such as health and development, communication skills, cognitive skills, academic skills, adaptive skills, vision/hearing, motor abilities, and socio-emotional skills, as needed (SBCSELPA, 2021a).

Eligibility under the education code for autism. The education code defines autism as a developmental disability that affects a child’s verbal and nonverbal communication and social interactions. Children with autism may engage in repetitive activities and stereotyped movements, resist changes in daily routines, and have unusual responses to sensory experiences. For children to receive special education services, the impairments must adversely affect the child’s educational performance (U.S. Department of Education, 2019).

Free Appropriate Public Education (FAPE). The IDEA stipulates that all children with disabilities are entitled to receive a free public education, including an Individualized Education Program (IEP) in the least restrictive environment (LRE) (U.S. Department of Education, 2017b; U.S. Department of Education, 2019).

Conceptual and Theoretical Framework

Schultz’s (2010) Framework

The theoretical framework for this study will incorporate Schultz’s (2010) framework, which is based on the scholar-practitioner leadership model. This model seeks to fulfill the mission of change, specifically by restructuring schools committed to
practices that ensure equity and social justice. More specifically, centering on student equity and justice. This study was built upon the literature related to two concepts: (1) the experiences of access for Latino students for educational services, and (2) the referral process for special education services in California schools, including Santa Barbara County. The study will utilize the transformative paradigm as the focus is on the experiences of diverse groups, in particular, students with disabilities (Mertens, 2020).

**Disparities in the Referral Process**

Current research has focused on sociological factors that exist for Latinos in the United States. Still, research has not examined disparities that exist in the referral and assessment process for Latino students with autism from Spanish-speaking and Mixteco-speaking families in Santa Barbara County. More specifically longitudinal research has provided significant evidence of socioeconomic, racial, and ethnic disparities in obtaining medical care and diagnosing children with autism (CDC, 2012; Fontaine & Bearman, 2011; Liptak et al., 2008; Mandell et al., 2009).

**Sociocultural Barriers**

Latino families have experienced a range of socio-cultural barriers that have adversely impacted the early identification and treatment options of children with autism. These barriers have included reduced parental sources of knowledge about autism, language barriers, and cultural stigma regarding disabilities (Magaña et al., 2013; Durkin et al., 2010; Bearman & Fountain, 2011). Research has revealed that Latino parents have reported prior negative experiences with pediatricians during the referral consultation stage compared to parents from other ethnic backgrounds (Broder-Fingert et al., 2013;
Assessment and Referral Barriers

One factor that has delayed assessment referrals for Latino students was that there have been limited opportunities to receive a developmental screening from a primary care provider in Spanish students’ primary language. In addition, there has been a perception by primary care providers that these families have less parental knowledge of autism (Zuckerman et al., 2013). These factors have ultimately influenced whether students were referred and the age at which students were referred for clinical evaluation and school-based referrals.

School-Based Assessment Barriers

The barriers that families have faced in the diagnostic and assessment process for a medical diagnosis of autism and for receiving Early Start and special education services in schools have negatively contributed to proper identification and have promoted overall service disparities for Latino students with autism. This has been particularly true of students from a bilingual or low socioeconomic status (SES) background. In addition, bias in the assessment tools and the process has contributed to the misidentification of autism under the category of intellectual disability (Harris et al., 2019).

Summary

Research has revealed that due to assessment bias and diagnostic issues, children of color are underrepresented in the early detection of autism and its early intervention and in receiving appropriate special education services. In addition, Latino children with
bilingual backgrounds were more susceptible to being misidentified with other special education areas of eligibility instead of autism.

The current study will investigate the various assessment and services delays and disparities that exist in each service model for children and families, including health care, early intervention services, the child find system, regional center eligibility, the diagnostic process for identifying autism, and the transition from Early Start to special education services. The disparities that Latino children and their families have experienced with the diagnostic and referral process have occurred due to many factors, including limited pediatrician screening for autism, bias in the assessment of Latino children, and the referral process for diagnosis and services by medical providers.

Finally, the study will explore the process for making referrals in Santa Barbara County for special education services, including the prevalence of Latino students receiving special education services in California in general and Santa Barbara County in particular. Future research may be needed to determine if Spanish-speaking students with autism and their families have similar experiences to those described in the research related to assessment bias and diagnostic and referral disparities.

**Design of the Study**

**Setting**

The study intends to examine how the special education referral process addresses the needs of Spanish-speaking and Mixteco-speaking Latino preschool students with autism in Santa Barbara County. The study will also investigate what barriers or supports impact students’ eligibility for early start services, special education services, the clinical
diagnosis of autism, and the school-based eligibility for an IEP under the category of autism.

Participants

The target sample size of the study is 5-8 families and will depend on the interest of participants and families that meet the study criteria. Families that are eligible to participate in the study need to meet specific demographical information, such as the following: identify as Latino, use Spanish or Mixteco as one of their primary home languages, reside in Santa Barbara County, and have a child who is eligible for special education services under the category of autism. In addition, the child’s special education services should have started at the preschool level (between age 3 and 5).

Recruitment of study participants. The researcher obtained approval from the Institutional Review Board (IRB) approval and consent from the Santa Barbara County Special Education Local Plan Area (SBCSELPA), the Santa Barbara County Education Office (SBCEO), and participating local school districts prior to contacting participants.

Once approval is granted, the researcher/county psychologist contacted special education staff to see if any families meet the criteria for the study. The researcher utilized the special education data management system to determine which families meet the requirements for the study. The researcher contacted any families that meet the requirements and/or are recommended by staff to explain the research and provide additional information. The families were provided with the research flyer and were asked if they were interested in participating.
Families that Have Limited Literacy Skills

The researcher contacted families that have limited literacy skills in Spanish or Mixteco. A follow-up by the researcher was scheduled via an in-person meeting, phone call, or zoom meeting for any families that have limited literacy skills or have difficulty reading, writing, or understanding the flyer or the parent form (Appendix H and I). The flyer was read directly to the families in their primary home language. If the family has a primary home language of Mixteco and Spanish, the researcher asked them what language they prefer to use during the interviews. If the family indicates Mixteco, a translator was used to help explain the study.

Parent Form

The researcher provided a written or electronic parent form in Spanish to families to review before participating in the study. The parent form indicates that the survey is voluntary, that they may stop participating in the study at any time, that there is no financial incentive to participate and that their information will remain confidential.

Special Consideration for Families that Speak Mixteco as a Primary Home Language

The researcher checked with families that have a primary home language of Mixteco and Spanish to see which language they prefer. If they indicated Mixteco, they were provided with the opportunity to have a Mixteco translator present during the interviews. In addition, families were provided with the opportunity to complete the survey orally if they prefer with the Mixteco translator or in Spanish.
The researcher contacted the families ahead of the interviews to determine their preferred language and ensure that the correct translator is present based on their dialect of Mixteco Alto or Mixteco Bajo. If the family prefers for the information to be translated into Mixteco, the survey questions were provided in written format in Spanish to the Mixteco translator. Families that express a preference for Spanish without a Mixteco translator, completed the survey and participate in an interview with the researcher. If the family requests the need for a translator during the meeting (at any time), the interview was rescheduled with a Mixteco translator.

**Potential Risks Associated with the Study**

Families interested in participating in the study were provided with the parent form in Spanish (Appendix I) before starting the survey and interview. The parent form indicates that some potential risks of participating in the study may include some psychological distress related to recalling or describing negative or aversive experiences with the special education referral process or medical referral process for obtaining a diagnosis of autism. To reduce or eliminate the risk, the parent form indicates that families can opt-out of any question or opt out of the survey or interviews altogether if they feel uncomfortable without any repercussions or consequences.

**Confidentiality of Information Shared During Survey and Interview**

Parents were informed on the parent form and reminded during the interviews, that all information shared or expressed with the researcher in the survey and interview were maintained confidential, unless they voluntarily self-disclose the information to others. The interview sessions were video recorded and will only be viewed by the researcher for transcription and to analyze the interviews. Families were informed that to
ensure confidentiality, the information shared during the interviews were transcribed with the “Student #__’s Mother,” or “Student #__’s Father” The researcher will include excerpts of the parent interviews in the results section of the dissertation.

The researcher/county psychologist reached out to parents that he has worked with to informally ask if they would like to participate. Families that have previously worked with the researcher from 2014-current were contacted first via phone, text, or email. These families were contacted first since they are familiar with the diagnostic and special education process and may feel more comfortable talking to the researcher about their experiences. If they are interested, they were sent the consent form to review.

The researcher recruited parents from various years from 2014-current to ensure a more diverse sample. If this is not possible due to families declining to participate, families currently receiving special education services and meeting the research criteria were contacted next.

A research flyer and text were sent to families currently receiving special education services. Families interested in participating were informed that the study was voluntary and that their information would remain confidential. The researcher provided a written or electronic parent form for the family to review before participating in the study.

Data Collection Tools and Procedures

A mixed-methods approach was used for the study. The data for the study was collected via a survey and an interview with the researcher. Families were provided the option to complete the survey via phone, on Zoom or in-person with the researcher. The
purpose of the survey and interview is to determine whether the referrals and assessments were conducted promptly after an initial concern was expressed to the pediatrician/physician or Special Education Department at the county office. In addition, the survey questions helped the researcher understand if families experienced any delays or barriers during the referral process for obtaining a diagnosis of autism, early start services, or special education services.

**Collection of quantitative and qualitative data.** Qualitative and quantitative data were collected via survey and parent interviews by the researcher. The researcher did not utilize an interpreter for Spanish-speaking families since he is a native Spanish speaker, has a B.A. in Spanish, Community and Culture (emphasis on Literature from UCLA) and is also fluent in writing and reading Spanish at the university level. An interpreter was used for families with a primary home language of Mixteco Alto or Mixteco Bajo. The purpose of the interview questions was to examine the families’ experiences during the referral and diagnostic process for special education services based on their developmental concerns related to autism.

The survey questions and interview protocol for parents is included in Appendix E and Appendix F. Parents complete a paper survey with questions regarding the referral and assessment process. A follow-up in-person interview with the researcher was scheduled once the survey was received. Families could meet in-person at the office utilizing PPE and COVID protocols or schedule a virtual zoom meeting or phone call. Only one parent is required to participate per household, but both parents can join if they would like to.
A survey was selected instead of a survey on Qualtrics to ensure that all parents can participate regardless of their experience or knowledge with technology. Parents could complete the survey in person, on zoom or via phone in Spanish or Mixteco. The survey consists of multiple-choice questions and open-ended questions. If the parent prefers to complete the survey via zoom or phone, the researcher will write in their responses on the form. Parents were also provided the opportunity to complete the survey in the office with the researcher or dropped off at their residence if they prefer. These options were provided to ensure that families could complete the survey based on their preference and comfort level. The families were provided with opportunities to ask the researcher clarifying questions during the interview for anything unclear.

**Collection of quantitative data.** Quantitative data were collected for data analysis via the interview and survey with families, including student’s age, gender, ethnicity, home language, age of first concern (AOC), age of diagnosis (AOD), age of referral to Early Start services, age of referral to special education services, and age that special education services were initiated. The students’ initials were not disclosed when the findings were discussed in the study. A student number was used when the data is discussed in the study's findings to ensure the confidentiality of the participant and family.

**Data Analysis**

**Qualitative data analysis.** The interviews with families were recorded and transcribed for analysis by the researcher since he is biliterate. As a part of the thematic analysis of the qualitative portion, the researcher open coded and identified themes for
the study’s findings, such as the overall experience and parental involvement in the special education referral process for their child with autism; to identify delays, if any, that had occurred during the special education referral process, for receiving special education services and for obtaining a clinical diagnosis of Autism; and if applicable, possible recommendations that could lead to improved referral and assessment practices for Latino students in schools.

**Quantitative data analysis.** For the quantitative analysis portion of the study, data were collected and analyzed via univariate testing by ANOVA to determine if there is a correlation for delays among any of the following categories: the student’s age, gender, ethnicity, age of first concern (AOC), age of diagnosis (AOD), age of referral to Early Start services, age of referral to special education services, and age that special education services were initiated. The analysis aims to determine whether there is a significant delay between the AOC and AOD for Latino preschool students with autism from Spanish-speaking and Mixteco-speaking families in Santa Barbara County.

**Treatment fidelity.** A culturally sensitive framework was utilized during the parent interview to reduce potential bias to increase treatment fidelity. For example, the interview questions were administered in the families’ primary language of Spanish. The interviewer utilized open-ended questions. In addition, the interviewer probed unclear responses and asked only one question at a time (Mertens, 2020). The interviewer audio-recorded the interviews so that the families’ responses could be accurately transcribed into Spanish in their entirety. A portion of the interview selected as excerpts for the study was transcribed from Spanish to English.
Although none of the families requested a Mixteco-interpreter, the plan was to utilize a Mixteco translator and audio or video record the session. The goal was to transcribe the family responses into Spanish first (with the Mixteco interpreter) and then to English.

Families were encouraged to express their opinions about the referral process openly and candidly. This is critical to ensure treatment fidelity since it is possible that some of the families being interviewed previously worked with the interviewer/school psychologist during the assessment process. They were informed that the purpose of the interviews was to receive feedback about what worked well or needs to be improved in the process. If families are only expressing positive feedback, the interviewer reminded families also to express areas of improvement, if possible. Any observations reported from the families were summarized in the Results section of the dissertation, including potential bias observed.

**Internal validity and external validity.** The researcher developed an interview protocol that was utilized during the semi-structured interviews so that the survey questions were consistent with the participants (Newcomer et al., 2015). Terms are defined in the survey to ensure that all parents understand the terminology. Inclusion and exclusion criteria are clearly defined in the study to ensure that only eligible participants that matched the criteria are included in the study.
Significance of the Study

The study intends to address some of the gaps in the literature related to the disparities that Latino children and their families have encountered in the diagnostic and referral process associated with receiving a diagnosis for autism, Early Start services, and special education services. Previous studies have provided potential factors that may lead to the underdiagnosis of children with autism. However, the exact causes of this underdiagnosis have not been found (Ratto et al., 2016).

Before 2014, no studies examined autism diagnostic delays from the Latino family perspective (Zuckerman, 2014). Recent studies have indicated that further research is needed to make appropriate policy recommendations for the early diagnosis and intervention for students with autism (CDC, 2017). Furthermore, no studies have examined the disparities or the diagnostic/referral process for preschool students with autism from Spanish-speaking or Mixteco-speaking families in California, and specifically, not for Santa Barbara County.

This study may help improve referral and assessment practices based on parent interviews and a review of the literature about Latino students from Spanish-speaking or Mixteco-speaking households. In addition, the study may also help reduce the gaps in the literature about Latino children with autism and potentially reduce the barriers that contribute to diagnostic and service delays.
Summary

Multiple studies have revealed that the diagnostic process can be affected by barriers parents experience when attempting to receive a referral for an assessment. Ultimately, early intervention services and special education services (Jimenez et al., 2014). The diagnosis of autism has been influenced by race/ethnicity and parents’ education level and economic status (Nowell et al., 2015).

The age when a child diagnosed with autism was consistent with the fundamental cause theory, which states that social factors influence people’s access to health services (Magaña et al., 2013). Sociocultural, economic, educational, and health care barriers have had a significant impact on Latino children. For example, Latino children were less likely to receive early intervention services. In addition, Latino children were significantly older when diagnosed with autism (Magaña et al., 2013; Pederson et al., 2012; Ratto et al., 2016). Latino children were underdiagnosed with autism compared to White or African American children (Begeer et al, 2009).

This study examined how the special education referral process addressed the needs of Spanish-speaking and Mixteco-speaking Latino preschool students with autism in Santa Barbara County and what barriers have delayed assessments and the process for receiving early start and special education services. In addition, the study examined families’ experiences with receiving a clinical diagnosis of autism for their child, including any delays or barriers experienced during the referral or diagnostic process.

A mixed-methods approach was used for this study. Quantitative and qualitative data were obtained from families via a parent survey and interview via zoom or in-person. The researcher created the content and format for the study and interview since
an established survey or interview is not currently available due to limited research on the topic. The parent survey consisted of open-ended, yes/no, and multiple-choice questions. The parent interview questions and parent survey are included in Appendix E and F, including questions regarding the referral and assessment process.

For the quantitative analysis portion of the study, data was collected and analyzed via univariate testing by ANOVA to determine if there is a correlation with intervention delays based on the student’s demographic information. For the qualitative analysis portion of the study, the interviews with families were recorded and transcribed for analysis by the researcher since the primary language of participants is Spanish. The researcher coded and identified themes that emerged during the parent interviews and surveys, such as the overall experience and parental involvement in the special education referral process and for obtaining a clinical diagnosis of autism.

The researcher also examined how community, medical, school, or networking resources contributed to positive outcomes or served as barriers during the assessment, diagnosis, and eligibility process for Spanish-speaking and Mixteco-speaking Latino families. In addition, the researcher provided feedback and experiences expressed by parents that positively or negatively contributed to their child’s diagnosis or eligibility for an early start, special education, and school-based services. In addition, the researcher provided recommendations that can lead to an improved referral and assessment practices for preschool Latino students in schools from the parent perspective.
References


Santa Barbara County Special Education Local Plan Area (SBCSELPA) (2021b). SBCSELPA PowerPoint to Board. https://www.sbcselpa.org/sites/default/files/2021-10/11_1_21_JPA_Agenda_Packet.pdf


https://sites.ed.gov/idea/statute-chapter-33/subchapter-ii/1412


CHAPTER TWO: PRACTITIONER SETTING FOR THE STUDY
CHAPTER TWO: Practitioner Setting for the Study

The study will examine how the special education referral process and how the process for obtaining a diagnosis of autism address the needs of Spanish-speaking and Mixteco-speaking Latino preschool students with autism in Santa Barbara County, CA. The study will also examine what barriers delay assessments and ultimately diagnosis and eligibility for an early start or special education services. This section will examine the role and purpose that the Santa Barbara County Special Education Local Plan Area (SELPA), Santa Barbara County Education Office (SBCEO), and Tri-Counties Regional Center (TCRC) have in the identification and administration of specialized services for children with disabilities. In addition, the mission and vision of each organization (if applicable) were examined to determine how they align with best practices for organizational leadership.

Organizational Analysis

Santa Barbara County Special Education Local Plan Area (SELPA)

The Santa Barbara County SELPA (SBCSELPA) is a joint powers agency (JPA) that provides oversight, guidance, training, and support to local educational agencies (LEAs), parents, guardians, and the community. The SBCSELPA was formed as part of California’s Education Code Section 56195.1, requiring school districts to be a part of a local plan for special education services. According to SBCSELPA (2020), the state superintendent of public instruction reviewed the local plan to determine if it meets all state and federal requirements, including California Education Code and Regulations and the federal Public Law 105-17 (Individuals with Disabilities Education Act and associated regulations).
The SBCSELPA is comprised of a county education office, 20 public school districts, and four charter schools in Santa Barbara County, CA. As of October 1st, 2021, 8,630 students are currently receiving special education services in Santa Barbara County (SBCSELPA, 2021c). A chart is included below of the number of students receiving special education services from most of the LEAs in Santa Barbara County from SBCSELPA. The SBCSELPA provides LEAs, parents, and community members with a wide range of services, including grant writing for special education funding, providing community awareness on special education topics, participating in interagency collaboration, and attending state SELPA meetings (SBCSELPA, 2021c).

<table>
<thead>
<tr>
<th>District of Service</th>
<th>Special Ed Pupil Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adelante Charter</td>
<td>28</td>
</tr>
<tr>
<td>Blochman Union Elementary</td>
<td>22</td>
</tr>
<tr>
<td>Carpinteria Unified</td>
<td>358</td>
</tr>
<tr>
<td>Family Partnership Charter</td>
<td>42</td>
</tr>
<tr>
<td>Goleta Union Elementary</td>
<td>392</td>
</tr>
<tr>
<td>Guadalupe Union Elementary</td>
<td>141</td>
</tr>
<tr>
<td>Hope Elementary</td>
<td>105</td>
</tr>
<tr>
<td>Lompoc Unified</td>
<td>1,436</td>
</tr>
<tr>
<td>Los Olivos Elementary</td>
<td>23</td>
</tr>
<tr>
<td>Manzanita Public Charter</td>
<td>45</td>
</tr>
<tr>
<td>Orcutt Union Elementary</td>
<td>626</td>
</tr>
<tr>
<td>Santa Barbara Charter</td>
<td>20</td>
</tr>
<tr>
<td>SBCEO - Direct Service</td>
<td>92</td>
</tr>
<tr>
<td>Santa Barbara Unified</td>
<td>1,872</td>
</tr>
<tr>
<td>Santa Ynez Valley Special Ed Consortium</td>
<td>321</td>
</tr>
<tr>
<td>Santa Maria Joint Union High</td>
<td>1,009</td>
</tr>
<tr>
<td>Santa Maria-Bonita</td>
<td>1,798</td>
</tr>
<tr>
<td>SBCSELPA (20%)</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>8,330</strong></td>
</tr>
</tbody>
</table>

Each LEA differs in the district’s size and region that it covers in Santa Barbara County. Some school districts administer their special education services or partner with the Santa Barbara County Education Office to administer their preschool-related special education services, resource specialist programs (K-12), specialized services, and
moderate to severe special education programs. Other school districts have joined the Santa Ynez Valley Special Education Consortium, which administers special education services and programs in specific regions (SBCSELPA, 2021c).

Eligible students receive special education services in the least restrictive environment. The LEA also ensures that all special education students receive educational opportunities similar to their non-disabled peers (SBCSELPA, 2021a). For students who qualify for special education services, the specialized services provided on their IEP may include psychological services (counseling), specialized academic services (SAI), speech therapy, adapted physical education, school nursing, vision/hearing (DHH), vision services and occupational therapy.

**Role of the Santa Barbara County SELPA**

The Santa Barbara County SELPA Local Plan stipulates that the local educational agency is responsible for complying with the Child Find obligation for students suspected of having a disability (SBCSELPA, 2021b). For example, the LEA assesses students, determines the eligibility for special education services, and develops Individualized Education Programs (IEPs) for students eligible for these services.

SBCSELPA provides LEAs, parents, and community members with guidance on federal and state special education laws. SBCSELPA oversees LEAs to ensure that all students receive a free and appropriate public education, including special education assessments and services per the IDEA. In addition, SBCSELPA allocates state and federal funding for special education services to the LEAs (SBCSELPA, 2021b).
SBCSELPA provides teachers, specialists, and classified staff with professional development opportunities on a range of special education topics, including mental health, non-violent crisis intervention (CPI), distance learning, evidence-based practices for autism, dyslexia training, translator training for IEPs, student information systems training (SIRAS) and networking meetings for specialists. SBCSELPA also partners with local professional organizations such as the Central Coast Association of School Psychologists to present an annual symposium and legal training for school psychologists and school administrators (SBCSELPA, 2021c).

**SBCSELPA’s Mission Statement for LEAs**

According to the SBCSELPA, the objective for all LEAs is that students with disabilities receive equal opportunities to learn and that all students can learn. The ultimate goal is for all students with disabilities to become contributing members of their communities (SBCSELPA, n.d.).

**SBCSELPA Mental Health Services**

SBCSELPA administers mental health services for students, including wraparound counseling services. SBCSELPA also assists with nonpublic school placements when necessary for a student to attain educational progress and socio-emotional wellness. In addition, SBCSELPA collaborates with LEAs to administer GROW classrooms for students with significant socio-emotional needs. GROW classrooms help students meet academic goals and attain social-emotional wellness through self-regulation and coaching (SBCSELPA, 2021c). A visual chart is included below from SBCSELPA on the continuum of mental health services:
SBCSELPA’s Collaboration with Schools and the Community

The SBCSELPA has a community advisory committee (CAC) that involves parents, educators, and community agencies on special education topics (SBCSELPA, 2021c). The SBCSELPA also partners with the California Autism Professional Training and Information Network (CAPTAIN) to implement evidence-based practices in schools, homes, and communities for children with autism (SBCSELPA, 2021b). This partnership also involves districts, family resource centers, and regional centers and is a part of a statewide support system (SBCSELPA, n.d.).
Alternative Dispute Resolution and Independent Educational Evaluations

Parents and school districts may also request assistance from SBCSELPA, such as alternative dispute resolution (ADR). ADR cadre members can assist resolve disputes during IEPs when requested (SBCSELPA, 2020). In addition, parents can also receive assistance with SBCSELPA for receiving an Independent Educational Evaluation (IEE) or to file a complaint about the due process if ADR does not resolve the disputes (SBCSELPA, 2020).

Santa Barbara County Education Office

The Santa Barbara County Education Office (SBCEO) is one of California’s 58 county offices of education. The SBCEO provides services to 20 school districts and 69,006 students in Santa Barbara County (SBCEO, 2020a). The SBCEO serves as the local educational agency at the request of K-12 school districts with less than 900 students.

The 2020-2021 annual budget indicates that the SBCEO allocates 71% of resources to student support services (SBCEO, 2020c). These support services include special education services for students with mild to moderate and profound disabilities (SBCEO, 2020c). In addition, the SBCEO allocates 11% of its resources to district support, 7% to internal support, and 3% to educator support (SBCEO, 2020c).

The SBCEO administers special education programs for students from preschool to age 22. The programs include services for students with moderate to profound disabilities, community-based transition services, and students in court and community schools (SBCEO, 2021e). The SBCEO provides educational services to over 700 students in the county through its divisions and programs (SBCEO, 2020a).
The SBCEO provides infant services in partnership with the Tri-Counties Regional Center (TCRC) for students with Individualized Family Service Plans (IFSPs) (SBCEO, 2021d). School districts may also partner with the SBCEO to provide regional special education programs, such as deaf/hard of hearing and vision services or occupational therapy (SBCEO, 2021g). The districts that partner with the SBCEO to administer some or all of their special education programs include Lompoc Unified School District, Santa Maria-Bonita School District, Orcutt School District, Cuyama Joint Unified School District, Santa Ynez Valley Union High School District, Cold Spring School District, and Montecito Union School District (SBCEO, 2021a).

**SBCEO’s Mission Statement**

The researcher contacted the county superintendent’s office to obtain the mission, vision, and value statements for SBCEO. The superintendent’s office informed the researcher that the statements were currently under development. However, the office noted that the informal mission statement is “service and leadership” (A. Freedland, personal communication, October 4, 2021). The county logo contains the words “Service & Leadership” below the heading “Santa Barbara County Education Office,” as shown below:
SBCEO’s Programs and Services

The role of the Santa Barbara County Education Office (SBCEO) is to provide technical support to districts, facilitate countywide networks, and organize professional development and support services for educators. In addition, the SBCEO provides instructional support and direct services to special education students and students incarcerated in the juvenile hall (SBCEO, 2020a).

The SBCEO oversees over 200 programs for educators, districts, students, families, and community partners across Santa Barbara County. A few of the programs administered by the SBCEO are summarized below as part of the organization analysis, including the Children and Family Resource Services (CFRS), Partners of Education, and child development and educational programs. The management chart for the SBCEO is included below for reference (SBCEO, 2021e):
Figure 2

SBCEO Management Chart

Children and Family Resource Services (CFRS)

Among the programs that the SBCEO oversees is the Children and Family Resource Services (CFRS). CFRS assists students and families, including bilingual and Spanish parent education via the Santa Barbara County Promotores Network. The Welcome Every Baby/Family Connects (WEB/FC) provides newborn home visitation services to families. The Health Linkages program provides oral health and orthodontic services to students. In addition, the Center on the Social and Emotional Foundations for
Early Learning (CSEFEL) program provides evidence-based social-emotional training for educators, parents, and community members (SBCEO, 2021b).

**The Mission of Children and Family Resource Services (CFRS)**

The mission of Children and Family Resource Services (CFRS) is to build resilient communities that are family-focused using strength-based and high-quality support services. The Promotores utilize the family’s native language and knowledge of the family’s cultural practices to promote community resources and health information at health fairs, screenings, and peer education (SBCEO, 2021g). CSEFEL training is intended to provide families, educators, and the community with knowledge about effective instructional practices for children and social-emotional learning strategies for children at home and school via the pyramid model (SBCEO, 2021b). The pyramid model teaches early childhood professionals evidence-based practices for enhancing social-emotional development for all children through prevention and intervention strategies (CSEFEL, 2015).

**Mission of the Early Childhood and Family Wellness Coalition**

The Early Childhood and Family Wellness Coalition is a partnership between several community agencies, including the Santa Barbara County Education Office, Children and Family Resource Services (CFRS), First Five Santa Barbara County, and the Santa Barbara County Behavioral Wellness. The coalition includes several collaborative and leadership teams that partner to support children's mental health, promote early identification of children with special needs, and reduce disparities in access to early childhood education (Children and Family Resource Services, n.d.).
The coalition employs evidence-based practices, including increasing parent access to community services and parent education. In addition, the coalition seeks to improve the health of families and provide needed mental services for families via community partnerships. The coalition’s organizational chart and vision of the coalition are included below in Figure 3 (Children and Family Resource Services, n.d.):

*Figure 3*

*Early Childhood and Family Wellness Coalition's Organizational Chart*
Partners in Education

Partners in Education provides community, vocational, and educational resources for students and families, including volunteer opportunities and paid internships for students at local businesses and refurbished computers for students and families. In addition, Partners in Education facilitates careers days and mock job interviews for schools. Teachers can also participate in professional development opportunities through the program and have access to guest speakers to present on topics such as college, careers, and motivational speaking in their classrooms. Students may also receive support in academic areas of need through virtual tutoring (SBCEO, 2019).
Mission of Partners in Education

The mission of Partners in Education is for business partners and individuals to work collaboratively with nonprofit organizations in the community. The foundation’s goal is to improve public education and support the community, children, and families. As part of the mission, the foundation seeks to prepare students for their future based on their individual personal goals (SBCEO, 2021a).

Child Development and Early Education Programs

The SBCEO administers child care centers and preschool programs throughout Santa Barbara County for infants, toddlers, and children between birth and five years old (SBCEO, 2021a). Depending on their household income, families may be eligible to participate in the child development and early education program. The program intends to provide infants, toddlers, and preschool-aged children with opportunities to participate in educational programs. The program’s objective is to help develop the student’s pre-academic, adaptive, and social-emotional functioning skills in a supportive environment (SBCEO, 2021c).

Special Student Events

The Santa Barbara County Education Office hosts special events for elementary, middle, and high school students throughout the academic year. These events include a countywide Battle of the Books, Science Fair, Authors’ Breakfast, Authors-Go-Round, Spelling Bee, Poetry Slam, and Math Superbowl (SBCEO, 2021a).
Special Education Department

The SBCEO Special Education Department is comprised of clerical staff, support staff, and administrators. The support staff includes school psychologists, special education teachers, speech and language pathologists, school nurses, occupational therapists, adapted physical education specialists, infant providers, visually impaired specialists, an audiologist, deaf and hard of hearing specialists, paraprofessionals, clerical staff, translators, a financial services manager, and an Individualized Education Program (IEP) chair (SBCEO, 2021j). The special education staff is assigned across regions and school sites throughout Santa Barbara County.

Organizational Structure of the Special Education Department

Similar to Sundstrom (1999), the Santa Barbara County Education Office organizes its teams by roles and assigned responsibilities. The Special Education Department collaboratively organizes work-related tasks with upper management and members of each professional group, similar to the scientific management approach used by Taylor (1911).

The SBCEO has Job-a-Like meetings for all workgroups within the organization, such as special education staff. These Job-a-Like meetings are facilitated by a county administrator and are attended by a diverse group of special education professionals, including teachers, school psychologists, speech therapists, adapted physical education specialists, occupational therapists, and school nurses. The meetings are often divided into regional teams that work together in specific programs or classrooms throughout Santa Barbara County. The Job-a-Like meetings aim to provide organizational support
and to clarify and review tasks and job roles/expectations, as also discussed by Levi and Slem (1995). During these regional meetings, special education professionals also engage in collaborative practices (problem solve), discuss professional development opportunities, provide colleagues updates in special education, and review assessments for incoming students.

**Assessment Process for Special Education Services**

The Santa Barbara County Education Office (SBCEO) assigns a school psychologist to be the case manager for children transitioning from infant services to preschool services. The Tri-Counties Regional Center refers students to the SBCEO if they already have infant services and have a suspected disability. The assigned school psychologist is responsible for making the initial contact with the student’s family referred for an assessment. The school psychologist develops the assessment plan for all areas of suspected disability in accordance with parental concerns and the Early Start provider report. As the case manager, the school psychologist helps ensure that the family’s concerns and questions are addressed throughout the assessment process.

In addition, the school psychologist is responsible for helping develop and finalize the multidisciplinary assessment report in collaboration with all team members. The school psychologist ensures that the student information system has assessment information from all assessment members in the IEP, including details concerning eligibility, goals, and services if the student is eligible.
Preschool Referral Intervention Meeting (PRIM) Process

Parents can refer their child to the Preschool Referral Intervention Meeting (PRIM) team when they suspect that their child’s behavior indicates a disability. The PRIM team consists of a credentialed school psychologist and speech and language specialist. A PRIM meeting is scheduled with parents and the PRIM team to discuss concerns and determine the next steps in the assessment process. Parents are highly encouraged to bring their children to the PRIM meeting. The PRIM meeting form can be reviewed in Appendix L. The steps in the PRIM process and intake questions are included below (SBCEO, 2021k):
**Figure 5:**

*SBCEO PRIM Process Outline*

<table>
<thead>
<tr>
<th>PRIM PROCESS</th>
<th>Updated 9/28/21</th>
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**Initial Contact and Follow-up**
1. Santa Maria Office staff takes call from parent; completes Intake/PRIM form
2. Santa Maria Office staff checks SIRAS for possible current status with SBCEO
3. Santa Maria Office staff double-checks child’s age/ address and refers accordingly
4. Santa Maria Office staff arranges to obtain Birth Certificate (immunization records optional) from parent

**Scheduling PRIM appointments**
1. Santa Maria Office staff schedules next available appointment with parent once Birth Certificate is collected
2. Santa Maria Office staff inputs information into spreadsheet *(Need to be very detail-oriented when taking information)*
3. Lompoc Office staff inputs information from spreadsheet onto Teams Master List *(Prim Tab)*
4. Preschool Specialists arrange Spanish Interpreters as needed and inputs name in spreadsheet
5. Santa Maria Office staff completes Covid Screening and confirms appointment the day prior
6. Santa Maria Office staff scans all forms for each child to Lompoc Office Staff and PRIM team
7. Santa Maria Office staff hands sheets to team day of PRIM

**PRIM Meeting Follow-Up**
1. School Psych inputs outcome in spreadsheet immediately after PRIM session
2. School Psych uploads group outcomes into Google Drive *(filled by date)*
3. School Psych uploads speech only
4. Nicole updates Master List *(Prim Tab)* with outcome
5. Nicole assigns Team Assessment Case Managers; Cathy assigns other member of Team
6. Cathy assigns SLP Case Manager
7. Lompoc Office staff completes SBCEO Add Student Form, attaches Birth Certificate, and CCs Case Manager
8. Santa Maria Office staff files hard copies of PRIM documents for case manager to access
9. If PRIM results in “No Referral,” place documents in Sam’s box, no PWN needed
Determination of the Type of Assessment versus No Assessment

The PRIM team interviews the parent(s) at the meeting to determine the child’s developmental milestones, concerns in pre-academic areas, social skills, health history, communication skills, adaptive skills, behavior at home/school, and attending skills. In addition, the PRIM team informally interacts with the child and observes them during play. Children who meet the majority of all developmental milestones with no areas of suspected disability do not require a speech or further team assessment.

In comparison, children are referred for a speech assessment by the PRIM team when there are characteristics present of a potential speech and language disorder. Children are referred for a team assessment by the PRIM team when they suspect that there are additional needs, as indicated by potential symptoms of autism, difficulties with attending skills, health concerns that may be impacting school performance, and social-emotional concerns. There are no set guidelines for the specific characteristics or areas of
concern that a student must demonstrate in order to receive a team assessment. Therefore, the determination of the next steps is up to the clinical judgment by the PRIM team in consultation with the parent(s).

Parent input is carefully considered throughout the PRIM process. If there are no current concerns for the child-related to a specific disability, the PRIM team informs the parent(s) that the IEP team or parent(s) can contact the PRIM team if they become concerned at a later time. If parents are worried about additional areas, the PRIM team carefully considers this request, including making an informal observation of the child.

**Consultation with School Psychologist**

SBCEO speech therapists may request a consultation with a school psychologist when there are some additional concerns for students that are currently eligible for special education services under Speech and Language Impairment. For example, a consultation may be requested when the student demonstrates concerns in cognitive/academics, health, gross motor, fine motor, social/emotional, or behavior. The speech therapist completes the request for a school psychologist consultation form and submits data for areas of concern to the school psychologist. The consultation for school psychologist form is included in Appendix J. Once the form and data are submitted, the school psychologist observes the student during a speech session or during a meeting. An IEP is scheduled with the team, including the parent to discuss areas of concern and potential next steps. The school psychologist provides recommendations for the next steps based on the observation and staff and parent concerns. The recommendations can include no further assessment, additional interventions, or additional assessment to
determine other areas of suspected disability for special education services. A flowchart of the process that speech therapists follow for obtaining a consultation with a psychologist is included in Appendix K.

**Referrals from Physicians**

There is no specific form or referral process for physicians for special education services. Physicians typically encourage parents to contact the special education department for a referral. Occasionally, a physician will fax a request for an assessment. When this occurs, parents are contacted by the office and encouraged to undergo the PRIM process to request an assessment. The PRIM team determines the next steps for the referral based on the suspected areas of disability. If the student is an infant (below age 3), the parents are contacted and encouraged to follow up the Tri-Counties Regional Center (TCRC) to initiate a referral for an Early Start assessment. If the student is in elementary school, the parents are contacted and referred to the local school district to initiate a special education referral for assessment.

**Tri-Counties Regional Center (TCRC)**

The Tri-Counties Regional Center (TCRC) provides early intervention services (Part C) to infants and toddlers from birth to 36 months who have developmental delays. The TCRC assesses infants and toddlers referred to the Early Start program in Santa Barbara County. The Early Start program provides eligible infants and toddlers with services such as specialized instruction, physical therapy, occupational therapy, speech and language therapy, behavior therapy, consultation services, and family resource center services (TCRC, 2015).
The TCRC develops and implements an Individualized Family Service Plan (IFSP) for infants and toddlers who are eligible for Early Start services based on their developmental needs from their assessment. The IFSP for eligible infants and toddlers may include goals in areas of need, such as social skills, adaptive skills, fine motor skills, gross motor skills, communication skills, and cognitive skills (TCRC, 2015).

**Interagency Agreement Between the Tri-Counties Regional Center and SBCSELPA**

An interagency agreement exists for the early start to the special education transition process between the Tri-Counties Regional Center and the Santa Barbara County Special Education Local Plan Area (SBCSELPA). This transition process occurs as part of Part C to Part B for children eligible for early start services (TCRC and SBCSELPA, 2017). The agreement outlines the steps taken by the referring agency (TCRC) and the LEA (SBCEO or local district) when a student turns three years of age.

The assessment team determines eligibility for special education services for students based on assessment results from the county or district assessment team. The county or district is responsible for assessing all children referred by the TCRC and developing an Individualized Educational Plan (IEP) for all eligible children as part of their transition to preschool services at age 3. A flowchart of the transition process from early start to preschool services (TCRC to SBCEO) is included below:
Figure 6

SBCEO’s Infant to Preschool Transition Referral Process
Organizational Analysis of the SBCEO’s Servant Leadership Practices

The Santa Barbara County Education Office (SBCEO) demonstrates qualities consistent with servant leadership. For example, the SBCEO demonstrates a solid commitment to building community and personal growth. The mission of the SBCEO’s departments is consistent with the tenets of servant leadership behavior described by Wong and Davey (2007) and Laub (1999). The SBCEO’s programs primarily emphasize the servant leadership quality of serving others, including students, parents, school districts, and the community. This is consistent with the SBCEO’s informal mission of service and leadership.

The philosophy of the SBCEO is to help families grow and succeed by providing parent education and opportunities to become involved in school. This philosophy aligns closely with the servant leadership theory because the primary objective is to help families with their areas of need and with education on various topics. The leaders and employees of the SBCEO work to accomplish the mission by building community, valuing people, displaying authenticity, and engaging in shared leadership, which aligns with the servant leadership qualities described by Laub (1999). The programs that work with families incorporate trust, humility, and empowerment, as Dennis and Bocarnea (2005) described. The programs at the SBCEO provide consultation and involve the stakeholder to promote evidence-based practices with families and parents.

Programs such as Special Education Services and Promotores allow parents to engage directly in the process with county staff. The work of special educators and Promotores requires staff to use several servant leadership qualities, as indicated by Spears (2002), to be effective in working with parents. The qualities that staff need
include strong listening and empathy skills. In addition, the work with parents requires staff to be committed to the growth of others and to fostering a collaborative relationship to help families.

Furthermore, the program objectives require special educators, child development staff, and the Promotores to engage in many of the tasks related to servant leadership’s concepts of follower performance and growth. For example, children and parents are the primary focus during the interactions with staff. The Promotores’ staff listens to parents, provides honest feedback, and embraces parents’ growth, all of which are qualities consistent with servant leadership (Northhouse, 2019). The staff speaks the children’s native language, is respectful, and values the diversity of families (SBCEO, 2021b).

**Analysis of the SBCSELPA’s, Tri-Counties’, and SBCEO’s Mission Statements**

The mission statements of all three organizations (i.e., SBCSELPA, Tri-Counties, and SBCEO) are very similar since they serve the same students and families. For instance, the SBCSELPA, SBCEO, and the Tri-Counties Regional Center provide consultation services and support for families with children with disabilities. There is an emphasis on helping all students learn, work, and succeed in the community. For instance, SBCSELPA’s mission is that all students can learn (SBCSELPA, 2021c). The SBCEO has indicated that it believes in the voice of the family, the student’s viewpoint, and the community’s desire to support students and enhance the student experience and improve learning outcomes (SBCEO, 2021i). Tri-Counties Regional Center has stated that it provides person- and family-centered support for individuals with developmental disabilities to maximize their opportunities for living, working, learning, and participating in recreation in the community.
Although the missions are similar, each organization’s objectives for working with families are different because each organization provides unique services and support. For instance, the SBCEO offers direct services to students: infant services, special education services, and preschool services for general education students (SBCEO, 2021b). Tri-Counties Regional Center coordinates Early Start, children’s, and adult services for individuals with disabilities (TCRC, 2021). When there are concerns related to special education services, the SBCSELPA provides parent/guardian resources workshops, and collaborates with parents (SBCSELPA, personal communication, October 10, 2021).

Although it is not stated in the mission statements, the three organizations strive to leave a positive impact on society, consistent with servant leadership. The organizational goals of helping families and students succeed can ultimately be transformative and collectively lead to positive outcomes. There is also an emphasis on incorporating the community through partnerships with the three organizations. This is consistent with servant leadership’s focus on creating value and giving back to the community (Northouse, 2019).
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CHAPTER THREE: SCHOLARLY REVIEW FOR THE STUDY
CHAPTER THREE: Scholarly Review for the Study

Diagnosis of autism

Children can be diagnosed with autism starting at age two by primary care physicians, pediatricians, and clinical psychologists (Enneking et al., 2019). In comparison, children from birth to 2 years and 11 months can be assessed for eligibility of Early Start services by any local, regional center in California. The school district or county education office (LEA) assessment team can assess children starting at age 3 to determine eligibility for special education services at the preschool level (age 3-5). A speech and language assessment at the preschool level is completed by a speech and language therapist. Other specialists can be added in addition to speech and language assessments if there are concerns in other areas.

A team assessment at the preschool level typically comprises a special education teacher, school psychologist, speech and language therapist, and school nurse. Other areas can be assessed when concerns are present such as gross motor concerns or fine motor skills, by an adapted physical education specialist or an occupational therapist. Some school districts or county education offices also utilize a physical therapist, Board Certified Behavioral Analyst (BCBA), or an Augmentative and Alternative Communication (AAC) specialist as part of the assessment or as a service provider to address areas of need on the student’s IEP.

The process of completing a referral and assessment varies by agency, the child’s age, and the service delivery model. Diagnostic assessments from the multidisciplinary team, psychologist, or physician may include a medical evaluation, standardized
assessments, rating scales or questionnaires, comprehensive developmental history, structured interviews, and behavioral or classroom observation(s) (Enneking et al., 2019).

**Pediatrician Guidelines for Diagnosing autism**

Developmental screening is a critical component for pediatricians to address parental concerns and diagnose autism and developmental delays. It is recommended that all children receive a developmental screening for autism from a pediatrician between 18 and 24 months (Lipkin & Macias, 2020). The screening tools ask parents about their child’s developmental milestones, social skills, communication skills, and restricted and stereotyped behavior (Hyman et al., 2020). Children may demonstrate restricted and repetitive behaviors such as sensitivity to sensory input, highly restricted interests or routines, difficulty with transitions, echolalia, and repetitive motor movements or activities (lining up toys) (CDC, 2021). The screening tools can help parents report high-risk symptoms related to autism. The goal of universally screening children for autism is to help identify children at risk for autism as part of the referral or assessment process.

Research studies have indicated that developmental surveillance should not be the only source for referrals because office visits are brief, and children may not demonstrate the symptoms of autism during their visit (Hyman et al., 2020). It is recommended that clinicians engage in shared decision-making with parents when considering further screening or evaluation (Sheldrick et al., 2019).

**Comprehensive Child Find System (Sec. 303.302)**

Child Find indicates that children suspected of having a disability, as young as birth, must be referred to an early intervention services agency for an assessment by the primary referral source (U.S. Department of Education, 2017a). The primary referral
sources can include parents, public agencies, schools, and LEAs (U.S. Department of Education, 2017a). Despite the Child Find requirement and the importance of early intervention, there continues to be delays in referring children for assessment even when parental concerns are expressed regarding autism (Magaña et al., 2013).

**Regional Center Eligibility**

Eligibility for regional center services and supports for children and adults with developmental disabilities is determined by California’s Lanterman Developmental Disabilities Act (or Lanterman Act.) California law defines a substantial disability as three types of impairment in the following skill areas: communication, learning, adaptive, mobility, independent living, and self-sufficiency (Disability Rights California, 2012). A substantial disability is expected to last indefinitely and starts before age 18.

**Benefits of Early Intervention**

Research has indicated that it is critical to identify and diagnose children as infants to provide needed support and services, including Early Start and special education services. (Emerson et al., 2016; CDC, 2020). Early intervention services can help children with autism attain positive outcomes, such as improved communication and social skills (Milbourn et al., 2017). Early intervention services can also help improve children’s intellectual functioning and lessen behavioral and functional impairments (Fountain et al., 2011). Parents with early intervention services and collaboration with Early Start providers have reported that their children exhibited improved functioning and skills at home (Milbourn et al., 2017).
Service Delivery Model for Helping Families

The service delivery model for helping families requires active state and local services that are flexible, culturally competent, and responsive to the family’s needs. The Lanterman Act specifies that professionals collaborate with parents to meet the diverse needs of culturally and linguistically diverse children (State of California Department of Developmental Services, 2021).

Prevalence of Early Intervention Delays

While children can be diagnosed with autism as early as age 2, parental concerns related to development are typically reported between 18 and 24 months (Zwaigenbaum et al., 2015). Non-Latino White children with autism are more likely to receive a comprehensive evaluation and diagnosis before age three compared to other children (Christensen et al., 2016). Children from underrepresented backgrounds have lower rates of diagnosis when compared to non-Latino White children. More specifically, Latino children are at a higher risk of being underdiagnosed with autism and experiencing referral delays from a medical professional for early intervention services (Ratto et al., 2016; Milbourn et al., 2017).

Assessment Bias for Children from Immigrant Families and Minority Backgrounds

Children from immigrant families and minority backgrounds face more significant barriers to receiving a diagnosis of autism. Communication deficits and social skill concerns may be attributed to language acquisition or acculturation factors rather than autism by pediatricians and early intervention service providers (Begeer et al., 2009). Research has found that limited parental knowledge related to disabilities can delay the identification of children (Blacher et al., 2014, 2019).
Children from immigrant and bilingual backgrounds may experience test bias during the assessment process or diagnostic bias from clinicians. Due to cultural test bias, children who speak a primary language other than English are more likely to perform lower on cognitive assessments and are more likely to be misdiagnosed with an intellectual disability (ID) (Nowell et al., 2015).

Research studies suggest that some autism assessment diagnostic tools (i.e., Autism Diagnostic Interview-Revised or ADI™-R) may not reliably identify Latino children with symptoms of autism, especially from Spanish-speaking households (Blacher et al., 2014; Vanegas et al., 2016). Additional sources of information may be required to obtain accurate language and communication domains because some items or concepts on the ADI™-R may be difficult to convey or interpret for parents in languages such as Spanish.

In addition, studies suggest that Latino parents may report fewer impairments in communication and report higher impairments in social skills (Blacher et al. 2014; Blanche et al., 2015). Previous studies also suggest that the ADI™-R communication domain may not be as reliable with Latinos due to lower sensitivity and specificity rates. Latino parents may also underreport some symptoms due to limited knowledge of the risk factors of autism (Overton et al., 2007; Magaña, et al., 2013; Venegas et al., 2016).

Diagnostic delays primarily occur for Latino families due to economic factors and health care access disparities (Hidalgo et al., 2015; Zuckerman et al., 2013). In addition, delays may occur due to the clinician’s limited cultural competence and parents’ limited knowledge and cultural beliefs related to autism and developmental delays (Zuckerman et al., 2014). Parents frequently report that they have limited or no understanding of autism
because children in Mexico or their communities are not typically diagnosed with disabilities. Parents also report mental health and disabilities stigmas by the community, including the child’s symptoms and diagnosis of autism and receiving early intervention services (Zuckerman et al., 2014).

Gaps in Research

Scholars have critiqued the research from peer-reviewed studies for having insufficient sample sizes of ethnic minority children (Parish et al., 2012). This gap in the research has made it difficult to accurately estimate how many ethnic minority children have health care access and how many utilize services such as early intervention (Parish et al., 2012). In addition, limited research has discussed the specific autism-related services that Latino children receive after they are diagnosed with autism (Magaña et al., 2013).

Mixed-methods research conducted by Jimenez et al. (2014) found that a significant portion of all children (more than 1/3) who have suspected developmental delays were not referred to early intervention services for an assessment. In addition, one research study found that only a portion of children referred by pediatricians (50%) were evaluated for early intervention services (Jimenez et al., 2014). The study also revealed a negative correlation between referrals to Early Start for parents who only had developmental concerns in one domain (Jimenez et al., 2014).

Factors Associated with Early Intervention Referral Delays

Studies have shown that most potentially eligible children (90%) did not receive early intervention services (Jimenez et al., 2014). Access to health care has been a significant barrier for Latino families. Studies have indicated that compared to other
ethnicities and races, Latino families were most at risk for having insufficient medical care, including limited access, utilization, and quality of care (Yu et al., 2006). Children from underrepresented racial and ethnic backgrounds have experienced developmental screening that was either inadequate or performed at lower rates.

One pediatrician’s screening study revealed that only 29% of pediatricians offered autism screening in Spanish, while only 10% of pediatricians offered both general developmental screenings and autism screenings in Spanish (Zuckerman et al., 2013). This rate was significantly below the average of 81% of primary care pediatricians who provided some form of developmental screening in English (Zuckerman et al., 2013). Most pediatricians reported that they had difficulty recognizing symptoms of autism in Latino children, even when they performed the autism screening in Spanish (Zuckerman et al., 2013).

**Prevalence of Autism Diagnosis Delays for Latino Children**

The age that which a child receives a diagnosis of autism can be influenced by the child’s race and socioeconomic status. This is consistent with the fundamental cause theory which asserts that social factors impact people’s access to health services and outcomes with those from a nondominant socioeconomic status, race, and ethnicity experiencing adverse outcomes (Magaña et al., 2013). For example, Latino children were less likely to receive early intervention services from birth to 3 years old. They were provided fewer services when they qualified than non-Latino White children (Magaña et al., 2013).
Multiple studies have demonstrated that Latino children have experienced the most significant delays for receiving a diagnosis of autism compared to White children. Overall, Latino children were diagnosed with autism at age 8, on average, while White children were diagnosed at age 4, on average (Overton et al., 2007; Christensen et al., 2016).

**Misdiagnosis and Other Developmental Disorders for Latino Children**

Research has also found that Latino children were more likely to be misdiagnosed with other psychological or behavioral disorders than autism (Overton et al., 2007). Children in poverty and Latino children have more difficulty obtaining care from a specialist to diagnose a developmental delay, which has resulted in lower overall diagnosis rates of autism (Liptak et al., 2008).

Research has confirmed that children from immigrant backgrounds were at higher risk of having neurodevelopment disorders, including autism (Becerra et al., 2014; Schmengler et al., 2021). Research has been limited and inconsistent regarding the risk level for children of immigrants related to other disabilities (Schmengler et al., 2021).

Despite Latino parents having expressed developmental concerns at similar ages as non-Latino White parents, medical providers did not consistently and proactively addressed the concerns of Latino parents related to autism (Magaña et al., 2013). Studies on medical screenings have indicated that pediatricians have difficulty assessing a child’s risk for autism when the family’s primary home language is Spanish (Zuckerman et al., 2013). In addition, pediatricians have expressed the perception that Latino parents have less knowledge about autism than non-Latino White parents (Zuckerman et al., 2013).
Systemic Barriers Experienced by Culturally and Linguistically Diverse Families

Research by Burke and Goldman (2018) indicates that disability agencies and other formal service delivery systems often fail to connect or educate culturally and linguistically families regarding available supports and resources for assisting their children. In addition, research from Cobb (2014) indicates that formal service delivery systems like schools, early intervention services providers, clinics, and hospitals often serve as barriers to connecting culturally and linguistically diverse with advocates. Limited research exists examining individuals advocating for other families with special education services (Burke & Goldman, 2018).

Schools may employ deficit thinking when working with culturally and linguistically families (Burke & Goldman, 2018). Advocates that work with culturally and linguistically diverse families indicate that they often feel disempowered when working with their child’s school. For example, families from immigrant backgrounds report that the school does not listen to their concerns and does not offer resources or information regarding their child’s disability (Burke & Goldman, 2018). Culturally and linguistically families report that their child’s school often assumes that they are ignorant or do not care about their children (Burke & Goldman, 2018).

Culturally and linguistically diverse families report experiencing systemic language barriers during meetings with schools. For example, some families do not have access to translation at IEP meetings (Lo, 2008). In addition, schools may utilize untrained translators, making it difficult for parents to understand. Parents also report that
even when translators are present, they often do not understand the discourse in IEP meetings (Burke & Goldman, 2018).

Culturally and linguistically diverse families from immigrant backgrounds may also feel disempowered due to their undocumented or immigrant status. This may make it more difficult for them to speak up during an IEP meeting or ask questions since they perceive limited rights or protections (Burke & Goldman, 2018).

Research indicates that culturally and linguistically diverse families benefit from working with others with shared cultural experiences, disability experiences, and shared understanding of family values (Burke & Goldman, 2018). In addition, culturally and linguistically diverse families benefit from services that make services more equitable such as facilitated IEP meetings and parent training on disabilities and services in their home language from schools (Burke & Goldman, 2018).

**Research Gap with Mixteco-Speaking Families**

A significant research gap is present with Mixteco-speaking families in the literature. There are currently no journal articles or books focused on the special education process, diagnostic process, or disparities experienced with families with a primary home language of Mixteco. The research primarily focuses on the language in the home for Mixteco-speaking families. Research by Ijalba, Velasco, and Crowley (2019) on language culture and education indicates that families that have to use a dialect such as Mixteco typically use Spanish in the home since it provides capital and greater opportunities for children.
Impact of autism on Parents

Parents of children with autism are likely to face elevated stress levels, including concerns about their child’s behavior and impaired communication and social skills (Harper et al., 2013). Latino families may face the stigma of autism and encounter family conflict due to cultural beliefs and limited knowledge related to disabilities (Dubay et al., 2018).

Some Latino parents express the value of involving other family members during their child’s therapy session because it helps to improve the interactions between the child and family. In contrast, other parents indicate that they prefer to keep their child’s diagnosis private and not involve the rest of their family due to the stigma associated with autism (Dubay et al., 2018; Blanche et al., 2015).

Some Latino parents have reported negative experiences with family in that relatives give advice that contradicts the recommendations of professionals, inaccurate information, or denies that any other disability impacts the child who has autism (Dubay et al., 2018). In addition, some Latino parents have depended upon coping mechanisms, including reliance on faith to overcome their children’s challenges. In contrast, others have embraced a wait-and-see approach before seeking services (Blanche et al., 2015).

Special Education Services for Children with autism

Children with autism most often qualify for special education services under autism eligibility. In contrast, 36% of children with autism meet eligibility for special education services under another area of eligibility, such as a Speech and Language Impairment. As a result, this can make it difficult for researchers and professionals to accurately measure autism prevalence rates and trends (Rubenstein et al., 2018).
There is a range in the demographics of students and special education services received throughout California (KidsData, 2021). For example, Latino students are the largest minority in California and constitute 55.3% of the overall population in California (CDE, 2020). The population of Latino students ranges from 15.2% to 88.4%, depending on the county in California (KidsData, 2021). The California public schools comprise 57.2% Latino and 23.1% White students (KidsData, 2021). In Santa Barbara County, the school demographics are as follows: 60.8% Latino, 5.4% African American, and 29.2% White (KidsData, 2021). The data for Santa Barbara County is consistent with California’s demographics because Latino children comprise the majority of the population (KidsData, 2021).

Special education data indicates that 18.8% of children in the United States received special education services from 2016-to 2019 (KidsData, 2021). The number of students who received special education services in California is lower than the national average, at approximately 12.8% of students (KidsData, 2021). Students receiving special education services in California are primarily Latino (47.9%), White (29.2%), and African American (5.4%) (KidsData, 2021).

During the 2019-20 school year, 14% of public school students were eligible for special education services. Nationally, 14% of Latino children and 15% of White children were eligible for special education (Irwin et al., 2021), with 11% of all students qualifying for special education under autism (KidsData, 2021). In Santa Barbara County, 12.0% of students received special education, of which the majority were Latino (60.6%), followed by White (31.5%) and African American (1.2%) (KidsData, 2021). The data for Santa Barbara County is consistent with the demographics of California in terms of the
total number of students eligible. Overall, the number of Latino children in Santa Barbara County receiving special education services is consistent with the school demographics of enrolled students.

There is a higher percentage of Latino students receiving special education in Santa Barbara County when compared to the national average (KidsData, 2021). However, this data should be viewed with caution because the students receiving special education services are consistent with the school demographics of enrolled students. The information does not represent an overidentification of Latino students in special education.

Finally, the prevalence of special education disabilities in California is 128.4 per 1,000 children, and 19.4% of eligible students qualify for special education services under autism (California Department of Education, 2021; KidsData, 2021; National Center for Educational Statistics, 2021). In Santa Barbara County, the prevalence of special education disabilities is 119.7 per 1,000 children, and 14.7% of eligible students qualify for special education services under autism (Irwin et al., 2021). The prevalence of students receiving special education services in Santa Barbara County is slightly lower (8.4%) than the California average (KidsData, 2021).
References


https://www.cde.ca.gov/nr/ne/yr21/yr21rel32.asp


https://www.jstor.org/stable/26374240


CHAPTER FOUR: CONTRIBUTION TO PRACTICE
CHAPTER FOUR: Contribution to Practice

The study examined the school referral process for special education services received in preschool for students and families from 2014 to the present. The study examined how sociocultural, economic, educational, and health care barriers affected Latino students in preschool during the special education referral process while also investigating Latino families’ experiences with their child who had received a clinical diagnosis of autism.

Part of this study’s intent was to propose possible changes and improvements for practitioners and school teams in the preschool referral process from the parents’ perspective for special education students in Santa Barbara County. This was the first study according to SBCSELPA and SBCEO to examine the barriers and disparities experienced by Latino special education students during the diagnostic and referral process in Santa Barbara county.

Professional Development Presentation to Special Education Administrators

A presentation will be developed to disseminate the study findings at a Santa Barbara Special Education Local Plan Area (SELPA) Special Education Administrators’ Meeting (SEAM). The presentation will serve as a professional development session for special education administrators.

Aim and Scope of the Professional Development

The purpose of the professional development presentation is to summarize the major themes highlighted from the parent interviews. The county and SELPA needs to consider the parental perspective on the special education referral process for Spanish-
speaking and Mixteco-speaking Latino students with autism in Santa Barbara County. In addition, the goal is to help administrators and school psychologists in the county understand what areas helped parents and what areas need some improvement. The ultimate goal is to continue supporting parents in all areas and problem solve and propose changes to help address any areas of concern.

Although not directly the intent of the study, a secondary goal is to keep increasing referral rates for Spanish-speaking and Mixteco-speaking Latino children transitioning from infant to preschool-related services (Part C to Part B), and ultimately, to help reduce or mitigate the disparities in the experiences of families in the referral process. In addition, recommendations from parents will be incorporated into the professional development.

**White Paper**

A white paper will summarize the research findings and discuss possible actions that school districts can take to reduce the disparities in referrals from Spanish-speaking and Mixteco-speaking Latino students.

*Keywords*: referral delays by pediatricians for autism; referral delays for early start services; autism diagnosis for Spanish-speaking and Mixteco-speaking families; barriers experienced by Latino families in special education eligibility; barriers experienced by Latino families in receiving special education services.
Figure 7:

*White Paper for Professional Development*

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**Socio-Cultural and School Barriers for Latino Students**

**Figure 7:**

*White Paper for Professional Development*

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**Socio-Cultural and School Barriers That Latino Spanish-Speaking and Mixteco-Speaking Families with a Preschool Child with Autism Spectrum Disorder Face in the Special Education Referral Process in Santa Barbara County, California**

by: Ivan D. Alvarez, Doctoral Candidate, University of Missouri at Columbia

April 2022
Abstract

According to multiple studies, a referral process bias has existed in the early identification of autism for children of color, in particular Latino children. Sociocultural, economic, educational, and health care barriers significantly have impacted Latino children.

The purpose of the study was to gather interview, survey, and quantitative data regarding the experiences of Spanish-speaking and Mixteco-speaking families who have a child with a clinical diagnosis of autism in Santa Barbara County who have received early start services or special education. Eight families that met the criteria agreed to participate in the study.

Method

Participants

The subjects of the study were Latino families in Santa Barbara County who speak a primary language of Spanish and/or Mixteco and that have a child with school-based eligibility or clinical diagnosis of autism. The student needs to have received early start services or special education. Eight families that met the criteria agreed to participate in the study.

Setting

Permission was granted by SBCEO for the researcher, to conduct in-person interviews at the Santa Maria or Lompoc county office with parents. The researcher completed zoom and in-person interviews at the SBCEO offices by appointment and completed the phone interviews at his home office.
RESULTS
The study findings according to the parent interviews and quantitative data highlight important themes that are consistent with the literature review. The interviews suggest that Latino families experience some early intervention referral delays prior to the age 3.

- Delays with Receiving Special Education Services Eligibility Under Autism
  - The interview and quantitative data suggest that families experience delays with receiving the eligibility under the criteria of autism for special education services
  - The average mean for the age that students received an eligibility of autism for special education services was 4 years, 5 months with the youngest child being 3 years old and the oldest child being 7 years, 8 months
  - This is substantially over the age of 3 years old that students can be eligible for service.

- Delays with Receiving A Referral for Assessment from a Pediatrician
  - The interviews suggest that Latino families experience developmental screenings that are either inadequate or performed at lower rates.
  - This theme was recurrent with parents even after they reported concerns at an early age, prior to age three, when related to their development, such as delayed communication skills, social skills, restricted and repetitive behaviors and difficulty with transitions.
DISCUSSION

The study findings indicate the following themes:

- Parental Understanding or Knowledge of Autism is Limited
- Use of Developmental Screeners By Pediatricians is Unknown
- Delays with Obtaining a Clinical Diagnosis of Autism or For Seeing a Specialist
- Use of “Consejos” Assist Parents with Referral and Developmental Milestone Knowledge

CONCLUSION

- Given the importance of early start referrals and referrals after age 3, it is critical for the Tri-Counties Regional Center staff to provide ongoing support and guidance to Latino families regarding the services and assessments.
- Some families reported that the referral process for the Tri-Counties Regional Center is unclear.
- While there are organizations that provide support in the community to parents, such as Alpha Resource Center for IEPs and Promotoras for health, some of the families network or parenting group that expressed the desire for an organization to form a parenting provides additional support to other families that have a child with autism.
- Finally, many families reported that the preschool assessment process and assessment team was helpful and clear. Families shared that they learned techniques for helping their children by observing the staff work with them.
- Parents also reported that the assessment team and teachers often helped increase their understanding of autism.
- One recommendation that parents had for schools is to provide adequate support for teachers in the special day classrooms, such as increasing staffing in the classroom.
Research Questions and Definitions

Research Questions

The research questions guiding this study include the following:

1. How has the special education referral process addressed the needs of Spanish-speaking and Mixteco-speaking Latino preschool students with autism by the Santa Barbara County Education Office?

2. What, if any, barriers have delayed assessments, diagnosis, and eligibility for special education services for Latino students with autism from Spanish-speaking and Mixteco-speaking families in Santa Barbara County from 2014-2021?

3. How do community, medical, school, or parent networking resources contribute to positive outcomes or serve as barriers during the assessment, diagnosis, and eligibility process for Spanish-speaking and Mixteco-speaking Latino families with a student with autism in Santa Barbara County?

Methodology

Participants

The subjects of the study were Latino families in Santa Barbara County who speak a primary language of Spanish and/or Mixteco and that have a child with school-based eligibility or clinical diagnosis of autism. The student needs to have received early start services or special education services. Eight families that met the criteria agreed to participate in the study. 5 out of 8 families reported that they had a primary home language of Spanish, and 3 out of 8 families had a home language of Mixteco and Spanish.
Setting

Permission was granted by SBCEO’s Kirsten Escobedo, Assistant Superintendent, for the researcher, to conduct in-person interviews at the Santa Maria or Lompoc county office with parents. Due to the offices being used for assessments, the times needed to be scheduled in advance by appointment with parents during lunch or after-hours. In addition, permission was granted for zoom interviews to be conducted at the Lompoc county office by the researcher, when space was available during lunch and after hours. The researcher completed the phone interviews at his home office (prior to work time) for the early morning appointments (7 am-8 am).

Recruitment of Participants

The researcher recruited families after IRB approval was obtained and once formal written permission was granted from the local school districts and the SBCSELPA to initiate the study. A representative from each district and SELPA signed the consent letters via DocuSign (Appendix G) to provide permission to initiate the study for parents in their district.

The researcher sent out emails to service providers and teachers in the county to recruit participants. The researcher verified student information for any recommended students using the special education management system to confirm eligibility for special education services under autism and verify that they had a home language of Spanish and/or Mixteco. Families that met the criteria were contacted to determine their interest in participating in the study, including completing a parent survey and interview. Several families that were recommended by staff did not proceed to the next phase since they did
not meet one or more criteria for the study. This did not impact the number of participants since eight families were recruited and participated in the study.

**Survey Design and Interview**

The researcher initiated contact with each family by explaining the research study and the requirements for voluntarily participating. The researcher reviewed the Parent Consent Form to Participate in a Research Study in Spanish with the families via phone, zoom, or in person. Families were provided opportunities to ask clarifying questions and to continue or opt-out voluntarily from the study. As indicated by IRB requirements, a signature from parents was not required to participate in the study. Once parents agreed to participate, a survey was completed with the researcher via the preferred method of contact: zoom, in-person, or phone interview. Families were also allowed to conduct the interview and survey during one session or two sessions.

The researcher informed the families that they would be video recorded for in-person meetings, video recorded via zoom for virtual meetings, and audio recorded for phone meetings. The researcher also shared with the families that their identities would be kept confidential and that the recordings would only be viewed by the researcher and not shared. The researcher shared that the first component would consist of a survey while the second component would consist of an interview with open-ended questions from a questionnaire.

The researcher initially asked language questions to the 3 Mixteco-Speaking families to ensure that the survey and interview were administered in their preferred language. The researcher informed the Mixteco-speaking families that the survey and interview could be done in Spanish or that they could have an interpreter in Mixteco, if they
preferred. 3 of the three families confirmed that Spanish was preferred. The researcher followed up and asked about the primary languages spoken in the home. All three families shared that they use both Spanish and Mixteco in the home with their children. The researcher informed all of the Mixteco-speaking families would be conducted in Spanish based on their preferences. However, the researcher shared that the survey and interview could be paused if they experienced any difficulties understanding the questions in Spanish and needed an interpreter. The researcher also shared that they could inform him at any time if they did not understand the questions in Spanish.

**Sessions/Format of Interview**

All eight families opted to complete the interview and survey during one session with the researcher. 4 out of the 8 families completed the survey and interview via zoom, 3 out of the 8 families completed the survey and interview via phone and 1 out of the 8 families completed the survey, and interview in-person. 4 out of 8 families selected an appointment time in the late evening (5-8 pm), 2 out of 8 families selected an appointment during lunch (11 am-1 pm), and 2 out of 8 families selected an appointment time during the early morning (7 am-8 am).

Families were provided the opportunity to complete the interviews with one or both parents present. 4 out of the 8 families could meet together (father and mother). In contrast, the remaining four families had only one parent meet with the interviewer. One parent cited an preference to complete it by herself, one parent cited work schedule conflict, one parent cited a divorce, and one parent noted that his wife passed away.

**Demographics of Families**
The survey responses were analyzed to obtain the demographics of the families that participated in the study. 8 out of 8 families reported that they identified as Hispanic/Latino. 5 out of the eight families reported Spanish as the primary home language, and 3 out of 8 families reported Spanish/Mixteco as the primary home languages.

**Qualitative Analysis**

**Student’s Age at Initial Parental Concerns**

Most families (5 out of 8) reported initial developmental concerns to their pediatrician between 2 years, 0 months, and 2 years, eight months. The remaining families reported them at younger ages (1 year, eight months) or older ages (3 years and five years). The mean age for students at the initial parent concerns is two years, six months. Table 1 (frequency table) includes a summary of all eight student’s ages at the initial parental concerns. Table 2 summarizes the range, mean, median, and mode derived from the data obtained for the student’s age at the initial parental concerns.

**Table 1**

*Student’s Age at Initial Parental Concerns*

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year, 8 months</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>2 years</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>2 years, 1 month</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>2 years, 4 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>2 years, 8 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>3 years</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>5 years</td>
<td>1</td>
<td>12.5</td>
</tr>
</tbody>
</table>

**Table 2**

*Student’s Age Range, Mean, Median and Mode at Initial Parental Concerns*
The majority of families (4 out of 8) reported that they received a referral from their pediatrician for their child to see a specialist or referral for an assessment between 2 years, 0 months, and 2 years, 9 months. The remaining families reported them at older ages (2 out of 8) (3 years or 4 years, 1 month) or no referral yet to see a specialist or referral for an assessment (2 out of 8). The mean age for students receiving a referral by their pediatrician is 3 years, 1.5 months. Table 3 (frequency table) includes a summary of all eight students’ age during the Pediatrician’s Referral. Table 4 summarizes the range, mean, median, and mode derived from the data obtained for the student’s age at the referral by the pediatrician.

**Table 3**

*Student’s Age during Referral by the Pediatrician*

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years</td>
<td>1</td>
<td>14.29</td>
</tr>
<tr>
<td>2 years, 8 months</td>
<td>1</td>
<td>14.29</td>
</tr>
<tr>
<td>2 years, 9 month</td>
<td>2</td>
<td>28.57</td>
</tr>
<tr>
<td>3 years</td>
<td>1</td>
<td>14.29</td>
</tr>
<tr>
<td>4 years, 1 month</td>
<td>1</td>
<td>14.29</td>
</tr>
<tr>
<td>4 years, 4 months</td>
<td>1</td>
<td>14.29</td>
</tr>
</tbody>
</table>

**Table 4**

*Student’s Age Range, Mean, Median and Mode at Referral by the Pediatrician*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Range</strong></td>
<td>3 years, 2 months</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>2 years, 6.3 months</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>2 years, 2.5 months</td>
</tr>
<tr>
<td><strong>Mode</strong></td>
<td>2 years</td>
</tr>
</tbody>
</table>
Student’s Age at Onset of Early Start Services

The majority of families (5 out of 8) reported that their children received early start service as part of an IFSP. 3 out of the 8 families were not referred to early start services by their child’s pediatrician. The age range that students started to receive early start services is from 2 years, 0 months to 2 years, 9 months. The mean age for the students starting early start services is 2 years, 6 months. Table 5 (frequency table) includes a summary of all eight student’s age at the onset of Early Start Services. Table 6 is a summary of the range, mean, median and mode derived from the data obtained for the student’s age at the onset of early start services.

Table 5

*Student’s Age at Onset of Early Start Services*

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>2 years, 5 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>2 years, 7 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>2 years, 9 months</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>No referral*</td>
<td>3</td>
<td>37.5</td>
</tr>
</tbody>
</table>

*not included in calculations above.

Table 6

*Student’s Age Range, Mean, Median and Mode at Onset of Early Start Services*

<table>
<thead>
<tr>
<th>Range</th>
<th>9 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>2 years, 6 months</td>
</tr>
<tr>
<td>Median</td>
<td>2 years, 7 months</td>
</tr>
<tr>
<td>Mode</td>
<td>2 years, 9 years</td>
</tr>
</tbody>
</table>
Student’s Age at Onset of Special Education Services (IEP)

The majority of families (6 out of 8) reported that their children started receiving special education service at age 3. The remaining families (2 out of 8) reported that their children started receiving special education services at older ages (4 years, 3 months or 5 years, 7 months). The mean age for the students receiving special education services is 3 years, 5 months. Table 7 (frequency table) includes a summary of all eight students age at the onset of Special Education Services (IEP). Table 8 is a summary of the range, mean, median and mode derived from the data obtained for student’s age at the onset of their Special Education Services (IEP).

Table 7

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 years</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>4 years, 3 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>5 years, 7 months</td>
<td>1</td>
<td>12.5</td>
</tr>
</tbody>
</table>

Table 8

<table>
<thead>
<tr>
<th>Range</th>
<th>2 years, 7 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>3 years, 5 months</td>
</tr>
<tr>
<td>Median</td>
<td>3 years</td>
</tr>
<tr>
<td>Mode</td>
<td>3 years</td>
</tr>
</tbody>
</table>

Student’s Age at autism Eligibility for IEP

The majority of families reported that their children received an autism eligibility for an IEP between the age of 3 years and 3 years, 2 months (3 out of 8) or between the ages of 4 years, 2 months and 4 years, 8 months (3 out of 8). The remaining families reported
that their children received an autism eligibility for an IEP at the age of 5 years, 7 months (1 out of 8) and 7 years, 8 months (1 out of 8). The mean age for the students receiving an autism eligibility for an IEP is 4 years, 5 months. Table 9 (frequency table) includes a summary of all eight student’s age at the time of the autism eligibility for an IEP. Table 10 is a summary of the range, mean, median and mode derived from the data obtained for student’s age when they received an autism eligibility for an IEP.

Table 9

*Student’s age at autism eligibility for an IEP*

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 years</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>3 years, 2 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>4 years, 2 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>4 years, 3 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>4 years, 8 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>5 years, 7 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>7 years, 8 months</td>
<td>1</td>
<td>12.5</td>
</tr>
</tbody>
</table>

Table 10

*Age Range, Mean, Median, Mode of Student’s autism eligibility for an IEP*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Range</td>
<td>4 years, 8 months</td>
</tr>
<tr>
<td>Mean</td>
<td>4 years, 5 months</td>
</tr>
<tr>
<td>Median</td>
<td>4 years, 2.5 months</td>
</tr>
<tr>
<td>Mode</td>
<td>3 years</td>
</tr>
</tbody>
</table>

Student’s Age at Clinical Diagnosis of autism

The majority of families (3 out of 8) reported that their children did not have a clinical diagnosis of autism at the time of the interview. 1 family reported that their child received a clinical diagnosis at age 2. The remaining families reported that their children received a clinical diagnosis from age 3 year, 2 months to 3 years, 4 months (2 out of 8).
or from age 4 years, 6 months to 4 years, 8 months (2 out of 8). The mean age for the
students receiving special education services is 3 years, 6 months. Table 11 (frequency
table) includes a summary of all eight student’s age when they received a clinical
diagnosis of autism. Table 12 is a summary of the range, mean, median and mode derived
from the data obtained the student’s age at receiving a clinical diagnosis of autism.

Table 11

*Student’s age at receiving a clinical diagnosis of autism*

<table>
<thead>
<tr>
<th>Value</th>
<th>Frequency</th>
<th>Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>3 years, 2 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>3 years, 4 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>4 years, 6 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>4 years, 8 months</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>No diagnosis*</td>
<td>3</td>
<td>37.5</td>
</tr>
</tbody>
</table>

Table 12

*Student’s Age Range, Mean, Median and Mode at clinical diagnosis of autism*

<table>
<thead>
<tr>
<th>Range</th>
<th>2 years, 8 month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>3 years, 6 months</td>
</tr>
<tr>
<td>Median</td>
<td>3 years, 4 months</td>
</tr>
<tr>
<td>Mode</td>
<td>4 years, 8 months</td>
</tr>
</tbody>
</table>

Graph of Initial Parental Concerns, Referral, Early Start/Special Education Services and Diagnosis

Figure 8 is a summary of the information gathered from all eight students from the
parental interviews and surveys related to the research questions and data collection. The
graph (Figure 8 below) includes the student’s age at initial parental concerns, the
student’s age at the referral by the pediatrician, the student’s age at the onset of early start
services, the student’s age at the onset of special education services, the student’s age for autism eligibility for special education services and the student’s age at clinical diagnosis of autism.

**Figure 8**
Student’s age at initial parental concerns, referral by pediatrician, early start/special education services (IEP), autism-eligibility for IEP and clinical diagnosis of autism

![Graph showing student's age at initial parent concerns, referral by pediatrician, early start and special education services (IEP), autism-eligibility for IEP and clinical diagnosis of autism]

**Multiple Pearson’s Correlation**

A Multiple Pearson's product-moment correlation was run to assess the relationship between the student’s age of initial parental concerns, student’s age of initial referral by
pediatrician, student’s age of the onset of early start services, student’s age of the onset of special education services, student’s age of autism eligibility for IEP and student’s age of clinical diagnosis of autism. 8 families participated in the study. Preliminary analyses showed the relationship to be linear with both variables normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$), and there were no outliers.

There was a statistically significant, strong positive correlation between the student’s age at the initial parental concerns and the age of student’s receiving special education services, $r(98) = .78$, $p < .005$, with the early age of initial parental concerns attributing to 61% of the student’s receiving an early referral for special services. The vice versa also holds true the older age of initial parental concerns accounting for delayed referral for special services.

Next, there was a statistically significant, strong positive correlation between the student’s age at the referral by the pediatrician and the age of student’s clinical diagnosis, $r(98) = .97$, $p < .001$, with the early age of referral by the pediatrician explaining 94% of the student’s receiving an early clinical diagnosis of autism. The vice versa also holds true the older age of pediatrician referrals accounting for delayed clinical diagnosis of autism.

There was no statistically significant correlation between the Student’s age at the Initial parental concerns to the Student’s age at the referral by the pediatrician $r(98) = .45$, $p = .765$, or to Student’s age at the onset of early start services $r(98) = .234$, $p = .765$, or to the Student’s age at autism eligibility for an IEP $r(98) = .075$, $p = .765$, or to the Student’s age at clinical diagnosis of autism $r(98) = .437$, $p = .765$
There was no statistically significant correlation between the Student’s age at the referral by pediatrician to the Student’s age at initial parental concerns, \( r(98) = .44, p = .765 \) or to the Student’s age at the onset of early start services \( r(98) = .85, p = .765 \) or to Student’s age at the autism eligibility for an IEP \( r(98) = -0.78, p = .765 \).

There was no statistically significant correlation between the Student’s age at the onset of early start services to the Student’s age at initial parental concerns, \( r(98) = .23, p = .765 \) or to the Student’s age at the referral by the pediatrician \( r(98) = .85, p = .765 \) or to Student’s age at autism eligibility for the IEP \( r(98) = .136, p = .765 \), or to Student’s age at the clinical diagnosis of autism \( r(98) = .989, p = .765 \).

There was no statistically significant correlation between the Student’s age at the onset of special education services to the Student’s age at referral by the pediatrician, \( r(98) = .51, p = .765 \) or to or to the Student’s age at autism eligibility for the IEP \( r(98) = .261, p = .765 \), or to Student’s age at the clinical diagnosis of autism \( r(98) = .588, p = .765 \). The correlation between the Student’s age at the onset of special education services and the Student’s age of early start services could not be calculated since the services for special education initiate after early start services.

There was no statistically significant correlation between the Student’s age at autism eligibility for the IEP to the Student’s age at initial parental concerns, \( r(98) = .075, p = .765 \), or to the Student’s age at the referral by the pediatrician, \( r(98) = -0.78, p = .765 \) or to the Student’s age at the onset of early start services, \( r(98) = .136, p = .765 \) or to Student’s age at autism eligibility for the IEP \( r(98) = .261, p = .765 \), or to Student’s age at the clinical diagnosis of autism \( r(98) = -.032, p = .765 \).
There was no statistically significant correlation between the Student’s age at the clinical diagnosis of autism to the Student’s age at initial parental concerns, $r(98) = .437, p = .765$, or to the Student’s age at the onset of early start services, $r(98) = .989, p = .765$ or to the Student’s autism eligibility for the IEP $r(98) = .588, p = .765$ or to the Student’s age at autism eligibility for the IEP $r(98) = .261, p = .765$.

**Summary of Correlation Results**

Table 13 is a summary of the correlations completed for all of the data collected in all categories from the parents interviews and surveys.

**Table 13**

*Correlations of Student’s age at initial parental concerns, referral by pediatrician, early start/special education services (IEP), autism-eligibility for IEP and clinical diagnosis of autism*
<table>
<thead>
<tr>
<th>Service Types</th>
<th>Pearson Correlation</th>
<th>Sig. (2-tailed)</th>
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<th>5</th>
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<tr>
<td>Autism Eligibility</td>
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<td>3</td>
<td>5</td>
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<td>5</td>
</tr>
</tbody>
</table>

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

c. Cannot be computed because at least one of the variables is constant.

Test of Normality

Table 14

*Test of Normality of Student’s age at initial parental concerns, referral by pediatrician, early start/special education services (IEP), autism-eligibility for IEP and clinical diagnosis of autism*
### Tests of Normality

<table>
<thead>
<tr>
<th></th>
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<td>Age at Onset of Special Education Services</td>
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<td>Age at autism eligibility for IEP</td>
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<tr>
<td>Age at Clinical Diagnosis</td>
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<sup>a</sup> Lilliefors Significance Correction

### Scatter Plots

Scatter plots were created for the 4 categories that demonstrated strong correlations according to the Multiple Pearson’s Correlation analysis including the Student’s Initial Parents and Student’s Age at Special Education Services (Figure 2.5) as well as Student’s age at Referral by Pediatrician and Student’s Age and Clinical Diagnosis (Figure 2.6).

### Interpretation of Scatter Plots

The first scatter plot (Figure 9) demonstrates a positive relationship related to a student’s age at initial parental concerns and the student’s age at the onset of special education services. The data points in the first scatter plot have a significant cluster of scores at age 3.00 years of age on the graph which is representative of the transition process that occurs from early start services to special education services at age 3. There are two outliers on the scatter plot, which represent delayed referrals to special education services in...
comparison to when initial parental concerns were first reported. The second scatter plot (Figure 10) demonstrates a strong positive linear relationship related to the student’s age at referral and age of clinical diagnosis. There are no outliers in the second scatter plot.

**Figure 9**

*Scatter Plot of Student’s age at initial parental concerns and at special education services*

**Figure 10**

*Scatter Plot of Student’s age at Referral by Pediatrician and Student’s Age at Clinical Diagnosis*
Qualitative Analysis

Coding of Transcripts

The transcripts of the parent interviews were coded and examined for themes in parental responses. In addition, the parental responses were examined for similarities and differences. Excerpts from the parental interviews are included in both English and Spanish. A summary of their responses is included below in each respective area:

Initial Concerns

Most of the families expressed some level of concern related to their child’s development as an infant or young child. Parents most often expressed initial concerns with their child’s delayed speech and language skills, attending skills, social skills, toilet training, repetitive or restricted behaviors and limited play skills compared to other children in their family.

Parents expressed the following concerns specifically:
Student #4’s Mother: "I realized that he was not progressing with the developmental stages (growth) because I took care of my brothers."

“Yo me di cuenta en que iba avanzando los meses del crecimiento de él porque yo cuidaba a mis hermanos.”

Student #4’s Mother/Father: "We noticed that the loud sounds (bothered him), he didn't want to talk... he didn't want to crawl... no eye contact."

“Notamos que los sonidos fuertos (le molestaban), no quería hablar….no hacía por gatear...no contacto visual.”

Student #1’s Father: “I remember when he played with some things or toys he didn't pay attention to that. Like when you see that other children at their age are very organized? No, he didn't care about organizing (the toys)."

“Me acuerdo que cuando el jugaba con algunas cosas o juguetes no ponia atención en eso. Y ves que otros niños a su edad son muy organizados? No, él no le importó organizer.”

Student #3’s Mother: "We started with the concerns around eight months (and more so) when she was already two years old and didn't make eye contact and hadn’t started talking."

“Empezamos con la duda como a los ocho meses que tenía ella y yo cuando ella ya iba a cumplir los dos años porque no conocía contacto visual y ni tampoco empezaba a hablar.” Student #3’s Mother: Dos años.

One parent expressed concern that her son regressed in the area of communication as an infant:
**Student #2’s Mother:** “When he was younger, he would imitate the sounds of animals. When he was less than two years old he would say like "wow" for the puppy and so on. And then suddenly everything stopped.”

“Cuando estaba chiquito, si decía los sounds de los animals. Cuando estaba menos de dos años decía como “wow” para el perrito y así. Y de repente paró todo.

One parent was unfamiliar with the developmental milestones, but noticed that the child’s communication skills and attending skills were significantly delayed:

**Student’s Mother #1:** "Why doesn't he speak? He should talk by now. He didn't want to participate, He didn't want to participate... And he just wanted to be things alone and like be in his own world."

“Por que no habla? Ya deberia de hablar. No quería participar, no quería participar...Y solo queria ser los cosas el solito y como que se cerraba en su mundo.”

One of the fathers expressed that they did not have as much experience or knowledge related to their child’s development since their spouse (wife) served as their child’s primary caretaker.

**Student #1’s Father:** "Well, I think it was you (right)? (looks at wife). She noticed first because she is his mother and has always been at home and she has never worked. She started telling me why doesn't he talk? He should already be talking."

“Bueno, pues yo pienso que tu, no? (looks at wife). Nota ella primero por que ella es la mamá y siempre ha estado aquí en la casa y ella nunca ha trabajado. Entonces ella empezó a decir por qué no habla? El ya debería de hablar.”
In addition, another father expressed that they did not have experience or knowledge with developmental milestone since the child was their first and they had no knowledge with being the primary caretaker.

**Father #4’s Father:** "And I'm the youngest sibling, so I was never exposed to any of that (taking care of siblings)."

“Y yo al contrario, soy el menor, entonces nunca estuve expuesto a nada de eso.”

**Familiarity with autism**

Most of the families expressed that they were not familiar with autism and that they did not have any experience with a child that had been assessed for autism. However, despite this many parents expressed concern that their child demonstrated some possible delays that would need additional support from professionals. Furthermore, families frequently expressed these initial developmental concerns to their child’s pediatrician from a young age:

**Student #3’s Mother:** "I told the doctor that she was already too big not to say mom and dad and that when one of us spoke to her, that she did not pay attention and out of nowhere she would become upset and things like that. And he (the pediatrician) told me she was like hyperactive, but it was normal. Then later, at the next appointment I had with him (the pediatrician) I followed up on my concerns since she was already going to be three years old and not talking and paying attention. That’s when (her case) was transferred (to early start services)."

“Yo le dije al doctor que ya estaba muy grande para no decir ni mamá y ni papá y que le hablaba uno y que no hacía caso y de la nada se enojaba y cosas así. Y él me dijo que era como que hiperactiva, pero que era normal. Entonces después, en
One of the parents suspected that her child had autism from the early age of 2:

**Student #2’s Mother:** I thought that my child had autism. I mean maybe yes because it is a spectrum. For example, he was not potty trained. At three years (old), he did not speak anything.” “Yo pensaba que mi niño tiene autismo. O sea maybe si porque es un spectrum. Por ejemplo no iba potty training. A los tres años no habalaba nada.”

One parent expressed that the preschool teachers became concerned about her child regarding his speech and language skills and encouraged an assessment:

**Student #8’s Mother:** “Since I was working, the teachers were the ones who realized it (symptoms of autism). And when they told me I made an appointment and told the doctor. And that's when they started checking him (assessing him)…He didn't talk well and the concern I had at school is that sometimes they don't understand him.”

“Como yo iba a trabajar, y las que se daban cuenta eran las maestras. Y cuando ellas me dijeron fue cuando hice la cita y le avise al doctor. Y fue cuando ellos lo empezaron a chequear….No hablaba bien y la preocupación que tenía es que la escuela a veces no le entienden.”

One parent expressed that her son struggled at the start of Kindergarten due to difficulties attending and with behaviors:
**Student #7’s Mother:** “He would get angry and run everywhere. He will get on the tables, he would say no, he would not still and wanted to go outside and play. The first thing he wanted is to go out and play.”

“Se enojaba y corría por todas partes. Se sube a las mesas, decía no, no estaba quieto y quiere salir a jugar. Lo primero que hace es quiere salir a jugar.”

One parent experienced difficulties with his child meeting basic developmental milestones, such as playing, walking and talking. This led to a follow-up with the pediatrician and ultimately a diagnosis of autism:

**Student #6’s Father:** We noticed because we taught him to play with all the toys when he was a child and he played differently....We made the effort to teach him to walk, to speak like a normal child. But no. He didn't do it that way that's why we noticed it. Then we started taking him to the doctor. Even when the child was born he (the pediatrician) told me that maybe the child has autism. And that’s when they started examining him and they then informed us that he has autism.

“Lo notamos porque le enseñamos a jugar con todo los jugetes cuando era niño y el niño jugaba diferente....Hizimos la lucho para que camine, que hable como nino normal. Pero no. No lo hacia así por eso lo notamos. Entonces ya lo empezamos a llevarlo al doctor..(Incluso), hasta cuando el niño nacio me dijo que quizas el niño tiene autismo. Y ya después cuando empezaron a los estudios que nos informaron que tiene autismo.”

**Advice from Friends or Family**

One parent shared that his family had limited knowledge of autism, so they consulted with their son’s pediatrician instead:
Student #6’s Father: "We asked a doctor because his mom and I weren't going to ask the family. They're not going to know. That's why we asked a doctor."

"Es que le preguntamos a un doctor porque su mamá y yo no le ibamos an preguntar a la familia. No van a saber. Por eso le preguntamos an un doctor."

Family History of Developmental Delays

One of the parents shared that her family experienced significant developmental delays in the area of speech and language and learning. Her mother was unaware that they were delays and shared that that’s just how they were. The parent shared that they discuss the developmental needs together as a family, including the delays that her son experiences with autism. They were not aware of autism before they learned that her son had it:

Student #7’s Mother "I always asked my mom about the delays with speech in our family but she always said that's just how we are. That we are slow to learn, because my sister had delays and that she could not speak until she was much older. But it wasn’t until I was 5 or 6 years old that I also started talking more or less. The same thing happened with my other cousins because I tell them about my son and so on. We didn't know anything about autism and it was new when we learned that my son had it."

"Siempre le había preguntado a mi mamá de los restrasos de hable de nosotros en nuestra familia pero me decia siempre que nomas así somos. Que somos lentos de aprender, porque también a mi hermana también le pasó eso que no podía hablar hasta que estaba mas mayor. Pero hasta que yo también tenía 5 o 6 años que yo empeze a hablar más o menos. Paso lo mismo tambien con otras primos me dicen"
que también por que le platico de mi hijo y así. No sabiamos nada de autismo y era nueva cuando aprendimos que mi hijo lo tenia.”

One of the parents shared that her experience with her child who has autism, propelled her to seek help sooner for her youngest child. She talked to his pediatrician as soon as she noticed that he was not meeting his developmental milestones. She shared that he now has services and a therapist thanks to checking in with the pediatrician’s referral. She did not want to wait like she did with her son with autism:

**Student #4’s Mother:** “Right now, I am concerned with my third child. He turned a year old and he does not babble much and he barely wants to walk. As soon as he turned one and I noticed that he had not started to walk, I started telling the doctor. I told him I had this suspicion and he referred me to the regional center and a therapist. I did not wait like I did for my son with autism.”

“Ahorita traigo un pendiente de mi tercer hijo. Ya cumplió el año, no balbucea mucho y apenas anda queriendo caminar.. Entonces en cuanto yo vi que se llegó al año y no empezaba a caminar, empecé a decírle a la doctora. Le dije que tenía esta sospecha y ya me referieron al centro regional y a una terapista. No me espere como mi hijo que tiene autismo.”

**Understanding of autism:**

Overall, some of the parents expressed limited understanding of autism since they had not had a family member with a diagnosis of autism or had an experience with a developmental delay. There was some initial skepticism for some parents, in particular fathers, about accepting the diagnosis of autism or eligibility of autism from the school since they saw their child as being intelligent and with having many strengths and skills.
Other parents expressed concerns about the outcomes and future of their child given the cultural stereotypes about disabilities, including autism. A few parents shared that the assessment team at SBCEO was instrumental to helping them accept that their child had symptoms of autism.

More specifically, one parent shared how he was initially skeptical that his child had symptoms of autism after being informed by the school assessment team (and the researcher). He gradually learned more about autism and accepted it over time. He also discussed that he became more aware of the symptoms:

**Student #5’s Father:** “Even when you told us, I was skeptical and thought no, I don’t think so. It was right after you guys told us. After a while we began to notice more things, such as that he got frustrated, he was stressed and since then we began to get more involved in what autism was, to know a little more about it. And we thought, well, if he has it then we need to work with him. Then there were more episodes when he got frustrated, when he became impatient and started to cry. I started to accept it.”

“Aunque ustedes nos dijeron, yo estaba escéptico porque decían no, no creo. Fue más bien después de que nos dijeron. Después de un tiempo que ya empezamos a notar más cosas, como que él se frustraba, se estresaba y ya que nos empezamos a envolver más en lo que era el autismo, a conocer un poquito más de eso. Y dijimos pues bueno, si lo tiene y pues hay que trabajar con él y ya después fueron más los episodios cuando él se frustra, cuando él se desespera y se pone a llorar. Le empeze de aceptar.”
The same parent continued to explain that he was also initially skeptical about accepting that his son had symptoms since no one in his family has autism:

**Student #5’s Father:** “I listened to you, but since there really is no one in my family that has autism. In fact I didn't have anyone in my family or her family with autism. We also don't have anyone with autism in the circle. We had heard about autism, but we didn't really know what it was or what autism looked like.”

“Lo escuche a usted, pero realmente, como en la familia, realmente no había nadie que lo tiene. De hecho no hay nadie en mi familia o en la familia de ella que lo tiene. Tampoco tenemos a nadie con autismo dentro del círculo. Había escuchado de autismo, pero realmente no sabíamos de qué se trataba o qué era el autismo.”

One parent shared how the assessment team for preschool special education services from Santa Barbara County Education Office helped them to process that their child had symptoms of autism, despite some initial reservations accepting it. The father expressed that he was skeptical because he compared his son to other family members who had similar difficulties with communicating and who later advanced over time. In addition, the family believed that he had great skills: which made it harder to accept:

**Student #5’s Father:** “Well, it was more when the team went and you told us that it appeared that (name of student) had symptoms of autism. The truth is that at the beginning since we noticed that he could count and say words, that we thought no since there have been others that were similar in our family. There are others (in the family) who started talking at three years or at four years old. And they take a long time to talk or they stop eating food, they become delayed a little, but then they move forward and advance. So the truth is I was very skeptical. I would tell
her (my wife) no, I don't think that is what it is, that he has autism, because we have seen, that (name of student) knows how to count from 1 to 10 in Spanish, from 1 to 10 in English, and he knows his letters. So (I thought) I don't think he has it.”

“Pues fue más cuando el equipo fue y tú nos decías que parecía que (name of student) si tenía (síntomas de) autismo. Yo la verdad como al principio él contaba, el decía palabras. Nosotros decíamos no y piensamos que porque otros sí lo han tenido en la familia. Hay otros que hablan a los tres años o a los cuatro años. Y si tardan mucho en hablar o dejan de comer cositas, se retrasan un poquito, pero después avanzan. Entonces la verdad es que you estaba muy escéptico. Yo le decía a ella que yo no creo que sea eso, que tenga autismo, porque pues hemos visto que (name of student) sabe contar del 1 al 10 en español, del 1 al 10 en inglés, sabe letras. Entonces (pensaba) no creo que lo tenga.”

A second parent expressed initial surprise that her child was not progressing as expected developmentally and learned more about autism from the preschool assessment team at Santa Barbara County Education Office. The parent also expressed that her child has made significant growth despite some initial concerns:

Student #5’s Mother: “I thought my child was normal, but there were areas of concern that I was worried about and that I would wonder such as ‘what is that?’ I thought it was a disease or something more serious was going to happen. But when you explained to me (autism) and the teacher explained to me that no, this is a condition. That the child fortunately or unfortunately, for better or for worse, the child is very intelligent. Yes, he’s way too bright much of the time. As you
explained our son will make significant progress and may have some setbacks along the way. And we've noticed this a lot which concerned me. But right I have seen that he has progressed a lot and he's been learning.

“Pensaba que mi niño era normal, pero había aspecto me preocupé y pensaba qué es eso? Yo pensando que era una enfermedad o que algo algo más grave iba a pasar. Qué era lo que iba a pasar? Pero, cuando me lo explicaste tu, me explicó la maestra que no, eso es una condición. Que el niño afortunadamente o desgraciadamente, para bien o para mal, el niño es muy inteligente. Sí, demasiado. Como me explicaste, el niño va tener muchos avances, pero a veces va a bajar. Y lo hemos notado mucho en eso, sí me preocupaba. Pero ahorita hemos visto que he avanzado bastante y esta aprendiendo.”

One parent shared that she initially felt nervous about the diagnosis of autism given the stereotypes that she had heard in the Hispanic community. She later became motivated to help her son overcome his challenges and to help him make a difference in the lives of others with autism. She described her son as her “life project:” (Proyecto de vida). She is motivated by his potential impact on others in the future and would like him to break the stereotypes:

**Student #4’s Mother:** “Well, I had heard a lot of Hispanic people say that he was going to be a slow learner or that he was not going to be able to get ahead or that he’s going to be another piece of furniture in the house. Our life felt like it almost ended at that moment, but not because of the diagnosis that my son had, but because I was unsure how I could help him. But from a moment I started researching before they gave me the diagnosis, which was autism. I started to
believe that I was going to make a difference. In fact, I (made it my mission) to make a difference in the life of the people I know who have autism, that he’s going to show them that you can succeed. He is my ‘life project’ and I have told him that I want him to facilitate lectures/conferences one day on autism so that he can explain to people that he is autistic but that he has a life just like everyone else does and that you can get ahead.”

“Pues yo había escuchado a mucha gente hispana decir o es que va a ser lento para aprender o no va a poder salir adelante. Se nos acabó la vida en ese momento. Estoy de acuerdo de en cuanto yo tuve el diagnóstico, sentí que se me acababa la vida, pero no por el diagnostico de mi hijo, sino porque no sabía como le iba poder ayudar. Pero yo desde un momento que empecé a hacer la investigacion antes de que me dieran el diagnóstico de autismo, iu fue que empecé a creer que yo iba hacer una diferencia, yo voy a hacer la diferencia entra la gente que conozco que tiene autista, de que les voy a demostrar que sí se puede. El es mi proyecto de vida que yo le he dicho a él que tenemos es de que yo que quiero que él llegue a ser conferencista de autismo y que le explique a mucha gente que le es autista, que tiene una vida como cualquier otra persona y puede salir adelante.”

One parent shared that she suspected that her son had autism given his delays in speech and social skills. She also expressed that she understood that autism is a spectrum:

**Student #2’s Mother:** “I thought my child had autism, because it's a spectrum.

For example, at the age of three, he did not talk at all… and he was not social.”
“Yo pensaba que mi niño tiene autismo, porque es un spectrum. Por ejemplo a los tres años no habalaba nada…. y no era social.”

**Impact of Special Education Services**

Overall, some parents expressed that the special education services helped improve their child’s communication skills, pre-academic skills, social skills, increase in friendships, attending skills, and a decrease in restricted and repetitive behaviors.

More specifically, one parent indicated that his son is demonstrating better communication skill as a result of the special education services. The progress that his son has made has been a “pleasant surprise:”

**Student #1’s Father:** “Yes, his speech has surprised me (positively). He now asks questions like, "are you hungry, yes or no?" He responds back no or says yes (to questions). Or sometimes he talks to his siblings and says, "no thank you," or sometimes says "can I go?" when he wants to go to the store.

“O sí, me ha sorprendido (positivamente) su habla. Ahora hace preguntas como "are you hungry, yes or no?" El te dice no o te dice yes (a preguntas). O aveces habla con sus hermanos y les dice, “no thank you,” o aveces le dice “can I go?”

One parent shared that her son is more social with children and has greater pre-academic skills as a result of the special education services:

**Student #8’s Mother** : “What has helped him the most is to learn to identify his colors and learn the names of the things he is studying…. Right now, he is also more (interactive) with the children. He is sometimes distant from others. I
believe that he is progressing because he attends school and he stays more with the children.”

“Lo que le ayudó más es como saber los colores y a aprender los nombres de las cosas que está estudiando….Ahorita tambien es más (interactivo) con los niños. Nomás que si todavía sigue un poquito más alejado de lo demas. Yo creo que avanza por que va la escuela y se queda más con los niños.”

One parent shared that he has seen a decrease in his impulsive and repetitive behaviors and that her son is able to stay focused longer:

**Student #1’s Father:** "(Since) he was diagnosed with autism I have seen that he has changed and is improving due to school. I don't see him like I used to. He has stopped doing a lot of activities because before he ran around the house and now he is quieter in one place and is focused."

“(Desde que) lo diagnosticaron con autismo he visto que a cambiado y va mejorando por la escuela. No lo miro como antes. Ha dejado de hacer mucha actividad porque antes corría en la casa dando vueltas y ahora está más quieto en un solo lugar y está enfocado.”

One parent shared that his son’s social skills, in particular making friends has become a strength for him over time. His son’s social skills were previously the primary concern when he was younger:

**Student #4’s Father:** “The primary concern was on the social aspect and that he wouldn’t want to interact with anyone and that his social circle was smaller. But thank God everything has gone well. He has made more new friends and is more social now.”
“La preocupación principal era en el aspecto social y de que no iba querer interactuar con nadie y de que su círculo social fuera más pequeño. Pero gracias a Dios todo ha salido bien. Ha hecho más nuevos amigos porque incluso y ahora es más social.”

One parent expressed gratitude for her son’s special education teacher in Kindergarten who saw significant potential in her son. She helped her son make progress with inclusion opportunities in the general education classroom. Ultimately, she helped him transition from the special day classroom to a general education classroom 100% of the time:

**Student #4’s Father:** She (the special education teacher) was the one who took the initiative when he was in kindergarten to send him a few minutes to another class with typical children in an inclusion class. It was up to her to take that initiative.… So much was the potential that she saw in him. She told us about her experience with other students in the past who had many similarities to those of our son. And she told us, I would love to keep him, but I don't want to stop him. I don't want to clip off his wings because of the potential that I see. She told us that she preferred for him to fly and for her to watch close by.”

“Ella (la maestra de educación especial) fue la que tomó la iniciativa de cuando estaba en kinder, ella tuvo la iniciativa de mandarlo unos ciertos minutos a otra clase con niños típicos en una clase de inclusión. Fue cosa de ella de tomar esa iniciativa.… Entonces tanto fue el potencial que ella vio en el que nos comentó su experiencia con otros estudiantes que había tenido en el pasado con muchas similares a las que tenía nuestro hijo. Y nos dijo a nostotros, me encantaría
mantenerlo, pero no lo quiero detener, no le quiero cortar la alas por el potencial que lo veo. Nos dijo que prefiere mejor que vuele y estar viendo lo de cercas.”

Negative Experiences with the Pediatrician or Specialists

Overall, some parents expressed concerns related to delays in diagnosing or referring their children when they shared initial concerns at an early age. Other parents shared that no action was taken by the pediatrician or were told that their child was typically developing when they asked about specific delays with developmental milestones. They also shared that they were not offered referral information or referrals for other agencies. Some of the families attributed these delays due to not speaking English or due to being Hispanic.

More specifically, one parent described how she initially felt helpless and disillusioned when her son’s pediatrician informed her that he would never walk when he was an infant. She also shared how her son’s pediatrician noticed symptoms of autism, but did not refer him for an assessment and did not diagnose him:

**Student #1’s Mother:** "The doctor always told me that he's never going to talk... and he also told me as soon as he examined him " your son will never walk." As a mother, I left disillusioned and told my husband. He told me not to believe him. As far as autism, he told me that he noticed symptoms, but he said that he was not sure until assessment were completed. He did not complete an assessment or refer him. But later they changed him (to another doctor) because he retired.”

“El doctor siempre me ha dicho que nunca va hablar…y también me dijo en cuanto lo examino “su hijo nunca va a caminar.” Como madre, me vine como desilusionada y le comenté a mi esposo no me quede callada. Yo le comente y el
me dijo no le creas. En lo del autismo, el me decía que miraba síntomas, pero decía que no estaba seguro hasta que el le haga unos estudios. No hizo una evaluación y no lo referio. Pero después me lo cambiaron (a otro doctor) porque se retiro.”

Another parent expressed concerns that her son’s pediatrician child viewed him as normal and was not assessed prior to 3 for autism:

**Student #3’s Mother**: “Before three, his doctor didn’t give it much thought (to my concerns) and said he was normal. Well, as he approached three, he finally said ok, autism is something that maybe he has.”

“Antes de los tres, el doctor en ese tiempo no le dio mucha importancia (a mis preocupaciones) y dijo que era normal. Pues ya cuando ya se acercó a los tres, el ya dijo ok, autismo es algo que a la mejor tiene.”

Other parents expressed similar concerns related to autism were not addressed and they never received a referral for an assessment. They expressed these concerns for over two years+ for their son which the family believes is related to them being Hispanic or not speaking English. They expressed other families that they knew that had similar experiences with delays with referrals for autism with the same pediatrician who ultimately retired.

**Student #4’s Mother**: “We would tell her (the doctor) our concerns every time we went. Unfortunately also being Hispanic and not knowing how to speak English. I was very late. He came to the opportunity to understand that I did want to have such a child.”
“Le comentábamos (a la doctora) nuestras preocupaciones cada vez que íbamos. Desafortunadamente también el ser hispano y no saber hablar el inglés. Me atrasé mucho. Llegó a la ocasión de darme a entender como que sí yo deseaba tener un hijo así.”

**Student #4’s Father:** “And the doctor practically told us the doctor is me. So when we commented concerns to the doctor in a way she ignored them. Later we received the notification by phone that the doctor was going to retire.”

“I prácticamente nos decía la doctora soy yo. Entonces cuando nosotros comentabamos nuestras preocupaciones a la doctora y en cierto modo los ignoraba. Después recibimos la notificación por teléfono de que la doctora se iba a retirar.”

**Student #4’s Mother:** “Unfortunately we weren't the only ones. I have talked to people who went to the same pediatrician, and had the same problems as us and it wasn’t until they got a new pediatrician that they found out that they had a son with autism.”

“Desafortunadamente no fuimos los únicos. He hablado con gente que iban al mismo pediatra, y tienen el mismo problema que nosotros y hasta que consiguieron un pediatra nuevo se enteraron que tienen un hijo con autismo.”

One parent shared that she was not offered referral information or behavioral services despite telling the first pediatrician that her son had autism. The parent reported that her experiences were better with her son’s second pediatrician who provided her with agency information and re-referred her son for behavioral services and speech and language therapy.
**Student #5’s Mother:** “I let my child’s previous doctor know that he was autistic. But she never told me look, you have to go to this agency or do you want or do you have these services? Nothing, she only knew that my child had autism. So, now that this new doctor started she told me I see that your son has autism. I said yes. And she says and how is his therapy going? I said, I don't have therapy. She asked me why? I said I cut ABA because I was receiving services. The new doctor referred my son again for behavioral services and for speech. My son is currently on the waiting list now.”

“Yo le hice saber a la doctora que estaba anteriormiente que el niño era autista. Pero ella nunca me dijo mira, tienes que ir a esta agencia o tienes o quieres buscar estos servicios? Nada, ella solamente sabía que el niño autista. Entonces, ahora que entró esta nueva doctora ella veo que tu hijo tiene autism. Le dije si. Y dice y cómo van sus terapias? Le dije, no tengo terapias. Me pregunto por qué? Dije las corté porque yo tenia servicios de compartamiento. La doctora nueva volvió a hacer la referencia para mi hijo y para los servicios de compartamiento y para speech. Mi hijo ahortia esta en la lista de espera.”

Another parent expressed concerns to her son’s pediatrician at age 4 as well as the additional concerns expressed by his preschool at age 5. She has not received an agency referral from her pediatrician, despite specifically requesting one. The pediatrician shared that her son appears to be doing well but the parent remains concerned. Parent shared that she will continue to try to obtain a referral for additional services and a clinical diagnosis.

**Student #7’s Mother:** “Yes, I told the doctor of my concerns and they told me that he’s okay and that he’s growing well and everything. And I asked why can't
he speak? It was very strange to me, because all my sisters have children and they already talk and already understand everything. And also at school they told me that they are worried because he is behind. He was 4 when I made the appointment for the doctor. Because when he was 4 he couldn't talk much and I told the doctor what's going on with my son? (He told me) he’s normal, he’s normal, talk to him and little by little he will be okay. And so I tell him what do I do with my son because he can't talk? Although I told the doctor that he does not listen to me. And they sent me a number to call him, but I called that number but they didn't even answer me. And time passed and it wasn’t until my son started at his new school that they told me again. I made another appointment because he can't talk much is struggling at school. I still don’t have an assessments for autism from his doctor. My son just has the school services. I am going to keep trying.”

“Si yo les dije a los doctores de mis preocupaciones y me dijeron que el está bien y que está creciendo bien y todo. Y yo dije porque no puede hablar? Se me hacia muy raro, porque todos mis hermanas tienen hijos y ya hablan y ya entienden todo. Y también en la escuela me dijeron que están preocupados porque si esta atrasado de la escuela. Tenía 4 cuando hice la cita. Porque cuando tenía 4 no podía hablar mucho y pues le dije a la doctora pues qué está pasando con mi hijo. (Me dijo) es normal, es normal, hablale y ya poco a poco y está bien. Y pues yo le digo pues qué hago con mi hijo porque no puede hablar? Aunque le digo él doctor no me hace caso. Y me mandaron un número para llamarle, pero le llame a ese numero pero ni me contestaron. Y pasó el tiempo y hasta ahora que empezó a la nueva escuela y me vuelven a decir otra vez y pues le digo no, a fuerza tengo que
Positive Experiences with the Pediatrician or Specialists

Overall, some parents expressed that they had a positive experience with their child’s pediatrician due to their assistance in the referral process for early start services, special education services, regional center, referral to a Neurologist or an autism assessment with a specialist. Some parents shared that they needed to changed pediatricians in order to receive the referral or an assessment.

More specifically, one parent shared that her son’s pediatrician helped with the referral process with the school and that the special education services started soon after:

**Student #6’s Father:** “The doctor was the one who started helping and then they called me from school. And so it started going forward and then school... The doctor sent some papers to the school and a specialist and a psychologist, began to work with my son. I accepted the help for my son because he needs it.”

“El doctor fue el que empezó de ayudar y luego ya me llamaron de la escuela. Y así empezó por adelante y ya después la escuela… El doctor le mandó unos papeles a la escuela y empezó a llegar una especialista, un psicólogo comenzaron a trabajar con mi hijo. Acepte la ayuda para mi hijo por que lo necesita. Y el doctor les mando algunos papeles a la escuela y ahí empezó la ayuda.”

A mother and father experienced delays with receiving a referral from the first pediatrician but had a positive experience with the second pediatrician. The second
pediatrician completed a referral to the regional center and Santa Barbara County Education Office during his first appointment.

**Student #4's Mother:** “My son started with the (Second) pediatrician at three years old. As soon as I told him my concern, he told me ok, let him examine him or complete some small tests. He did some small tests and then he told me I'm going to transfer you to the regional center. He said was referring him because he saw something related to autism.”

“Como a los tres años mi hijo comenzó con el (Segundo) pediatra. En cuanto yo le dije mi inquietud, él me dijo ok, déjame revisarlo y hacer unas pequeñas pruebas. Le hizo unas pequeñas pruebas y luego luego él me dijo yo te voy a transferir al centro regional. Dijo que lo referio porque si le veo algo relacionado de autismo.”

**Student #4's Father:** “On the first appointment, the pediatrician sent the referrals. And he told us that it was a process. The county contacted us very rapidly for the assessments.”

“En la primera cita, el pediatra mando las referencias. Y nos dijo que era un proceso. El condado nos contacto a nosotros pero fue bien rapido para los examenes.”

One parent shared that her pediatrician referred her son to a physician who is an autism specialist at the early age of two and provided guidance on the referral process. She shares recommendations to parents when they ask her how she was able to complete a referral at such an early age:
**Student #2’s Mother:** “Before my son was two years old, the pediatrician recommended me to a doctor who is an autism specialist in Santa Barbara. The pediatrician recommended that he be diagnosed because only with a diagnosis will they provide you with free services. A lot of people ask me how did you do it? I tell them that it’s all because of that doctor. They say I haven't heard of her and they share that their children are already three, four or five years old. And I tell them then tell your pediatrician, and have your pediatrician assess him/her. I share that they can refer you to the doctor for her waiting list because she is the only one in the whole county.”

“Antes de que me hijo tenía los dos años, su pediatra me recomendó a una doctora que es especialista de autismo en Santa Barbara. Me recomendó que lo diagnosticaran porque me dijo que solamente con su diagnóstico te pueden dar los servicios gratis. Mucha gente me dicen cómo le hiciste? Les digo es que mi niño desde chiquito pues fue con esa doctora. Dicen no a mí no yo no he escuchado de ella y sus niños ya tienen los tres, cuatro o cinco años. Y les digo pues dile a tu pediatra, ya que tu pediatra te los examine. Les digo también que te puede referir a la doctora para su waiting list porque es la única en todo el condado.”

One parent shared that she has had a positive experience with her son’s second pediatrician, which was the opposite of her first pediatrician. The second pediatrician promptly recommended a referral for a neurologist who helped provide guidance including conducting assessments, a genetic study and discussion of not pursuing medication. The parent shared that the neurologist helped address all of her primary concerns:
Student #5’s Mother: “The second doctor referred us quickly to the neurologist. We just took him and she sent us to do some exams and she completed an assessment. One of the studies she referred him for was genetics and regarding the medication she told me personally I do not agree with giving medicine to children. She interact with him and told me he acted well with her. She asked me a lot of questions and she told me that she didn’t think medicine was necessary. She shared that ‘I opt for medicine, when I see that a child is absolutely hyperactive.’ This doctor helped me a lot.”

“La segunda doctora nos referio luego luego a la neuróloga. Apenas lo llevamos y ella nos va a mandar a hacer estudios y hizo examenes. Uno de ellos es el estudio de genética y del medicamento ella me dijo yo en lo personal no estoy de acuerdo en darles medicamentos a niños. Interactuo con el y me dijo que actuó bien con ella. Me hizo muchas preguntas y ella me dijo para mí creo que no es necesario la medicina. Yo opto por la medicina, cuando veo que un niño es imperativo por completo. Esta doctora me ayudo mucho.”

Positive Experiences with Educators and Service Providers
Overall, parents expressed positive experiences with school staff with helping their children meet their goals, making progress at school, developing new skills and with moving to less restrictive special education settings and accessing greater inclusion opportunities. Some parents also expressed appreciation for past providers, such as teachers who they continue to work with and with community agencies such as the Tri-Counties Regional Center for providing the initial early start services.
More specifically, one parent shared the positive experience of working with her son’s preschool special education teacher in the SBCEO LEAP autism program. She continues to ask for advice and asks questions to this day. She also shared that she has respect and sees that her son’s current special education teacher in elementary school works well with children with autism, including her son. She is very pleased with the experiences with her son’s special education teachers:

**Student #5’s Mother:** “My son’s previous preschool teacher of the autism program has been the one who I run to with any questions to this day. If I have some documents to fill out, I call her to help me. Whenever I need help, she is the one who helps me. My son’s current teacher is a person that has my respect and works great with children with autism. He told us that he has a son with autism and says, ‘Look, I live autism 24 hours a day.’ And he calls me frequently to guide me and says no, look do this.”

“La maestra previa de mi hijo en el preescolar del programa de an utismo ha sido la que corro con ella para cualquier pregunta todavia. Tengo unos documentos que llenar y voy a ir a que ella me ayude. Siempre que yo necesito ayuda, ella es la que me ha ayudado. El maestro ahorita de mi hijo tiene mis respetos y trabaja bien con ninos con autismo. El nos dijo que tiene un niño autista y Él dice, ‘mira, yo vivo el autismo las 24 horas.’ Y el me habla frequentemente para guidarme y me dice no, mire haz esto.”

The parents of a child shared the positive experience and appreciation that they have for the assessment team from the Santa Barbara County Education Office and the Tri-Counties Regional Center who helped guide his family. The teams helped their family
understand autism and ultimately qualify for school-based eligibility and receive a clinical diagnosis of autism. They expressed how the assessment team from Santa Barbara County Education presented the information clearly and explained how they could help their child:

**Student #4’s Father:** “We’ve talked a lot about that we are so appreciative of the great teams we’ve had. We’ve learned a lot from the teams we’ve had. The referral and evaluation of the school did not take long, because everything was completed very fast. The whole team composed of you (the school psychologist), the teacher, speech therapist, nurse helped us before the meeting to understand the condition of autism at school and the (Tri-counties) regional center helped us with the medical diagnosis of autism.”

“Hemos hablado mucho por lo que hemos estado tan agredicido con el gran equipo que hemos tenido. Hermos aprendido mucho del equipo que hemos tenido. La referencia y la evaluacion de la escuela no tardo tanto, porque todo fue muy rapido. El equipo que estuvo compuesto por ti (el psicologo escolar), por la maestra, terapista de habla y enfermera nos ayudaron antes de la reunion de entender la condicion de autismo en la escuela y el centro regional nos ayudo con el diagnostico medico de autismo.”

**Student #4’s Mother:** “When you came, the nurse, the therapist, and the teacher helped us alot. That is, everything I asked was answered in a way that I could grasp. It helped us understand how we could help my son.”
“Cuando viniste tu, la enfermera, la terapista, y la maestra nos ayudaron mucho. O sea, todo lo que yo les preguntaba me lo contestaban de una manera que yo lo podía captar. Nos ayudaron entender como le podía ayudar a mi hijo.”

The parents of a child expressed how they were appreciative of the special education teacher who saw significant potential in their child early on. His teacher helped him gradually increase his inclusion time. The support provided lead to him moving from a special day classroom to a general education class full-time the following year:

**Student #4’s Father:** “So much was the potential the teacher saw in our son that she told us about her experiences with previous students that had similar skills as our son. She provided him a lot of time in the general education inclusion class. She later told us ‘I would love to keep it, but I don't want to stop it, I don't want to cut his wings because of the potential that I see it since I prefer it to fly better. I'm going to watch him from a far.’ ..... She recommended that he enroll in a general education classroom the following year.”

“Tanto fue el potencial que la maestra vio en nuestro hijo que nos comentó su experiencia con estudiantes que haber tenido el pasado con muchas similares a las que tenía mi hijo. Le dio mucho tiempo en la clase general de inclusion. De lo que nos dijo ‘a mí me encantaría mantenerlo, pero no lo quiero detener, no le quiero cortar la alas por el potencial que lo veo desde prefiero mejor que vuele y yo voy a estar este viendo lo de lejos’ ..... Nos recomendio que fuera a una clase de educacion general el próximo año.”

The parents of a child indicated that he’s appreciative that the Tri-Counties Regional Center provided support and encouraged them to initiate and attend the early start
intervention sessions. The parent also shared that they would not have participated in the early intervention program had they not demonstrated interest:

**Student #3’s Father:** “Truthfully, the reason we started in the program was because they insisted a lot from Tri-Counties (Regional Center) for us to do it. They also called me to remind me not to miss classes or anything like that for my daughter. I appreciate that. If I would have seen disinterest in them for the daughter, I would not have done it (the program). But truthfully, they insisted and called us to attend the classes with our daughter.”

“En verdad, la razón que comenzamos en el programa fue porque nos estuvieron insistiendo mucho de tres candados para que lo hiciéramos. También me estuvieron hablando para recordarme de que no faltara a las clases ni nada de eso de la niña. Eso se si los agradezco. Posiblemente se hubiera visto desinterés también por la niña, no lo hubiera hecho (el programa). Pero en verdad, nos insistieron y nos llamaban para que fuiéramos a las clases con nuestra niña.”

The parents of a child reported that the transition to the classroom from early start services was an adjustment for their son and the family. However, the family credits that the experience was positive due to the strategies, support and encouragement provided by the SBCEO LEAP preschool special education teacher and classroom staff:

**Student #5’s Father:** “At first it was difficult because he had a couple of days that he cried. It was difficult for him to adapt to what he had to do and for us too. He wasn't at the house in order to be in class and it was different. For us it was worrisome. The teacher worked with our son and he started to adapt. We saw that she had a lot of patience and we saw that he began to stop crying and he stopped
being lazy in the morning. But later he learned his routines. The teacher began to use strategies to work with him. And then she started giving us tips and gave us a lot of information to help him (with the routine). In reality, I think that we only have words of appreciation and positive things to say about the teacher and with everyone in the autism class.”

“Al principio era difícil porque tuvo un par de días que lloró. Fue difícil para acoplarse a lo que tenía que hacer y para nosotros también. No estaba en la casa para estar en la clase y era diferente. Para nosotros era preocupante. La maestra trabajó con nuestro hijo y se empezó a acoplar. Vimos que le tenía mucho paciencia, vimos que empezó a dejar de llorar, como dejó de tener flojera en la mañana. Pero ya después sabía sus rutinas. La maestra empezó con estrategias de trabajar con él. Y entonces nos empezó a dar todos esos tips, nos daba mucha información para ayudarle (con la rutina). En realidad creo que solo tenemos palabras de agradecimiento y cosas positivas de decir de la maestra y de todos en la clase de autismo.”

**Mixed Experiences with Educators and Service Providers**

Overall, parents expressed both positive experiences with some initial concerns with early intervention services, school or teachers. These initial concerns were ultimately addressed by teachers and related service providers or by moving their child to a new service provider, class or school. Positive experiences include the time dedicated by teachers, school staff, principal and early interventionalist to meet the needs of students and parents. Some parental concerns expressed include supervision by staff of their child
or teachers who they perceive to not be as interested to help or do not demonstrate that they care as much.

More specifically, the parents of a student shared that their initial experience with the first school was disappointing and challenging. They shared concerns with the supervision of their child during recess and they ultimately switched his schools when he got hurt one day. The father expressed that the experience at the second school has been great. They are pleased with the teacher and principal who have been very helpful:

**Student #5’s Mother:** “We had to move my child from the first school. At the first school, I would leave in the morning every day and wait sometimes out there, because sometimes they would leave my child outside and they would go to the classroom. I would watch him through the fence to see where my child went. Then one day they called us that my child had been hurt, that he had hit a sign and that was when we chose to change his schools.”

“Tuvimos que mover mi niño de la primera escuela. En la primera escuela me iba en la mañana todo los días y esperaba a veces allá afuera, porque a veces al niño me lo dejaban afuera y ellos se iban al salón. Entonces ya iba y lo miraba por la reja para ver a dónde se iba el niño. Entonces un día nos llamaron que se había lastimado el niño, que se había pegado con un sign y fue cuando optamos por cambiarlo de escuela.”

**Student #5’s Father:** “At the new school, the teacher and the principal are very good. They are always amazing and support and help us.”

“En la nueva escuela la maestra y la directora, son muy buenas. Son increíble siempre y nos apoyan y ayudan.”
One parent shared that he had experience with two types of teachers. Teachers who make a difference and help children and teachers who are not as interested to help or do not demonstrate that they care as much. This has caused some additional concern since he shared that children with autism need help:

**Student #1’s Father:** “Children with autism have lower grades and require more help. I worry more when we’ve seen that there are people like the teachers in some classes who are not interested in helping them or do not care if they have children like that. But not everyone is like that. There are teachers that really do help the children.”

“Ninos con autismo, tienen mas baja sus calificaciones y ocupan ellos más ayuda. Pues me preocupo más, porque a veces hemos visto que ay personas como las maestras en unas clases que no les interesa o no les importa si ay niños así. Pero no todos son así. Ay maestra que sí les ayudan de verdad a los niños.”

One parent shared that the school principal was very supportive and always made time to meet with the family regarding any concerns. He was appreciative of the time she made to meet with them, even with her very busy schedule and appointments:

**Student #5’s Father:** “When we had a concern or doubt, the school principal always told us you know I have an appointment, but let me check. And she would let us know for example, I have 15 minutes this day, I have 10 minutes this day. She always looked for a way to make a space for us even though she had other appointments. Sometimes she would apologize and tell us I only have 5 minutes but I can talk to you right now if you want. We were often times concerned but the school principal helped us a lot.”
“Cuando teníamos una preocupación o duda, la directora de la escuela siempre nos decía sabes que tengo una cita, pero déjame chequer. Y me decía sabes que tengo 15 minutos este día tengo 10 minutos nada más. Lo que sí te pido es que estés a tiempo. Siempre buscaba el modo de hacernos un espacio aunque tenía otras citas. A veces decía discúlpame pero tengo 5 minutos y te puedo escuchar ahorita si quieres. Entonces siempre que se podía nos daba ese oportunidad a nosotros. Como te digo, nosotros nos preocupan mucho pero la directora de la escuela nos ayudó mucho.”

One parent shared the initial negative experience with the first early start interventionist and then shared her positive experience with the second early start interventionist. The parent was concerned about the limited experience and interactions during the sessions for the first early start interventionist. However, she reported that the second interventionist was very patient, experienced and worked well with her son:

Student #1’s Mother: “What I didn’t like about the teacher (for early services) is that she forced him to grab a toy, but she put it farther away so that he could crawl and I didn't see that as acceptable and I kept quiet. I didn't say anything and then I told my husband because our son cried when she did that. The worst part was watching my son cry. And then they put someone else as his teacher for him. That person was more attentive and worked very well with my son. The first one was younger and without any experience and everything was done fast and with signs. The second one was the opposite, she was experienced and very patient.”

“Lo que no me gusta de la maestra (de servicios temprano) es que lo forzaba a agarrar un juguete, pero le puso como para que gatara y eso no lo vi aceptable y
me quedé callada. No dije nada y luego le comenté a mi esposo porque el niño lloró cuando hizo eso. Y más mal fue cuando vi a mi hijo llorar. Y después me pusieron a otra persona para su maestra. Esa persona era más atenta y trabajaba muy bien con mi hijo. La primera era más joven y sin nada de experiencia y como que todo era rápido y con señas. Y la segunda era lo contrario, tenía experiencia y era muy paciente.”

Advice (“Consejos”) Received from Other Parents

One of the parents shared that her weekly tea session with her friends, helped her understand that her son needed a referral for early start services. One of her friends suspected that her son had developmental delays and encouraged her to call the Tri-Counties Regional Center for early start services. The parent credits her friend’s knowledge and guidance as to the reason for her son receiving early start services and special education services. Her son’s pediatrician did not make a referral or informed the parent of the services available:

Student #1’s Mother: “I used to go to a tea with other mothers every week when my son was young. One of my friends from the tea focused a lot on my son because he did not speak and appeared to be delayed developmentally. He didn't speak. She would tell me don’t give him everything. She said to let him say it first before providing the item to him. Through another friend, she recommended that I talk to the Tri-Counties Regional Center and that I ask for an assessment for my son at the age of two and a half. I didn't know about these early start services. My son's pediatrician had never told me about the services. Thankfully, two of my friends provided me with some guidance with the referral process.”
“Iba antes a un te con otras mamas cada semana, cuando mi hijo estaba chiquito. Una de mis amigas se enfoco mucho en mi hijo porque no hablaba y paracia que estaba atrasado en su desarrollo. No hablaba. Me decia no se lo des todo. Me decía dejale que el lo diga antes de darselo. Por medio de otra amiga, me recomendó que la hablara al centro regional para pedirles un examen para mi hijo a los dos años y medio. Yo no sabia de esos servicios temprano. El pediatra de mi hijo nunca me había dicho de los servicios. Afortunadamente, mis dos amigos me brindaron orientación con el proceso de referencia.”

“Consejos” (Advice) For Other Parents

Overall, many parents expressed consejos (advice) for other parents regarding disabilities including understanding developmental milestones, talking to their child’s pediatrician about their concerns at an early age, asking for a referral to a developmental specialist to assess, and disregarding cultural fears or stereotypes about disabilities. Parents recommended that they trust the specialists and psychologists during the assessment process and accept the diagnosis of autism for their son or daughter. Parents also recommended having an positive mindset, educating oneself about autism, seeking intervention and special education services and observing specialists that work with their child to learn techniques and strategies to help their child. Next, parents also recommended that other parents insist that they would like a referral and assessment now when their concerns are dismissed by the pediatrician. Finally, parents also recommended involving fathers in the process, when possible during doctor appointments, early intervention sessions, school meetings (IEP’s) and assessments.
More specifically, one parent shared that although she had a positive experience with her son’s pediatrician, clinicians and the school, she experienced difficulties with initiating the ABA services. She emphasized that it is critical for parents to follow-up with the referrals until they are complete and services are initiated. She compares her experience with applying for a job. Parents need to demonstrate interest in the process and follow-up with the service provider:

**Student #2’s Mother:** “Yes, everything went well with the doctors and the school. It’s just that where I did struggle and that I had to push was with the services for ABA. They took a long time to respond back. You have to keep pressuring and pressuring and pressuring them so that they respond and start the services. If not, and if you don't follow-up with them then they won’t move on your referral. It's like when you go and apply to a job and wait to be called. No, you don't have to wait. You have to dial them today in an application so that they see that you have an interest. This is my advice to parents. Don’t wait.”

“Si, todo me salió bien con los doctores y la escuela. No más en donde sí batallé fue con los servicios de ABA. Taradan mucho para contestarte. Tienes que estar presionando y presionando y presionando para que te responden y comiencen los servicios. Si no no se mueven con la referencia. Es casi cuando tu vas y aplicas a un trabajo y esperas a que te llamen. No, no tienes que esperar. Tú tienes que marcar hoy y enseñar que tienes el interés. Este es mi consejo para los padres. Que no se esperen.”

One parent recommended that parents be involved in the referral process and that they have patience and awareness of their child’s needs:
Student #1’s Mother  “May they seek out your services and that they be more aware of their children’s needs from an early age. And that they also have a lot of patience with your son and be involved during the (referral) process.”

“Que les busquen a ustedes para servicios y que sean más conscientes de las necesidades de sus hijos desde temprano edad. Y que tambien le tengan mucha paciencia con su hijo y que esten involucrados en el proceso (de referencia).”

One parent recommended that fathers be actively involved with their children, including their schooling and medical appointments. He shared that in the Hispanic culture, it is typically the mother that handles the responsibilities of the children but advised against this approach. He shared that it ultimately benefits the children when everyone works together and alleviates the stress and pressure off the mother. He also shared that everything is possible with knowledge and encouraged parents to seek the services and support:

Student #4’s Father: “That they seek help and that they are not alone. It’s possible, it's just knowing or learning how. More than anything, in our Hispanic culture we have to get involved as fathers because typically in Hispanic culture my wife is the one who takes care of the children. She is the one who is in charge of the doctor and school. No, it is (our responsibility) to be involved as a father because everything depends with how we help our children. I'm going to get involved to relieve the stress for my wife. Because it's obviously her, my wife, who is stressed when we put everything on her. Well and what better way to help her out. The way that we improve this is by getting involved and it's much better and easier for everyone.”
“Que busquen ayuda y que no estan solos. Si se puede simplemente es saber o aprender cómo. Más que nada en nuestra cultura hispana tenimos que involucrarnos como papas, porque típicamente en la cultura hispana mi esposa es la que se encarga ella de los hijos. Ella es la que se encarga del doctor y escuela. No es (nuestra responsabilidad) de estar involucrado como papa porque todo depende como lo ayudamos a nuestros hijos. Yo me voy a involucrar para alevenar el estrés de mi esposa. Porque obviamente es ella, mi esposa, la que está estresada cuando le ponenos todo en ella. Bueno y también cual sera la mejor manera de uno de ayudarle a ella. Y lidiar con eso es involucrarse y es mucho mejor y mas fácil para todos.”

One parent recommended that parents have a positive mindset, educate themselves and to talk to their child with autism about their condition. She advised parents against allowing their children to feel or be labeled by their condition. The parent shared that each child is an individual and has different skills and that it is important to have hope that their child will make progress with time:

**Student #4’s Mother**: “Ask and educate yourself. Keep in mind that just because your child still does not advance, that he will not be the same all his life. Also know that the level of autism is wide. Maybe your child has less skills and your other child has more skills. Have the mindset that you can accomplish it. You can move forward if you put your mind to it. Always talk to the child who has the condition of autism and explain what it is. And let him know that he shouldn’t feel labeled. I’ve always told my son to always walk with his head held high. Never look down.”
“Pregunta y informate. Ten en cuenta que solamente por que tu hijo todavía no avanza, que no se estar igual todo la vida. También se que el nivel de autismo es súper grande. Quizás tu hijo tiene menos habilidades y el otro tiene más habilidades. Piensa en que si se puede. Si puede avanzar si a uno se le propone. Pero siempre hay que hablarle al niño que tiene la condición de autismo y explicarlo que es lo que es. Y que no se siente etiquetado. Y que siempre le he dicho a mi hijo que siempre camine con la frente en alto. Nunca agaches la mirada.”

One parent shared that parents should consult with a specialist or doctor to assess and work with their child, rather than feel shame or fear to do so. In addition, parents should be flexible with the scheduling so that the specialist or doctor can help their child promptly. The parent also shared that it’s also helpful to learn the techniques used by the specialist or doctor in order to help their child with autism:

**Student #4’s Mother:** “Don't be embarrassed to ask for help or to consult with a doctor, psychologist or Tri-counties. Because many times as parents we do not ask out of shame or fear of what others will say. The other advice is that they watch what the therapist or doctor does and learn the techniques well, because the doctor or therapist will only be with your child a maximum of 1 or 2 hours and as a parent you are with your child 24/7. But also as parents we need to be flexible with the days and times for the therapists and doctors to assess or work with our child. You have to be willing for the psychologist, the nurse, the therapist to go at any time. I told them to come at any time, whatever day.”
“Que no les de vergüenza preguntar por ayuda o de consultar con un doctor, psicologo o con tres condados. Porque muchas veces como padres no preguntantamos por vergüenza o por el qué dirán. El otro consejo es que lo que vean que haga el terapista o el doctor lo aprendan bien las tecnicas, porque el doctor o el terapista va esta un máximo de 1 o 2 hora con su hijo y uno como padre está 24/7 con ellos. Pero también como padres tenimos que ser flexible con los días y tiempos que te ofrecien los terapistas y doctores para evaluar o trabajar con nuestro hijo. Tienes que estar dispuesto para que vaya el psicólogo, la enfermera, la terapista a culquier tiempo. Les dije que veyan a la hora que sea, el día que sea.”

The parents of a child recommended that parents consult with their child’s pediatrician regarding any concerns and that they request an evaluation as soon as possible. One parent also recommended that they understand and educate themselves when their child’s skills are no longer developmentally normal, such as age three, and that they seek the help at that point:

**Student #3’s Father:** “Parents should know that if they suspect that something is not normal with their children, that they can request an evaluation as soon as possible with the doctor.”

“Los padres deben saber que si llegan a sospechar que algo no esta normal con sus hijos, que pueden pedir una evaluacion la mas pronto posible con el doctor.”

**Student #3’s Mother:** “Also, parents should know that if they have any concerns that it is better to consult with the doctor when they are younger in order to put to rest those concerns because the services help their child. Also, not all children are
the same. Children reach a certain age like 3 years and it’s important to know that it is not normal and to seek the help at that point.”

“También, los padres deben saber que si tienen preocupaciones cuando estan chiquitos que es mejor ir con el doctor y sacarse de dudas por que los servicios les ayuda a los niños. También, no todos los niños son iguales. Pero también los niños llegan a una cierta edad como a las 3 años y tienes que saber que no es normal y tienes que buscar la ayuda a ese punto.”

One of the parents shared that parents need to talk to their child’s pediatrician and insist that they check their children for autism. She also recommended that parents should also trust their doctors, psychologists, teachers and children. The key is to have patience and learn from the specialists on how they can help them:

**Student #8’s Mother:** “What I recommend to parents is that they trust their doctors, psychologists, teachers and their children. They are there to help you. It is important that they talk to their doctors and insist and insist until the doctors check their children for autism. And as I tell parents who are just starting with children who have autism is that they need to have the patience more than anything because sometimes it is difficult with them, but with studying and talking to specialists you gradually learn how to help your son. More than anything the key is to have patience.”

“Lo que recomiendo a los papás es de que confíen en los doctores y psicólogo, maestros y en sus hijos. Ellos están allí para ayudarlos. Es importante que le hablen con sus doctores y insistir y insistir hasta que los doctores chequen a los niños para el autismo. Y como le digo los papás que apenas están comenzando
con niños que tienen autismo es que les tengan paciencia más que nada porque a veces es difícil con ellos, pero estudiando y hablando con los especialistas poco a poco uno aprende como ayudarle a tu hijo. Más que nada, la clave es tener paciencia.”

The parents of a child advised parents to check in and consult with their child’s pediatrician as soon as they have concerns related to autism. One parent also shared that it’s important to accept the services and any advice or guidance provided by the specialist. They also advised parents to prepare a list questions ahead of every meeting or appointment with the pediatrician:

**Student #5’s Father:** “Well, the advice mainly is that if there is a possibility that your child has autism, do not make the mistake of refusing to accept the help, take the advice and start the services. They will realize later if there is a mistake. It's best to start services so that specialists work with your child as early as possible. The other thing is that sometimes in the moment you forget the questions you have for appointment or meetings. The best thing to do is make a list of questions to ask doctors, specialists, or teachers ahead of meeting.

“Pues el consejo principalmente es que si hay la posibilidad de que su hijo tenga autismo, que no cometan el error de negarse a aceptar la ayuda, que tomen el consejo y comiencen los servicios. Pues ellos ya se darán cuenta más adelante si hay una equivocación. Lo mejor es empezar los servicios para que los especialistas trabajen lo más temprano posible con su hijo. La otra cosa es que a veces en el momento se les olvida las preguntas que tienen para citas o juntas.
Entonces es mejor hacer una lista de preguntas para hacerle a los doctores, especialistas, o maestra antes de la junta.”

**Student #5’s Mother:** “They are also advised to check in and consult a lot with their child’s doctors, such as the pediatrician especially about the referrals and assessments for autism. It’s important that they do these appointments as soon as possible.”

“También les recomendo que se asesoren y que consulten mucho por medio de los doctores, como el pediatra de su hijo especialmente sobre las referencias y examenes para el autismo. Es importante que los hagan estas citas lo mas pronto posible.”

One parent recommended that parents consult with their child’s pediatrician as soon as they suspect that their child has symptoms of autism. The parent also recommends requesting an assessment promptly when they are younger and to not commit the mistake of waiting until they are older to start an assessment (such as at age 4-5):

**Student #6’s Father:** “Well, I recommend that they call the child’s doctor because he is the only one who can help you with the diagnosis of autism.

Because when you ask family, they're not going to know about it. Only the doctor will know. Well, if there is a new person who suspects that your child has autism please do not wait long to complete the assessments. Do not wait so long because there are people who (wait) until 4 or 5 years to start the assessment. For children it is better that the studies be done soon when they are young. It's best if parents start with consulting with their child’s doctor. And if their child has autism, it is best to accept it.”
“Pues yo recomiendo que le llamen al doctor de su niño porque él es el único que puede ayudarle a uno con el diagnóstico de Autismo. porque se le preguntan a la familia, ellos no van a saber sobre eso. Solamente va saber el doctor. Pues si hay una persona nueva que suspecha que su hijo tiene autismo que no esperen tanto para ser los estudios. Que no esperen tanto porque hay personas que (se esperan) hasta los 4 o 5 años para empezar a ser los estudios. Para los niños es mejor que lo hagan los estudios pronto cuando estan pequeños. Es mejor que los papas empiecen con llamar al doctor porque. Y si el niño tiene autismo, lo mejor es aceptarlo.”

**Advice for Schools**

Overall, many parents shared advice for schools including ensuring that special education teachers have sufficient support in the classroom with resources and staffing, having personnel that are patient and calm when working with students with special needs, having low class sizes for special education classroom, and providing additional resources or guidance to parents that believe that their child only has a speech and language delay but that appears to have symptoms of autism.

More specifically, the parents of a child share that have had excellent teachers and principals. They have also had some special education teachers that should be teaching general education instead. Their advice for schools is that their special education teachers need to be patient and calm when working with students with special needs. They also recommended that the schools provide special education teachers with sufficient support in their classroom:
Student #5’s Father: “We've seen it all. We have had teachers and principals who have been excellent and we have had others who simply do their job, right? And we have had excellent special education teachers and special education teachers who should be dedicated to teaching regular children. Because what we have noticed is that it takes a lot of calm and a lot of patience to deal with children with autism. Sometimes we ourselves wanted to justify some attitudes of the teachers and say well, it is very difficult to deal with so many children. Our advice to the school is to provide teachers with sufficient support and for teachers to be dedicated to your students with special needs.”

“Hemos visto de todo. Nos ha tocado maestros y directores que han sido excelentes y nos han tocado otros que pues simplemente hacen su trabajo, no? Y nos ha tocado, a maestras de educacion especial que son excelente y maestras de educacion especial que deberían dedicarse ha ensenar a los niños regulares. Porque lo que sí hemos notado nosotros es que se necesita mucha calma, mucha paciencia para tratar con los niños con autismo. A veces nosotros mismos queríamos justificar algunas actitudes de los maestros y decir bueno, es que es bien dificil lidiar con tantos niños. Nuestro consejo para la escuelas es proporcionar a los maestros el apoyo suficiente y que los maestros se dediquen a sus estudiantes con necesidades especiales.”

Student #5’s Mother: “Our advice is to give special education teachers a little more help such as more assistants in these types of classrooms. I have heard of another school that does not have enough help in the class and they have children
with wheelchairs and the teacher struggles with having enough support. So sometimes there are schools that need a lot more staff to be able to help teachers.”

“Nuestro consejo es que les den a las maestros de educación especial un poquito más de ayuda como por ejemplo más ayudantes en este tipo de salones. He sabido de otra escuela que no tiene la suficiente ayuda en la clase y tienen a niños con silla de ruedas y lucha por tener suficiente apoyo. Entonces ay a veces hay escuelas que necesitan mucho personal para poder ayudar a los maestros.”

The parents of a child recommended that special education classrooms should have fewer students since they require dedicated support and attention from staff. They shared that although the teachers do the best that they can, they appear overwhelmed and stressed out and need additional support. They recommend the addition of support staff to help the teacher and students since they have special needs:

**Student #1’s Father:** “My recommendation is that teachers should work with fewer children in the special classes, because right now they are working with too many children who require specialized services with dedicated attention from staff. Sometimes not all the attention is given because they have too many children in the special education class. They should have fewer children in classes to give them more attention and more help to the children since they have special needs.

Mi recomendación es que las maestras deberían de trabajar con menos niños en las clases especiales, porque ahorita están trabajando con muchos niños que requieren servicios especializados with dedicated attention from staff. A veces no se da todo la atención por que tienen muchos niños en las clases especiales.
Deberían de tener menos niños en las clases para darles más atención y más ayuda a los niños por que tienen necesidades especiales.”

**Student #1’s Mother:** “The schools should also separate the children who need the most help into different special education classes to help them better. Teachers and students also need more assistants to help children with special services. Although they do the best that they can, the special education teachers appear overwhelmed/stressed out and they need more support. It is a very difficult job.”

“Las escuelas deberian apartar los niños que necesitan la más ayuda en diferentes clases de educacion especial para que les ayuden mejor. Las maestras y los estudiantes tambien neceistan más ayudantes para que ayuden a los niños con los servicios especial. Aunque hacen lo mejor que pueden, los maestros de educación especial parecen estresado y necesitan más apoyo. Es un trabajo muy deficil.”

The parent of a child shared that parents often do not have adequate services in schools or a diagnosis of autism yet because they often believe that their child only has speech and language difficulties. She shares her experience for receiving an early diagnosis of autism. She encourages others parents to seek support from their school and pediatrician for a screening for autism and potentially a referral to see a behavioral and developmental pediatrician. She encourages school to provide support for parents that believe that their child only has speech/language deficits who demonstrate symptoms of autism:

**Student #2’s Mother:** “A lot of people tell me that their child has a speech delay from their school. And I tell them my child too and they tell me how did you do it? I tell them since that I took my child from a young age to a behavioral and developmental pediatrician. And I tell them that I had him diagnosed with autism
at age two. They tell me no, I haven't heard of her or about those types of services. And their children are already three, four or five years old. And I tell them to tell their child’s pediatrician, since they can check them for symptoms of autism that they can refer then refer you to the specialist for her waiting list. Because she is the only specialist in Santa Barbara in the entire county. I like to help because of parents don't know this. It’s important too for schools to help parents when they don’t know too much about Autism and believe it is only a problem with speech.”

“Mucha gente dice, o mi niño tiene un speech delay de su escuela. Y les digo también mi nino tambien y me dicen cómo le hiciste? Les digo no, es que me niño desde chiquito la lleve a la doctora de compartamiento y desarollo. Y les digo que me lo diagnosticaron a los dos con autismo. Dicen no a mí no yo no he escuchado de ella ni de ese tipo de servicios. Y sus ninos ya tienen los tres, cuatro o cinco años. Y les digo pues dile a tu pediatra, ya que tu ella te lo puede chequar para autismo y ya te puede referier a la especialista para su lista de espera. Porque es la unica especialista en Santa Bárbara en todo el condado. Me gusta ayudar porque los padres no saben esto. Es importante tambien que las escuelas les ayuden a los padres que no saben mucho del autismo y que piensan que es nomas problema de habla”

**Next Steps for their Children**

Overall, some parents shared potential next steps for children including receiving support from their child’s pediatrician to complete an ABA referral for services, requesting an assessment with their pediatrician or specialist to diagnosis autism, and initiating a
referral for services from Tri-Counties Regional Center (TCRC). The researcher provided support to two parents to initiate the referrals with TCRC.

More specifically, one of the parents indicated that her child’s pediatrician is in the process of assisting them with a referral for ABA services. The parent indicated that she previously paused the services since she did not have a positive experience with the initial ABA provider. She has experienced significant delays and is in the process of reapplying. The parent shared that she is on the waitlist and that there this is a shortage of therapists at this time:

**Student #5’s Mother:** “My child's pediatrician asked me at his last appointment, how his therapies are going? I said, I don't have any therapies. He asked me, “why?” I said I stopped them because I had ABA previously. I told the pediatrician that I did not agree with the supervisor. She wanted to work in a way with my child on certain behaviors, which were not helpful or important to us. So the services lasted almost a year, at which point I informed the ABA company that I needed to help my son to advance in the area of language. They did not, so I canceled it. I realize that I made the mistake of canceling it because right now I am wasting time because I have no services. My son recently had the appointment with his pediatrician and referred me back to ABA and speech services. He is on the waiting list now. Right now the same insurance called me and told me that they are no longer going to work with that company, but that they are going to send the families directly with agencies that accept special education children for speech starting in January. But they needed my permission. So right now I'm on hold. The ABA is delayed because they do not have sufficient therapists”
“La pediatra de mi hijo me pregunta en la ultima cita y cómo van sus terapias? Le dije, no tengo terapias. Me dijo por qué? Dije las corté porque yo tenia ABA. Le dije a la pediatra que salí de acuerdo con la supervisora. Ella quería trabajar de alguna manera con mi hijo en ciertos comportamientos, que no eran útiles o importantes para nosotros. Duró casi un año los servicios, a lo cual le dije yo necesito que avance en el lenguaje y no me sirvió de nada. Entonces yo lo cancelé. Cometí el error de cancelarlo porque ahorita estoy desperdiciando todo ese tiempo porque no tengo servicios. Tuvo la cita con su pediatra y me volvió a hacer la referencia para los servicios de ABA y speech. El esta en la lista de espera ahorita. Ahorita la misma aseguranza me llamaron y me dijeron que ya no van a trabajar con esa compania, sino que van a mandar a las familias directamente con agencias que agarran niños especiales para speech empezando en enero. Pero necesitaban mi permiso. Entonces ahorita ya estoy en espera. El ABA está atrasado porque no tiene suficientes terapistas.”

One of the parents indicated that he would like to pursue an autism diagnosis for his son. His son currently meets eligibility for special education under the autism criteria. In addition, the parent would like to request a more comprehensive speech and language evaluation so that they can understand more about his communication and potential outcomes:

**Student #1's Father** “Well, although my son already has the autism eligibility from school, I would like to have a diagnosis from his doctor. I would also like for him to have a more comprehensive assessment for communication and explain
to us what awaits him from here on out? Or what hope we can have so that he can communicate more?"

“Bueno, aunque mi hijo ya tiene los eligibilidad de autismo en la escuela, me gustaría tener un diagnostico de su doctor. También me gustaría que le hicieran un diagnóstico más profundo en la area de comunicacion y que nos expliquen qué nos espera de aquí en adelante? O qué esperanzas tenemos para que él se pueda comunicar más?”

One of the parents shared that she would like to obtain a formal diagnosis and made a doctor’s appointment for an assessment. She also reached out to the Tri-Counties Regional Center the previous year and did not receive a callback. She expressed frustration since she does not know what else to do. After hearing this, the researcher provided contact information to the parent and sent an email to the Tri-Counties Regional Center coordinator to follow up on her case. The referral is currently in progress and a coordinator was assigned to his case:

**Student #7’s Mother:** “I would like to have a diagnosis of autism from the doctor for my son. He already has (eligibility) from the school. I already made a doctor’s appointment for an autism study. The doctor told me that everything was fine last year and I didn’t know what to do anymore. He also gave me the number for the (Tri-Counties) Regional Center for assessment and they never called me. I don't know what else to do because they don't listen to me.”

“Me gustaria tener un diagnostico de autismo del medico para mi niño. Ya le tiene de la escuela. Le ese una cita para llevarlo al medico para hicierle un estudio. El medico me dijo que todo esta bien el años pasado y ya no se que hacer. También
me dio el numero para el centro regional para estudios y nunca me hablaron. No se que mas de hacer por que no me hacen caso.”

Analysis of Findings

Delays with Early Intervention Referrals

The dissertation findings according to the parent interviews and quantitative data highlight important themes that are consistent with the literature review. The interviews suggest that Latino families experience some early intervention referral delays prior to the age 3.

Delays with Receiving Special Education Services Eligibility Under Autism

In addition, the interview and quantitative data suggest that families experience delays with receiving the eligibility under the criteria of autism for special education services. The average mean for the age that students received an eligibility of autism for special education services was 4 years, 5 months with the youngest child being 3 years old and the oldest child being 7 years, 8 months. This is substantially over the age of 3 years old that students can be eligible for service.

Delays with Receiving A Referral for Assessment from Pediatrician

The interviews also suggest that Latino families experience developmental screenings that are either inadequate or performed at lower rates. This theme was recurrent with parents even after they reported concerns at an early age, prior to age three, when related to their development, such as delayed communication skills, social skills, restricted and repetitive behaviors and difficulty with transitions. The quantitative data from parents indicates that pediatricians referred their children for an assessment at the mean age of
3.15 years old. The range was wide and occurred for students as young as 2 years old (in one case) and as old as 4 years, 4 months.

The data indicates that pediatricians are generally referring children prior to them turning three year old for early start, however most are older in age when they are referred. For example, the data indicates that only one student was referred at the youngest age of two while the remaining students were referred at ages closer to age 2 years, 8 months and 3 years (50%) and over 4 years old (25%). This data suggests that there are referral delays present for most families since children can be referred as early as age 2. In addition, 3 of the 8 families (37.5%) interviewed were never referred by their pediatrician for early start services, despite parents sharing concerns about their developmental milestones prior to age 3.

**Parental Understanding or Knowledge of autism is Limited**

The interviews suggest that some Latino families had some knowledge or awareness of developmental milestone delays, either from their prior experience with older children or advice from family members or friends familiar with developmental delays. Although most families were unaware of the characteristics and had limited knowledge of autism, the majority sensed that their child was delayed. The most often concerns reported by parents included regression in skills as they matured, delayed communication skills or predominately non-verbal communication, limited interest with social interactions with peers or family, and difficulty attending to tasks. The age that parents reported their concerns depended on their level of concern and knowledge of developmental milestones. Parents with significant concerns generally reported these concerns to their child’s pediatrician prior to age 3.
Use of Developmental Screeners By Pediatricians is Unknown

It is unclear from the interviews alone whether or not developmental screeners were utilized and to the extent they were utilized by pediatricians to rule out disabilities, so this area of research should be examined in future research. The parent interview suggest that some of the families that were not referred for an assessment at early age by their child’s first pediatrician needed to change pediatricians before they were referred. The three families that reported that they changed pediatricians shared that the new pediatrician was open to a referral for assessment and was responsive to addressing the parental concerns. Furthermore, many of the families shared that their concerns with the initial pediatrician were often dismissed and that no action was taken. They reported that they did not receive the information related to early intervention or assessment with the first pediatrician. The parents also shared that they were concerned because other families appeared to be impacted by similar delays in referrals and that they recommended that they also reach out to request an assessment to their new pediatrician.

The parent interviews suggest that Mixteco families experience some additional delays due to the language barriers with non-Spanish speaking physicians.

Delays with Obtaining a Clinical Diagnosis of autism or For Seeing a Specialist

Although quantitative data was not collected on access to health care on the survey, all of the families reported during the interviews that their children saw a pediatrician through Medi-Cal or through their private insurance as infants. There were no delays reported in access to medical insurance according to the parent interviews. However, according to the parent interviews, what appeared to be meaningful is that access to clinical specialists that conduct assessments with autism was a barrier for most families. Only one out of the
eight families reported being provided a referral to see a Behavioral and Developmental Specialist. Most of the families interviewed shared that they initially were assessed by the Tri-Counties Regional Center or the Santa Barbara County Education Office as part of their transition to preschool at ages closer to 3. This appears to be consistent with previous research that indicates that families from minority backgrounds or with non-dominant language experience different standards of care for the referrals for their children. This is also consistent with the CDC research that indicates that racial and ethnic disparities exist for obtaining a clinical diagnosis for children with autism.

**Use of “Consejos” to Assist with Referral and Developmental Milestone Knowledge**

The interviews suggest that many families often utilized and benefited from the advice of friends or family who had prior experience or knowledge of referrals or developmental milestones. This is consistent with research that indicates that Latino families often rely on informal sources of information rather than formal resources such as pediatricians or specialists. This can be attributed to the disparities experienced that delay the referrals in the first place or with the pediatrician taking no action. Even when families were provided with the resources, they continued to encounter disparities and delays, including no response or difficulty reaching staff or an assessment team at the agency to complete the referral or assessment. This occurred for even families that were proactive with reaching out, and parents advised others to continue to reach out and call multiple times until they received an update.
Organizations or Individuals that Helped Parents During the Process

Tri-Counties Regional Center and the Santa Barbara County Education Office

The most commonly referenced organizations by parents interviewed for the study were the Tri-Counties Regional Center and the Santa Barbara County Education Office. Parents often shared that they found the staff with both organizations as helpful and essential partners for providing their children with early intervention services and special education services. Some of the parents noted that the coordinators for the Tri-Counties Regional Center and the early intervention staff reached out frequently to encourage them to accept services and attend sessions.

Educators That Helped Parents

The parents most often shared that teachers and support staff (school psychologists and speech therapists) helped them understand the impacts of autism, the need for services, and for assisting them to connect to clinical providers. They also credited the teachers for providing them with strategies and working diligently to help their children with autism succeed in their classroom environment. Some parents continued to seek support from classroom teachers from preschool, even a few years after their children transitioned to elementary school.

Parents Need Additional Support with Tri-Counties Regional Center Referral

The parent interviews suggest that families that do not currently have Tri-Counties Regional Center services are experiencing some delays with connecting to staff for a referral for clinical assessments and services. Two of the eight families directly asked for help from the researcher during or after the interview, and he provided contact information and followed up with the coordinators to have them referred for an
assessment. This potential delay may be attributed to the remote referrals and assessment due to the COVID-19 pandemic or limited parental knowledge of the referral process, including how to request an evaluation or services.

Limitations of Study

Impact of COVID-19 Was Not a Part of Data Collection

The study did not evaluate the impact of COVID-19 since the primary focus of the study is to examine disparities that occurred from 2014-present for students. However, although research does not currently exist on referral delays, the pandemic may be another potential barrier to the referrals and diagnosis of autism, particularly for Latino families from Spanish-speaking and Mixteco-speaking backgrounds. In addition, most students did not attend preschool during the pandemic for some time until it reopened. Many of the referrals come from preschools directly or indirectly, and they may recommend that parents seek a referral from their pediatrician, the Tri-Counties Regional Center, or the Santa Barbara County Education Office.

Impact of Developmental Milestones Modified by CDC is Unknown

Furthermore, the CDC also modified the developmental milestones for children due to the pandemic, which may impact referral rates, assessments, and diagnosis of autism. Limited research exists to make any hypothesis or conclusion in this area with evidence. It is recommended that the impact of COVID-19 be examined in future research, particularly for the incoming preschoolers and Kindergarteners, to reduce the effects and barriers for families. It may take several years before quantitative and qualitative studies are completed in these areas. This can add to the potential obstacles and increase
disparities that Latino families already experience during the referral and diagnostic process (pre-pandemic).

Recommendations by Parents for Stakeholders

Parents Need to Check in Early with Pediatrician with Developmental Concerns

The interview with parents revealed several potential recommendations for schools, medical professionals, clinicians, and families new to the referral process. The theme most often heard from parents was that families new to the referral process should check in with their child’s pediatrician as early as possible when they suspect that their child has delays.

Pediatricians Should Refer Children Early for Assessment with Parental Concerns

The interviews indicate that parents that expressed developmental concerns to their pediatricians but were not offered an assessment shared some recommendations for parents. Similar to the interviews, the research indicates that children of color often do not receive routine developmental or autism screenings from a pediatrician in their primary language (Janvier et al., 2016). It is recommended that pediatricians conduct a comprehensive developmental screening with all infants and toddlers early to determine symptoms of autism in the family’s primary home language. In addition, it is recommended that the shared decision-making be utilized by pediatricians with parents to ensure that concerns by parents are noted and addressed accurately with referrals and assessments as early as possible. Shared decision-making can help prevent delays in the diagnosis of autism and for initiating early intervention and special education services.
Pediatricians Should Conduct Developmental Screenings with Children Regularly

Although it is unknown whether doctors or clinicians conduct screenings for autism from this current study, the literature on best practices indicates that developmental screening should be done early for all infants using autism screening and diagnostic instruments starting at age 2 (Nowell et al., 2015; Elder et al., 2017). Early identification is critical, in particular for students from ethnic and linguistically diverse backgrounds so that referrals and services can be initiated as soon as the infant or toddler is eligible.

Parenting Network or Parenting Group is Needed

Research indicates that culturally and linguistically diverse families benefit from working with others with shared cultural experiences, disability experiences, and shared understanding of family values (Burke & Goldman, 2018). They also benefit from services such as parent training on disabilities and services in their home language from schools (Burke & Goldman, 2018). A parenting network can help with eliminating or reducing barriers that parents face such as reduced sources of knowledge about autism, language barriers, and cultural stigma regarding disabilities (Magaña et al., 2013; Durkin et al., 2010; Bearman & Fountain, 2011).

While there are organizations that provide support in the community to parents, such as Alpha Resource Center for IEPs and Promotoras for health, some of the families expressed the desire for an organization to form a parenting network or parenting group that provides additional support to other families that have a child with autism. Some of the families shared that they would like the opportunity for new parents to meet with parents more experienced with the special education process and diagnostic process to discuss their concerns and offer other parents support in their primary home language.
One family in particular even volunteered to serve as facilitators if a parenting group was formed.

**Additional Outreach and Information is Needed by Parents from Regional Center**

Given the importance of children receiving early start referrals from birth to age 2 years, 11 months, it is critical for the Tri-Counties Regional Center staff to provide ongoing support and guidance to Latino families regarding the services and assessments. Latino families may face the stigma of autism and encounter family conflict due to cultural beliefs and limited knowledge related to disabilities (Dubay et al., 2018). This support is crucial since this is often the first time families are completing a referral for services and report that they have limited knowledge or experience with what to expect. This can cause parents to feel helpless or concerned about receiving additional support for home-based services or clinical diagnosis.

Although some families reported that the assessment and services were provided promptly by the Tri-Counties Regional Center, some families also indicated that they experienced significant delays during the intake process with the Tri-Counties Regional Center or that they are currently experiencing them (with a referral in progress). This required some families to attempt to reach the Tri-Counties Regional Center staff multiple times or not receiving a response back in a timely manner when requesting assistance to complete a referral. In addition, some families reported that the referral process for the Tri-Counties Regional Center is unclear. They do not recall being provided with an overall timeframe for how long the referral process will take or when to expect a call from the assessment team or provider.
SBCEO Should Continue Providing Guidance and Support for Parents

Many families reported that the preschool assessment process and assessment team was helpful and clear. Families shared that they learned techniques for helping their children by observing the staff work with them. They also reported that the assessment team and teachers often helped increase their understanding of autism. One recommendation that parents had for schools is to provide adequate support for teachers in the special day classrooms, such as increasing staffing in the classroom.

Recommendations by Parents for Referrals by Agencies

The parents also suggested that medical professionals and schools should provide more assistance with connecting families concerned with their child’s developmental delays or symptoms of autism with agencies or clinicians in the county. Furthermore, parents shared that the referral information should include specific clinicians that diagnose autism or connecting them with agencies such as the Tri-Counties Regional Center for early start services or with the Santa Barbara County Education Office or school district for special education services.

Recommendations for Researchers

Limited research exists related to the barriers and delays experienced by Latino Spanish-speaking and Mixteco-speaking families to obtaining early intervention services, special education services and a clinical diagnosis of autism at an early age. The current study demonstrated that Latino families experience barriers during the process of obtaining services and diagnosis of autism. Longitudinal studies should be conducted by researchers to further examine the barriers that families and students are experiencing in the referral and assessment process.
The purpose of further study is to gradually reduce and eliminate any disparities and barriers faced by Latino families during the diagnostic and referral process for early intervention services, special education services and a clinical diagnosis of autism as soon as they are eligible at a young age. Taking no further action likely prolongs and may even exacerbate the disparities and barriers that Latino families already face during the process which can also include health, educational, language, immigrant status, limited health care coverage, limited understanding of autism and cultural stigmas of disabilities. Ultimately, further research can help practitioners, pediatricians and schools increase the access for children with special needs and their families to early intervention services, special education services, and with obtaining a clinical diagnosis of autism.

Additional studies should utilize quantitative data to help clinicians, pediatricians, and school practitioners understand the extent of the delays expressed by the families at a larger scale. In addition, researchers should obtain a sample size reflective of the demographics of the families for this study, including Latinos from Spanish-speaking and Mixteco-speaking households. The data should be obtained from a variety of regions in the United States to ensure that these barriers are measured quantitively, including in Santa Barbara County, California, and nationally in regions that have a significant population of Latinos.

It is recommended that researchers obtain the following quantitative data when interviewing the families, including the student’s age, gender, ethnicity, home language, age of first concern (AOC), age of diagnosis (AOD), age of referral to Early Start services, age of referral to special education services, and age that special education services were initiated.
**Recommendations for Test Publishers**

Research indicates that children from immigrant and bilingual backgrounds may experience test bias during the assessment process or diagnostic bias from clinicians in particular during the cognitive and autism assessment. More specifically, children from bilingual backgrounds may perform lower on cognitive assessments which can lead to misidentification of cognitive disabilities (Nowell et al., 2015). Furthermore, some autism diagnostic tools may not reliably identify Latino children with symptoms of autism, especially from Spanish-speaking households (Blacher et al., 2014; Vanegas et al., 2016).

Test publishers should include an adequate representation of Latino parents from bilingual backgrounds (Spanish and Mixteco) in the norms for the next parent rating scale revision. It is recommended that publishers develop questions for parents on the autism assessments in a culturally-responsive manner that define the characteristics of Autism with specific examples for parents in Spanish and Mixteco.

Furthermore, including bilingual families in the norms and asking for feedback can help ensure that the terms are clear and the questions are understandable regardless of parent’s educational level and familiarity with autism. This is critical since research indicates that Latino parents may underreport some symptoms due to limited knowledge of the risk factors of autism (Overton et al., 2007; Magaña, et al., 2013; Venegas et al., 2016). Publishers should also recommend that clinicians, pediatricians or school psychologists interview parents with the autism scales in their primary language to ensure that parents understand the characteristics of autism adequately before providing a rating on the questions.
It is recommended that test publishers include higher percentages of Latino children with bilingual backgrounds in the test norms during the next revision of autism and cognitive assessment tools to ensure that the assessment tools are reliable and consistent with the current population according to the 2020 Census data. Accurate representation of bilingual students in the test norms can help reduce the test bias that exists in the assessment process.

These recommended changes for publishers are critical to ensure culturally-responsive assessment tools and ultimately eliminate the test bias that exists with current assessment tools. It is important for Latino children to be identified as early as possible as infants with a clinical diagnosis of autism (starting at age 2) and for special education services (starting at age 3). The ultimate goal is to help increase the number of Latino children that are accessing intervention services, and special education services and that families are receiving support to help their children at early stages without delays.

**Recommendations for SBCSELPA**

It is recommended that SBCSELPA collaborate with a network of community partners, pediatricians and schools to ensure that student referrals for autism as well as early intervention and special education services are provided early to all student populations, including Latino students from bilingual backgrounds (Spanish and Mixteco). One possible model to help eliminate these barriers is Help Me Grow. Help me Grow is a system model (Figure 11) which incorporates a centralized access point, family and community outreach, health care provider outreach and data collection (Help Me Grow, 2022). This is essential to ensure that the barriers for Latino students are
eliminated during the referral process so that they receive diagnosis of autism and services for early intervention and special education as early as possible.

**Figure 11**

*Help Me Grow Model*
References


CHAPTER FIVE: CONTRIBUTION TO PRACTICE
CHAPTER FIVE: Contribution to Scholarship

Contemporary School Psychology Journal Article Submission

A summary of the research study will be submitted to *Contemporary School Psychology* journal, published by the California Association of School Psychologists. The journal publishes peer-reviewed articles and research on various school psychology topics, from early childhood education to students with severe disabilities. The audience for the journal is practicing school psychologists nationwide.

The intent of submitting the article to this journal is to increase awareness about a rarely researched topic, especially for bilingual school psychologists. The study aligns with the journal’s mission because it addresses the needs of children, summarizes challenges faced by professionals and families, and is related to increasing inclusive practices.

The results of my study, including interviews and surveys with parents, can help practitioners understand any areas of strength and need in the referral process for special education with Spanish-speaking and Mixteco-speaking bilingual students in Santa Barbara County, CA. This is a critical area to address as preschool referrals are vital to the early identification of students with disabilities.

The study can also help additional researchers further explore the findings and conduct other research in areas of need in California and nationally to ensure that Latino students are appropriately referred for special education services. The ultimate goal is to reduce the disparities families face in the referral process. This will help to ensure that students are assessed as early as possible when parents express additional concerns related to a potential disability to their pediatrician or school.
Aim and Scope of the Study

The study appears to meet three of the significant components that the journal seeks when considering publication:

1. Providing best practices that address the needs of children.
2. Providing critical research that will enhance practices in school psychology.
3. Using a different theoretical framework for presenting a topic in school psychology.

Link to publication: https://www.springer.com/journal/40688

Keywords: disparities in referrals, Spanish-speaking families, Mixteco-speaking families, special education referrals, autism spectrum disorder

Draft Manuscript for the Contemporary School Psychology Journal

A draft manuscript of my findings and research will be submitted after my dissertation defense to the Contemporary School Psychology journal. The draft manuscript is included in Figure 12.
Figure 12

Draft Manuscript to the Contemporary School Psychology journal

SOCIO-CULTURAL AND SCHOOL BARRIERS THAT LATINO SPANISH-SPEAKING AND MIXTECO-SPEAKING FAMILIES WITH A PRESCHOOL CHILD WITH AUTISM SPECTRUM DISORDER FACE IN THE SPECIAL EDUCATION REFERRAL PROCESS IN SANTA BARBARA COUNTY, CALIFORNIA

Ivan DeJesus Alvarez

Received: date / Accepted: date

Abstract According to multiple studies, a referral process bias has existed in the early identification of autism for children of color, in particular Latino children. Sociocultural, economic, educational, and health care barriers significantly have impacted Latino children. For example, Latino children are less likely to receive access to early intervention services, are at increased risk for delays in the diagnosis of autism spectrum disorder (ASD), and are significantly older at the time of diagnosis (Magaña et al., 2013; Ratto et al., 2016). In addition, the delays in autism diagnosis among Latino children have been poorly understood among medical professionals and school personnel (Zuckerman et al., 2013).

The purpose of the study was to gather interview, survey, and quantitative data regarding the experiences of Spanish-speaking and Mixteco-speaking Latino families in Santa Barbara County, California, who have a child with autism spectrum disorder. The study examined the school referral process for special education services received in preschool for students and families from 2014. The study examined how sociocultural, economic, educational, and health care barriers affected Latino students in preschool during the special education referral process while also investigating Latino families’ experiences with their child who have received a clinical diagnosis of autism. The intent was to utilize the study results to propose possible changes and improvements for practitioners and school teams in the preschool referral process from the parents’ perspective for special education students in Santa Barbara County.

Ivan DeJesus Alvarez
Santa Barbara County Education Office, University of Missouri at Columbia
1 Introduction

Early identification of autism in children is associated with positive outcomes, including improved long-term prognosis, early intervention, and improved family acceptance of autism (Zuckerman et al., 2013). Early identification also reduces intellectual, behavioral, and functional impairments in students with disabilities (Fountain et al., 2008). Children who receive high-quality early intervention services have improved short- and long-term outcomes in relation to language and socio-emotional skills, cognitive functioning, adaptive functioning, peer relationships, educational performance, vocational training, and employment (Vismara & Rogers, 2010).

2 Methods

Participants

The subjects of the study were Latino families in Santa Barbara County who speak a primary language of Spanish and/or Mixteco and that have a child with school-based eligibility or clinical diagnosis of autism. The student needs to have received early start services or special education services.

Eight families that met the criteria agreed to participate in the study. 5 out of 8 families reported that they had a primary home language of Spanish, and 3 out of 8 families had a home language of Mixteco and Spanish.

2.1

2.1.1 Setting

Permission was granted by SBCEO for the researcher, to conduct in-person interviews at the Santa Maria or Lompoc county office with parents. The researcher completed zoom and in-person interviews at the SBCEO offices by appointment and completed the phone interviews at his home office.

2.1.2 Recruitment of Participants

The researcher recruited families after IRB approval was obtained and once formal written permission was granted from the local school districts and the SBCSELPA to initiate the study. A representative from each district and SELPA signed the consent letters via DocuSign to provide permission to initiate the study for parents in their district.

The researcher sent out emails to service providers and teachers in the county to recruit participants. The researcher verified student information for any recommended students using the special education management system to confirm eligibility for special education services under autism and verify that they had a home language of Spanish and/or Mixteco.
Families that met the criteria were contacted to determine their interest in participating in the study, including completing a parent survey and interview. Several families that were recommended by staff did not proceed to the next phase since they did not meet one or more criteria for the study. This did not impact the number of participants since eight families were recruited and participated in the study.

2.1.3 Survey Design and Interview

The researcher initiated contact with each family by explaining the research study and the requirements for voluntarily participating. Once parents agreed to participate, a survey was completed with the researcher via the preferred method of contact: zoom, in-person, or phone interview. Families were also allowed to conduct the interview and survey during one session or two sessions.

The researcher informed the families that they would be video recorded for in-person meetings, video recorded via zoom for virtual meetings, and audio recorded for phone meetings. The researcher shared that the first component would consist of a survey while the second component would consist of an interview with open-ended questions from a questionnaire.

The researcher initially asked language questions to the 3 Mixteco-Speaking families to ensure that the survey and interview were administered in their preferred language. The researcher informed the Mixteco-speaking families that the survey and interview could be done in Spanish or that they could have an interpreter in Mixteco, if they preferred. 3 of the three families confirmed that Spanish was preferred.

Sessions/Format of Interview

All eight families opted to complete the interview and survey during one session with the researcher. 4 out of the 8 families completed the survey and interview via zoom, 3 out of the 8 families completed the survey and interview via phone and 1 out of the 8 families completed the survey, and interview in-person.

Families were provided the opportunity to complete the interviews with one or both parents present. 4 out of the 8 families could meet together (father and mother). In contrast, the remaining four families had only one parent meet with the interviewer. One parent cited a preference to complete it by herself, one parent cited work schedule conflict, one parent cited a divorce, and one parent noted that his wife passed away.

2.1.4 Demographics of Families

The survey responses were analyzed to obtain the demographics of the families that participated in the study. 8 out of 8 families reported that they identified as Hispanic/Latino. 5 out of the eight families reported Spanish as the primary home language, and 3 out of 8 families reported Spanish/Mixteco as the primary home languages.
3 Results

3.1

3.1.1 Delays with Early Intervention Referrals

The study findings according to the parent interviews and quantitative data highlight important themes that are consistent with the literature review. The interviews suggest that Latino families experience some early intervention referral delays prior to the age 3.

3.1.2 Delays with Receiving Special Education Services Eligibility Under Autism

The interview and quantitative data suggest that families experience delays with receiving the eligibility under the criteria of autism for special education services. The average mean for the age that students received an eligibility of autism for special education services was 4 years, 5 months with the youngest child being 3 years old and the oldest child being 7 years, 8 months. This is substantially over the age of 3 years old that students can be eligible for service.

3.1.3 Delays with Receiving A Referral for Assessment from Pediatrician

The interviews suggest that Latino families experience developmental screenings that are either inadequate or performed at lower rates. This theme was recurrent with parents even after they reported concerns at an early age, prior to age three, when related to their development, such as delayed communication skills, social skills, restricted and repetitive behaviors and difficulty with transitions. The quantitative data from parents indicates that pediatricians referred their children for an assessment at the mean age of 3.15 years old. The range was wide and occurred for students as young as 2 years old (in one case) and as old as 4 years, 4 months.

The data indicates that pediatricians are generally referring children prior to them turning three year old for early start, however most are older in age when they are referred. For example, the data indicates that only one student was referred at the youngest age of two while the remaining students were referred at ages closer to age 2 years, 8 months and 3 years (50%) and over 4 years old (25%). This data suggests that there are referral delays present for most families since children can be referred as early as age 2. In addition, 3 of the 8 families (37.5%) interviewed were never referred by their pediatrician for early start services, despite parents sharing concerns about their developmental milestones prior to age 3.

[Fig. 1 about here.]
4 Discussion

Parental Understanding or Knowledge of Autism is Limited

The interviews suggest that some Latino families had some knowledge or awareness of developmental milestone delays, either from their prior experience with older children or advice from family members or friends familiar with developmental delays. Although most families were unaware of the characteristics and had limited knowledge of autism, the majority sensed that their child was delayed. The most often concerns reported by parents included regression in skills as they matured, delayed communication skills or predominately nonverbal communication, limited interest with social interactions with peers or family, and difficulty attending to tasks. The age that parents reported their concerns depended on their level of concern and knowledge of developmental milestones. Parents with significant concerns generally reported these concerns to their child’s pediatrician prior to age 3.

4.1

4.1.1 Use of Developmental Screeners By Pediatricians is Unknown

It is unclear from the interviews alone whether or not developmental screeners were utilized and to the extent they were utilized by pediatricians to rule out disabilities, so this area of research should be examined in future research. The parent interview suggest that some of the families that were not referred for an assessment at early age by their child’s first pediatrician needed to change pediatricians before they were referred. The three families that reported that they changed pediatricians shared that the new pediatrician was open to a referral for assessment and was responsive to addressing the parental concerns. Furthermore, many of the families shared that their concerns with the initial pediatrician were often dismissed and that no action was taken. They reported that they did not receive the information related to early intervention or assessment with the first pediatrician. The parents also shared that they were concerned because other families appeared to be impacted by similar delays in referrals and that they recommended that they also reach out to request an assessment to their new pediatrician.

The parent interviews suggest that Mixteco families experience some additional delays due to the language barriers with non-Spanish speaking physicians.

4.1.2 Delays with Obtaining a Clinical Diagnosis of Autism or For Seeing a Specialist

Although quantitative data was not collected on access to health care on the survey, all of the families reported during the interviews that their children saw a pediatrician through Medi-Cal or through their private insurance as
infants. There were no delays reported in access to medical insurance according to the parent interviews. However, according to the parent interviews, what appeared to be meaningful is that access to clinical specialists that conduct assessments with autism was a barrier for most families. Only one out of the eight families reported being provided a referral to see a Behavioral and Developmental Specialist. Most of the families interviewed shared that they initially were assessed by the Tri-Counties Regional Center or the Santa Barbara County Education Office as part of their transition to preschool at ages closer to 3. This appears to be consistent with previous research that indicates that families from minority backgrounds or with non-dominant language experience different standards of care for the referrals for their children. This is also consistent with the CDC research that indicates that racial and ethnic disparities exist for obtaining a clinical diagnosis for children with autism.

4.1.3 Use of “Consejos” to Assist with Referral and Developmental Milestone Knowledge

The interviews suggest that many families often utilized and benefited from the advice of friends or family who had prior experience or knowledge of referrals or developmental milestones. This is consistent with research that indicates that Latino families often rely on informal sources of information rather than formal resources such as pediatricians or specialists. This can be attributed to the disparities experienced that delay the referrals in the first place or with the pediatrician taking no action. Even when families were provided with the resources, they continued to encounter disparities and delays, including no response or difficulty reaching staff or an assessment team at the agency to complete the referral or assessment. This occurred for even families that were proactive with reaching out, and parents advised others to continue to reach out and call multiple times until they received an update.

5 Conclusions

Given the importance of early start referrals and referrals after age 3, it is critical for the Tri-Counties Regional Center staff to provide ongoing support and guidance to Latino families regarding the services and assessments. This support is crucial since this is often the first time families are completing a referral for services and report that they have limited knowledge or experience with what to expect. This can cause parents to feel helpless or concerned about receiving additional support for home-based services or clinical diagnosis.

Although some families reported that the assessment and services were provided promptly by the Tri-Counties Regional Center, some families also indicated that they experienced significant delays during the intake process with the Tri-Counties Regional Center or that they are currently experiencing them (with a referral in progress). This required some families to attempt to
reach the Tri-Counties Regional Center staff multiple times or not receiving a response back in a timely manner when requesting assistance to complete a referral. In addition, some families reported that the referral process for the Tri-Counties Regional Center is unclear. They do not recall being provided with an overall timeframe for how long the referral process will take or when to expect a call from the assessment team or provider.

While there are organizations that provide support in the community to parents, such as Alpha Resource Center for IEPs and Promotoras for health, some of the families expressed the desire for an organization to form a parenting network or parenting group that provides additional support to other families that have a child with autism. Some of the families shared that they would like the opportunity for new parents to meet with parents more experienced with the special education process and diagnostic process to discuss their concerns and offer other parents support in their primary home language. One family in particular even volunteered to serve as facilitators if a parenting group was formed.

Finally, many families reported that the preschool assessment process and assessment team were helpful and clear. Families shared that they learned techniques for helping their children by observing the staff work with them. They also reported that the assessment team and teachers often helped increase their understanding of autism. One recommendation that parents had for schools is to provide adequate support for teachers in the special day classrooms, such as increasing staffing in the classroom.

Author biography

Ivan DeJesus Alvarez  Ivan is a Bilingual School Psychologist for the Santa Barbara County Education Office. He is currently a Doctoral Candidate at the University of Missouri Columbia in the Department of Educational Leadership & Policy Analysis (ELPA)
References

CHAPTER SIX: SCHOLARLY REFLECTION
CHAPTER SIX: Scholarly Reflection

The Process of Developing into A Doctoral Scholar-Practitioner

The process of developing into a doctoral scholar-practitioner was a culmination of multiple skill sets and knowledge, including reading relevant literature/theories, learning and applying research skills, as well as understanding the experiences of families through my work as a school psychologist. I initially became interested in my research topic during my work as a Bilingual School Psychologist for Santa Barbara County Education Office.

I became concerned with the number of parents that I worked with during the special education assessment process that cited delays in the referral process for receiving an early intervention or special education services in preschool or with obtaining a clinical diagnosis of autism. The demographics of the families most often reporting these delays or concerns were predominately Latino families, in particular from primarily Spanish backgrounds. They often shared that they had limited knowledge of developmental disabilities and resources, including how to receive a clinical diagnosis or community resources.

As a result, I became invested over time in understanding how, why and when these disparities occur for Latino families in the special education process and for receiving a clinical diagnosis. My doctoral coursework and dissertation afforded me the perfect opportunity to research the disparities that families often experience in the referral process and for receiving diagnoses. Ultimately, I created a study proposal with a literature review to engage in research-in-practice to examine these areas of need.
**Initial Research Topic**

The initial steps towards my journey as a scholar-researcher began with selecting my research topic during my first year as a doctoral year and evolved with time during the course of my second year. For example, I developed my initial research topic as part of my Statement of Research during the Doctoral Application process in October 2018. My initial topic centered on investigating the factors that lead to positive outcomes for Latino Spanish-speaking special education students with significant needs including autism. I created an initial outline for my study during the Fall 2019. I indicated that I was interested in examining the developmental screening tools and cultural practices for increasing the identification of autism in schools for Latino students. Furthermore, I shared that the study’s intent was also to review the counseling approaches that can reduce the cultural stigma of disabilities in the Latino community and increase parental knowledge of evidence-based practice for autism. Here's an excerpt from my initial outline:

“The current study will explore potential developmental screening tools and cultural practices that can help school personnel increase the identification of Latino Children with ASD in preschools (age 3-5).

The current study will also explore potential developmental screening tools and cultural practices that can help school personnel increase the identification of Latino Children with ASD in preschools (age 3-5).

Next, the current study will review curriculum and counseling approaches that school-based practitioners and community partners can use to help Latino parents
and families lessen the cultural stigma of disabilities and increase parent knowledge of evidence-based strategies for preschool children with ASD (age 3-5).”

**The Evolution of my Research Topic**

After conducting further research near the end of the Fall 2019 semester, I determined that I wanted to investigate parents’ specific concerns during the special education referral process and how school staff can become partners with parents. The first draft of my research question was revised to include the following information:

“My research goals include developing a dissertation in the field of special education with an emphasis on diverse and primarily Spanish speaking families that face significant barriers. My goal would be to research the factors that can create resiliency in diverse families with special education students at the preschool level (age 3-5). My research question would be centered on: What factors contribute to positive outcomes for diverse families with special education students, in particular with students with significant needs (i.e.: autism)? How can staff work with families that can lead to positive outcomes? What fears or concerns do families have about the process, and how can staff alleviate this and become partners with parents. Ultimately, I would be focused on developing a qualitative study focused on interviewing Spanish-speaking parents since limited research exists with this population. This would help expand the research in the field related to best practice.”
My research topic continued to evolve during my first and second years. For example, my initial research idea was to examine the experiences of Latino Spanish-speaking students and their families with obtaining special education services (K-12). The research prospectus draft that I created during the Spring 2020 was integral in helping me further refine my research topic. I continued to research the literature related to Latino families and autism and discovered a gap in the literature that needed to be addressed. More specifically, I found limited research that examined the experiences of Latino families from Spanish-speaking backgrounds with receiving a clinical diagnosis of autism in preschool, receiving early intervention services, and obtaining special education services. I could not find any research studies related to California, specifically Santa Barbara County. As a result, I combined the three areas as part of my revised research question. Here's the research question that I included in my research prospectus draft for the Spring 2020:

The research question guiding this study is: How is the special education referral process addressing the needs of Spanish-speaking Latino preschool students with autism in the Santa Barbara County Education Office from 2014 to the present? What, if any, barriers delay assessments and ultimately diagnosis and eligibility for special education services under the criteria of autism for Latino students from Spanish-speaking families and non-Latino students in Santa Barbara County Education Office from 2014 to present.

The demographics of the subjects for my study changed at the recommendation of my dissertation committee at my proposal defense (Fall 2021). My initial proposal was to interview 5-7 Latino families that have a primary home language of Spanish. My
dissertation committee recommended that I add Latino families that have the primary home language of Mixteco to my study. The intent of adding other families with another language to my study was to have a more representative sample of students for the northern region of Santa Barbara County. As a result, I revised my proposal to include interviews with 4 Latino families that have a primary home language of Spanish and 3 Latino families that have a primary home language of Mixteco.

**The Role of Research**

Throughout our doctoral coursework, I learned the principles of qualitative and quantitative research, including epistemology, methodology, descriptive statistics, data collection and data interpretation, in preparation for my dissertation in practice. I learned the basics of conducting transformative research in my courses with Dr. Williams, Dr. Cormier and Dr. Dache and from our textbook *Research and Evaluation in Education and Psychology* by Donna Mertens (2020). Yow (2015) indicates that oral history interviews can provide responses to questions for events that occur in the subjects’ lives for the study.

**Transformative Paradigm**

I selected the transformative paradigm for my study since it examines the experiences of a diverse group that is traditionally underrepresented in the research of a particular field. More specifically, I learned that the transformative paradigm could help with understanding the experiences of communities or families from the socio-cultural model, including populations with disabilities. Mertens (2020) was instrumental in helping me understand the sampling of underrepresented populations and helping me design the survey instrument.
Survey Methods

I used similar survey methods as specified by Mertens (2020). For example, I checked in with co-advisors to ensure that my survey questions and interview questions had formatting, clarity, and organization. Next, I translated the questions from English to Spanish once my co-advisors reviewed them. I had a bilingual doctoral student in my cohort review my questions in Spanish to ensure that the questions were interpreted correctly and had the same meaning as in English. Finally, I informally pilot tested the survey and interview questions with friends and family in Spanish to ensure that all questions were clear. I asked everyone who reviewed the survey questions to indicate how easy they could read and understand before finalizing the surveys.

Meeting with My Advisors

I worked closely with my co-advisors, Dr. Cormier and Dr. Wall, to ensure that my dissertation proposal was satisfactory, including methodology, theoretical framework, data collection, and study survey and interview questions. The meetings were valuable for my growth as a Scholar-Practitioner since they helped me with understanding or clarifying any research questions that I had related to my study (proposal). The meetings also helped me review, reflect and prepare for the next steps in the process to ensure that I was meeting timelines and making progress with my dissertation planning and writing. I highly appreciate the expertise that Dr. Cormier and Dr. Wall provided me throughout the process.
Use of Interview Questions (Guide)

Seidman (2019), in Interviewing as Qualitative Research recommends that the researcher use the interview guide cautiously since some respondents may ask or bring up experiences not included in the survey interview. I encountered this experience during the course of each interview with my families. Some families asked questions regarding their experience, discussed the experience of multiple children, or even asked for feedback on the next steps. When this occurred, I answered the question of the family and then reverted back to the original question from the survey as suggested by Krueger and Casey (2015). Since the interviews were recorded, I included all their responses in the transcripts. I was flexible with the order of the questions since sometimes families discussed their experiences at different points in the interview.

My Growth as a Scholar-Practitioner

My growth as a scholar-practitioner occurred most in the areas of qualitative and quantitative data, including using SPSS to analyze the data and coding data for themes. My skills with interpreting data increased in areas such as making inferences and conclusions based on the quantitively and qualitative data. I utilized the reference from Field (2018) as I used SPSS and interpreted the findings. Ultimately, the experience of completing a research study with parents helped me to connect their experiences with the existing literature or to indicate how their experiences differed, and to make possible recommendations. The most rewarding aspect of my research was to examine several gaps in the literature and engage in research with an underrepresented population: Latino families with a primary home language of Spanish and/or Mixteco who have a child with a clinical diagnosis of autism or that has the eligibility for an IEP under autism. I am
optimistic that future studies and dissertations will predominantly focus on Latino Spanish-speaking or Mixteco-speaking families with a child with autism or other areas of developmental disabilities in my region.

Future Steps

I am highly appreciative of the trust that the families placed in me. I shared with the families that I would include their experiences in my research/dissertation. The intent of sharing these experiences is to obtain their perspectives to review areas of strength in the process in schools and pediatricians and areas that need improvement. In addition, the intent is to help the stakeholders improve referrals and reduce or eliminate disparities for current and future parents and students.

Finally, all of the families expressed their appreciation to the researcher for listening to their experiences as parents. They expressed appreciation for the work of the early intervention providers, teachers, school psychologists, pediatricians that referred them early, and specialists that helped them. My ultimate goal is to continue to raise awareness of these disparities and share these recommendations with the stakeholders so that we can help support parents. I am interested with engaging or contributing to further research in the future to examine how these disparities are being addressed for Latino families.
References


Appendix
Appendix A: Flyer #1 for Parents in English

Spanish-Speaking and Mixteco-Speaking Families Needed for Research Study on Autism.

Did your child experience any delays in obtaining a referral, receiving special education services, or obtaining a diagnosis of Autism? You may be eligible to participate in a research study to help reduce delays.

You May Qualify If You
- Identify as Latino/Hispanic
- Use Spanish or Mixteco as one of your primary home languages
- Live in Santa Barbara County
- Have a child who receives special education services under the category of Autism
- Your child is currently receiving special education services in preschool (between age 3-5)

Potential Benefits

Participation in this study may improve the referral process for special education services.

Participation Involves
- Completing a paper survey and one interview with the researcher.
- Time commitment is 1 hour - 1½ hour
- May be done remotely or in person.

Location: Santa Barbara County Education Office, 511 N H St, Suite C Lompoc CA 93436 (by appointment only and with safety protocols).

*Participation is voluntary. You may stop at any time. The Santa Barbara County Education Office has approved the study.

FOR MORE INFORMATION
Please contact Ivan D. Alvarez, School Psychologist/Doctoral Student at 805-293-1898 or via email at ivan.alvarez@mail.missouri.edu
Appendix B: Flyer #1 for Parents in Spanish

Se necesitan familias que hablan Español o Mixteco para un estudio de investigación sobre el autismo.

¿Su hijo/a tuvo algún retraso en obtener servicios de educación especial o para obtener un diagnóstico de autismo? Si esto sucedió, entonces usted puede ser elegible para participar en un estudio de investigación para ayudar a reducir estos retrasos.

**Usted puede calificar si usted:**
- Se identifica como latino/hispano.
- Utiliza el español o el mixteco como una de tus principales lenguas en el hogar.
- Vivies en el condado de Santa Bárbara.
- Tiene un hijo/a que recibe servicios de educación especial bajo la categoría de autismo.
- Tu hijo/a está recibiendo o comenzó a recibir servicios de educación especial en preescolar (entre los 3 y los 5 años de edad).

**Su participación implica:**
- Completar una encuesta en papel y una entrevista con el investigador.
- El proceso tomará de 1 a 1½ hora.
- Se puede hacer de forma remota o en persona.

**Ubicación:** Oficina de Educación del Condado de Santa Bárbara, 511 N H St, Suite C Lompoc CA 93436 (solo con cita previa y con protocolos de seguridad).

**Su participación es voluntaria. Puede optar en cualquier momento. El estudio ha sido aprobado por la Oficina de Educación del Condado de Santa Bárbara.**

**Beneficios potenciales:** Su participación en este estudio puede mejorar el proceso de referencia para los servicios de educación especial.

**Para Más Información:** Favor de contactar a Ivan D. Alvarez, Psicólogo Escolar Bilingüe Estudiante Doctoral si estás interesado en participar. (805) 293-1898/ ivan.alvarez@mail.missouri.edu
Appendix C: Flyer #2 for Parents in English

Spanish-Speaking and Mixteco-Speaking Families Needed for Research Study on Autism.

Did your child experience any delays in obtaining a referral, receiving special education services, or obtaining a diagnosis of Autism? You may be eligible to participate in a research study to help reduce delays.

**You May Qualify If You**
- Identify as Latino/Hispanic
- Use Spanish or Mixteco as one of your primary home languages
- Live in Santa Barbara County
- Have a child who receives special education services under the category of Autism
- Your child is currently receiving or started receiving special education services in preschool (between age 3-5).

**Potential Benefits**
Participation in this study may improve the referral process for special education services.

**Participation Involves**
- Completing a paper survey and one interview with the researcher.
- Time commitment is 1 hour - 1 ½ hour
- May be done remotely or in person.

**Location**: Santa Barbara County Education Office, 511 N H St, Suite C Lompoc CA 93436 (by appointment only and with safety protocols).
*Participation is voluntary. You may stop at any time. The study has been approved by the Santa Barbara County Education Office.*

Please contact Ivan D. Alvarez, Bilingual School Psychologist/Doctoral Student if you are interested in participating. (805) 293-1898/ivan.alvarez@mail.missouri.edu

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Spanish-Speaking and Mixteco-Speaking Families Needed for Research Study on Autism.

Did your child experience any delays in obtaining a referral, receiving special education services or with obtaining a diagnosis of Autism? You may be eligible to participate in a research study to help reduce delays.

**You May Qualify If You**
- Identify as Latino/Hispanic
- Use Spanish or Mixteco as one of your primary home languages
- Live in Santa Barbara County
- Have a child who receives special education services under the category of Autism
- Your child is currently receiving or started receiving special education services in preschool (between age 3-5).

**Potential Benefits**
Participation in this study may improve the referral process for special education services.

**Participation Involves**
- Completing a paper survey and one interview with the researcher.
- Time commitment is 1 hour - 1 ½ hour
- May be done remotely or in person.

**Location**: Santa Barbara County Education Office, 511 N H St, Suite C Lompoc CA 93436 (by appointment only and with safety protocols).
*Participation is voluntary. You may stop at any time. The study has been approved by the Santa Barbara County Education Office.*

Please contact Ivan D. Alvarez, Bilingual School Psychologist/Doctoral Student if you are interested in participating. (805) 293-1898/ivan.alvarez@mail.missouri.edu
Appendix D: Flyer #2 for Parents in Spanish

Se necesitan familias que hablan Español o Mixteco para un estudio de investigación sobre el autismo.

¿Su hijo/a tuvo algún retraso en obtener servicios de educación especial o para obtener un diagnóstico de autismo? Si esto sucedió, entonces usted puede ser elegible para participar en un estudio de investigación para ayudar a reducir estos retrasos.

Usted puede calificar si usted:
- Se identifica como latino/hispano.
- Utiliza el español o el mixteco como una de sus principales lenguas en el hogar.
- Vive en el condado de Santa Bárbara
- Tiene un hijo/a que recibió servicios de educación especial bajo la categoría de autismo
- Tu hijo/a está recibiendo o empezó a recibir servicios de educación especial en preescolar (entre los 3 y los 5 años).

Beneficios potenciales: Su participación en este estudio puede mejorar el proceso de referencia para los servicios de educación especial.

Su participación implica:
- Completa una encuesta en papel y una entrevista con el investigador.
- El proceso tomará de 1 - 1 1/2 hora
- Se puede hacer de forma remota o en persona.

Ubicación: Oficina de Educación del Condado de Santa Bárbara, 511 N H St, Suite C Lompoc CA 93436 (solo con una previa y con protocolos de seguridad).

Favor de contactar a Ivan D. Alvarez, Psicólogo, Escuela Bilingüe/Educando Doctoral si está interesado en participar.
(805) 293-1898/ivan.alvarez@mail.missouri.edu

Se necesitan familias que hablan Español o Mixteco para un estudio de investigación sobre el autismo.

¿Su hijo/a tuvo algún retraso en obtener servicios de educación especial o para obtener un diagnóstico de autismo? Si esto sucedió, entonces usted puede ser elegible para participar en un estudio de investigación para ayudar a reducir estos retrasos.

Usted puede calificar si usted:
- Se identifica como latino/hispano.
- Utiliza el español o el mixteco como una de sus principales lenguas en el hogar.
- Vive en el condado de Santa Bárbara
- Tiene un hijo/a que recibió servicios de educación especial bajo la categoría de autismo
- Tu hijo/a está recibiendo o empezó a recibir servicios de educación especial en preescolar (entre los 3 y los 5 años).

Beneficios potenciales: Su participación en este estudio puede mejorar el proceso de referencia para los servicios de educación especial.

Su participación implica:
- Completa una encuesta en papel y una entrevista con el investigador.
- El proceso tomará de 1 - 1 1/2 hora
- Se puede hacer de forma remota o en persona.

Ubicación: Oficina de Educación del Condado de Santa Bárbara, 511 N H St, Suite C Lompoc CA 93436 (solo con una previa y con protocolos de seguridad).

Favor de contactar a Ivan D. Alvarez, Psicólogo, Escuela Bilingüe/Educando Doctoral si está interesado en participar.
(805) 293-1898/ivan.alvarez@mail.missouri.edu
Appendix E: Survey Questions for Parents (in English/Spanish)

To be completed via telephone, zoom or on Qualtrics (depending on parent preference)

English Introduction to Survey:

Thank you for participating in my study. Please answer the following questions as part of the study. Your responses will help our organization with understand your experiences. Any responses that are included in the study were done without any of your identifying information such as your name or child’s name. Your participation is voluntary and you can discontinue the study at any time without reason. Please contact the researcher directly if you have any questions about the survey.

Spanish Introduction to Survey:

Gracias por participar en mi estudio. Por favor, responda a las siguientes preguntas como parte del estudio. Sus respuestas ayudarán a nuestra organización a comprender sus experiencias. Cualquier respuesta que se incluya en el estudio se realizará sin ninguna de su información, como su nombre o el nombre del niño. Su participación es voluntaria y puede abandonar el estudio en cualquier momento sin motivo. Favor de ponerse en contacto directamente con el investigador si tiene alguna pregunta sobre la encuesta.

Demographics

- With which race(s)/ethnicity do you most identify with?
  - Answer choices: a) Hispanic/Latino b) Caucasian c) American Indian or Alaska Native American d) Asian e) Black or African American f) Bi-racial/Multi-racial h) Prefer not to state
• ¿Con cual raza(s)/origen étnico te identificas más?
  
  o Opciones de respuesta: a) Hispano/Latino b) Blanco c) Indio americano o nativo de Alaska d) Asiático e) Negro o afroamericano g) Otro
  h) Prefiero no decir

• What is/are your primary home language?
  
  o Answer Choices: a) Spanish b) Spanish/English c) Mixteco
    d) Mixteco/ Spanish e) English

• ¿Cuál es tu idioma(s) principal del hogar?
  
  o Opciones de respuesta: a) Español b) Español/Inglés c) Mixteco
    d) Mixteco/Español e) Inglés

**Diagnosis of autism**

• Do you have a child with a diagnosis of Autism?
  
  o Answer Choices: a) Yes b) No

• ¿Tiene un hijo/a con un diagnóstico de autismo?
  
  o Opciones de respuesta: a) Sí b) No

• How old was your child when your child received a diagnosis of autism?
  
  o Open response

• How did your child obtain a diagnosis of autism?
  
  o Answer choices: a) Pediatrician/physician b) Developmental or Behavioral Clinic c) Tri-counties Regional Center d) Clinical Psychologist
Early Start Services

- Did your child receive early start services (prior to age 3)?
  - Answer Choices: a) Yes b) No
  ¿Su hijo/a recibió servicios de inicio temprano (antes de los 3 años)?
  - Opciones de respuesta: a) Sí b) No

- How old was your child when he/she started receiving early start services?
  - Open response
  ¿Qué edad tenía su hijo/a cuando comenzó a recibir servicios de inicio temprano?
  - Respuesta abierta

- How did your child get referred for early start services?
  - Answer choices: a) pediatrician’s/doctor’s referral b) Parent referral (yourself) c) Daycare d) child development center referral
  ¿Cómo se refirió a su hijo/a para los servicios de inicio temprano?
  - Opciones de respuesta: a) Referencia de pediatra/medico b) Referencia de los padres (usted mismo) c) Guardería d) referencia del centro de desarrollo infantile

- Were the early start services provided in a bilingual format or were you able to communicate with the team in your primary language?
  - Answer Choices: a) Yes b) No
Special Education Services

- Special education services are available to students with disabilities. These services can include specialized academic instruction (classroom support), speech and language therapy, occupational therapy and adapted physical education.

Does your child currently receive special education services?

- **Answer Choices:** a) Yes b) No

- ¿Su hijo/a recibe servicios de educación especial actualmente?

- **Opciones de respuesta:** a) Sí b) No

- Does your child receive special education services for preschool?

- **Answer Choices:** a) Yes b) No

- ¿Su hijo/a recibió servicios de educación especial en preescolar?

- **Opciones de respuesta:** a) Sí b) No

- How old was your child when he/she started receiving special education services?

- **Open response**
• ¿Cuántos años tenía su hijo/a cuando comenzó a recibir servicios de educación especial?
  o Respuesta abierta

• How did your child get referred for special education services?
  ¿Cómo se refirió a su hijo/a para los servicios de educación especial?
  o Answer choices: a) Pediatrician referral b) Regional Center referral c) Parent referral (yourself) d) Preschool referral
  o Opciones de respuesta: Referencia de pediatra b) Referencia del Centro Regional c) Referencia de padres (usted mismo) d) Referencia preescolar

• The special education team may consist of the special education teacher, school psychologist, speech and language therapist, school nurse, adapted physical education specialist and occupational therapist. Were you able to communicate with the special education team in your primary language during the assessment or meetings?
  o Answer Choices: a) Yes b) No
  o • El equipo de educación especial puede estar formado por el maestro de educación especial, psicólogo escolar, terapeuta del habla y el lenguaje, enfermera escolar, especialista en educación física adaptada y terapeuta ocupacional. ¿Pudo comunicarse con el equipo de educación especial en su idioma principal durante la evaluación o las reuniones?
  o Opciones de respuesta: a) Sí b) No
Delays in Diagnosis or Services:

- Were there any delays in receiving a diagnosis of Autism for your child?
  
  o *Answer Choices*: a) Yes b) No

  o ¿Hubo algún retraso en recibir un diagnóstico de autismo para su hijo/a?
  
  o *Opciones de respuesta*: a) Sí b) No

- Children with disabilities can receive early start services from birth to 36 months and special education services starting at 36 months. Were there any delays with receiving early start or special education services for your child?

  o *Answer Choices*: a) Yes b) No

  o Los niños con discapacidades pueden recibir servicios de inicio temprano desde el nacimiento hasta los 36 meses y servicios de educación especial a partir de los 36 meses. ¿Hubo algún retraso en la recepción de servicios de inicio temprano o educación especial para su hijo?

  o *Opciones de respuesta*: a) Sí b) No

Familiarity with Autism

- Were you familiar with Autism prior to talking to your child’s pediatrician/doctor?

  o *Answer Choices*: a) Yes b) No

  o ¿Estaba familiarizado con el autismo antes de hablar con el pediatra/medico de su hijo/a?

  o *Opciones de respuesta*: a) Sí b) No
• Do you have another child or have a family member that has a diagnosis of Autism?
  
  o  *Answer Choices:* a) Yes b) No

  o  ¿Tiene otro hijo/a o tiene un miembro de la familia que tiene un diagnóstico de autismo?
  
  o  *Opciones de respuesta:* a) Sí b) No

• Did you do any research into Autism or talk to anyone who had a child with Autism prior to checking with your child’s pediatrician/doctor?

  o  *Answer Choices:* a) Yes b) No

  o  ¿Hizo alguna investigación sobre el autismo o habló con alguien que tuvo un hijo con autismo antes de consultar con el pediatra/medico de su hijo/a?

  o  *Opciones de respuesta:* a) Sí b) No
Appendix F: Interview Questions for Parents (in English/Spanish)

To be completed via telephone, zoom or in person (depending on parent preference and safety protocols in place due to pandemic)

English Introduction to Survey:
Thank you for participating in my study. You will have an opportunity to respond to a variety of questions during our interview today. Your responses will help our organization with understand your experiences. Any responses that are included in the study were done without any of your identifying information such as your name or child’s name. As previously noted, your participation is voluntary and you can stop at any time for any reason. Please let me know if you have any questions during the interview.

Spanish Introduction to Survey:
Gracias por participar en mi estudio. Tendrá la oportunidad de responder a una variedad de preguntas durante nuestra entrevista de hoy. Sus respuestas ayudarán a nuestra organización a comprender sus experiencias. Cualquier respuesta que se incluya en el estudio se realizará sin ninguna de sus informaciones de identificación, como su nombre o el nombre del niño. Como se señaló anteriormente, su participación es voluntaria y puede detenerse en cualquier momento sin motivo. Por favor, dejame saber si tiene alguna pregunta durante la entrevista.

Guided Questions

Initial Concerns:
- Who had the initial concerns related to your child’s development (for example: the pediatrician/doctor, you, a family member, friend?)
• What initial concerns led you to suspect that your child could be demonstrating symptoms of Autism?

• How many months (age) was your child when you expressed concern to your child’s pediatrician/doctor regarding developmental delays?

• Was a referral completed by your child’s doctor as soon as you expressed concerns? Why or why not?

• If there were delays with a referral, how long did take before your child’s pediatrician/doctor recommended an assessment after you expressed your initial concerns?

• After your child was referred for an assessment, how long did it take for you to receive a diagnosis of Autism?
o Después de que su hijo/a fue referido para una evaluación, ¿cuánto tiempo le
tomó recibir un diagnóstico de autismo?

Receiving a Diagnosis of Autism:

• What aspects of the referral process for receiving a diagnosis of Autism were
challenging? Please explain how and why.

o ¿Qué aspectos del proceso para recibir un diagnóstico de autismo fueron difíciles?
   Favor de explicar cómo y por qué.

• What aspects of receiving a diagnosis of Autism were positive?

o ¿Qué aspectos para recibir un diagnóstico de autismo fueron positivos?

Delays in the Referral Process for Clinical Diagnosis of Autism

• Did you have any delays with obtaining a referral or diagnosis for your child? If
so, please describe the delays that occurred?

o ¿Tuvo algún retraso en la obtención de una referencia o diagnóstico para su hijo?
   En caso afirmación, por favor describir los retrasos que se produjeron.

o Follow-up question if parent does not have a response: Delays in the
   referral or diagnosis can include language barriers, unfamiliarity with
   Autism and/or with health care coverage. Did you experience any of
   these or other barriers not mentioned?

o Pregunta de seguimiento si el padre no tiene una respuesta: Retrasos
   en el diagnóstico puede incluir barreras del idioma, falta de
   familiaridad con el autismo y / o con la cobertura de salud.

   ¿Experimentaste alguna de estas u otras barreras no mencionadas?
• Did you or your family have any hesitation initially with making a referral? Why or Why not?
  o ¿Tuvo usted o su familia alguna duda inicialmente en hacer recibir una referencia al especialista? Si es así, ¿cuáles fueron las razones y cuánto tiempo tardó antes de que hiciera a una referencia al especialista?
• If you had any hesitation initially, how long did it take before you made a referral to a specialist?
  o Si tuvo alguna duda inicialmente, ¿cuánto tiempo tardó en hacer una referencia al especialista?
• If you had difficulties with obtaining a referral, describe the process of how you eventually received a diagnosis?
  o Si tuvo dificultades para obtener una referencia al especialista, ¿cómo recibió finalmente un diagnóstico?

Community, Friends or Organizational Support Received:
• Did anyone provide you with advice or guidance with how to make a referral or how to receive services? If so, who and how did they help you?
  o ¿Alguien le proporcionó consejos o alguna orientación sobre cómo hacer una referencia para el especialista o para recibir servicios? Si es así, ¿quién y cómo te ayudaron?
• What specific advice or recommendations did they provide you that was valuable or helpful for you?
  o ¿Qué consejos o recomendaciones específicas le proporcionaron que fueron valiosos o útiles para usted?
• If there were any delays, did anyone help you through the process? If so, who and how did they help you?

• Si hubo algún retraso, ¿alguien lo ayudó a través del proceso? Si es así, ¿quién y cómo te ayudaron?

• Describe any support you received from organizations, professionals or friends to assist your family during the referral process? How did this help you?

  o ¿Recibió algún apoyo de organizaciones, profesionales o amigos para ayudarlo durante el proceso para la referencia al especialista? Si es así, ¿puedes describir cómo te ayudaron?

**Impact of Services:**

• Did you notice any changes in your child’s skills at home once he/she started receiving early start and/or special education services? If so, in what specific areas?

  o ¿Notó algún cambio en las habilidades de su hijo/a en el hogar una vez que comenzó a recibir servicios de inicio temprano y/o educación especial? Si es así, ¿en qué áreas específicas?

  o *Follow-up question if parent does not have a response:* These changes can include your child’s adaptive skills at home, language, social skills or other developmental areas.

  o *Pregunta de seguimiento si los padres no tienen una respuesta:* Estos cambios pueden incluir las habilidades de adaptación de su hijo en el hogar, el idioma, las habilidades sociales u otras áreas de desarrollo.
Recommendations from Parents:

- Do you have any recommendations for schools and pediatricians/doctors for improving the referral process?
  - ¿Tiene alguna recomendación para las escuelas y los pediatras/medicos para mejorar el proceso?

- What advice would you provide to parents new to the referral process for obtaining a diagnosis of Autism or with receiving a referral to special education?
  - ¿Qué consejo proporcionaría a los padres nuevos en el proceso de referencia para obtener un diagnóstico de autismo o para recibir una referencia a educación especial?

- Is there anything else you would like parents, school or pediatricians/doctor to know about your experience during the referral process?
  - ¿Hay algo más que le gustaría que los padres, la escuela o los pediatras/medicos supieran sobre su experiencia durante el proceso de referencia?
Appendix G: SELPA & District Consent Letters to Engage in Research with Parents

Santa Barbara County Special Education Local Plan Area (SBCSELPA)

DocuSign Envelope ID: AAAD1153-F9D4-41A9-B392-D633C536A47D

Dr. Ray Avila, Ed.D.,
Executive Director
Santa Barbara County Special Education Local Plan Area (SBCSELPA)
ravila@sbceo.org

December 11th, 2021

Dear Dr. Avila,

I am currently a Bilingual School Psychologist at the Santa Barbara County Education Office and a doctoral candidate in the Educational Leadership and Policy Analysis department at the University of Missouri at Columbia. The title of my study for my doctoral dissertation is Socio-Cultural and School Barriers that Latino Spanish-Speaking and Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California. My study received IRB approval (#2080962) from the University of Missouri on December 10th, 2021.

The purpose of this letter is to request permission to recruit and interview parents within the SBCSELPA region that receive or previously received preschool special education services. The study requires parents to meet certain demographic in order to voluntarily participate in the interview and surveys. For example, parents need to have a child that meets the educational criteria or clinical diagnosis for Autism. In addition, their child needs to have received special education services in preschool through the Santa Barbara County Education Services from 2014-21. The family needs to identify as Latino/Hispanic and use Spanish or Mixteco as one of their primary home languages.
The target size of the study is 5-8 families that reside in Santa Barbara County.

The results of the study will be disseminated to parents and to SBCSELPA in order to help improve current special education referral practices and supports. The interviews will be completed in the parent’s primary home language with the researcher. Surveys completed by parents and any audio or video recordings obtained during the parent interview will be maintained confidential and identifying information will be removed to protect parent’s privacy.

The location of the interviews were scheduled at a school or county office or on zoom, based on parent preference. The duration of the survey and parent interview is expected to last 60-90 minutes over two sessions. Flyers will be distributed to parents that may be eligible to participate. The researcher will follow-up with families that are have expressed interested in participating, who are referred by school staff or who have worked with the researcher previously and experienced delays.

My IRB approval letter, consent letter for parents in Spanish/English and the recruitment flyer are attached to this email for your reference. If you would like additional information such as interview questions for parents, please let me know. Written consent is in the process of being obtained from SBCEO, Lompoc Unified School District and Santa Maria Bonita School District for the study.

Should you agree to allow parents to voluntarily participate in this research, please sign the “Agreement to Participate” form below. If you have questions regarding the study, please contact Ivan D. Alvarez at (805) 293-1898 or ivan.alvarez@mail.missouri.edu I look forward to hearing from you.
Sincerely,

Ivan D. Alvarez, MA, LEP,
Bilingual School Psychologist,
Santa Barbara County Education Office
Doctoral Candidate,
University of Missouri at Columbia

Agreement to Participate
This is to affirm that the SBCSELPA is providing permission in conjunction with local district or county office special education directors, for parents within the Santa Barbara County SELPA to voluntarily participate in the dissertation study by Ivan D. Alvarez titled: Socio-Cultural and School Barriers that Latino Spanish-Speaking or Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California (IRB Study# 2080962). The study is expected to initiate during 2021-22 school year and is expected to conclude by Summer 2022 or Fall 2022. The recruitment of families will begin as soon as consent is provided.

Signature of Dr. Ray Avila,
SBCSELPA Executive Director

Alvarez, Ivan
SBCSELPA Parent Participation Consent Form, Page 3
Ms. Kirsten Escobedo  
Assistant Superintendent, Special Education Division  
Santa Barbara County Education Office (SBCEO)  

December 11th, 2021  

Dear Mrs. Escobedo,

I am currently a Bilingual School Psychologist at the Santa Barbara County Education Office and a doctoral candidate in the Educational Leadership and Policy Analysis department at the University of Missouri at Columbia. The title of my study for my doctoral dissertation is *Socio-Cultural and School Barriers that Latino Spanish-Speaking or Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California.* My study received IRB approval (#2080962) from the University of Missouri on December 10th, 2021.

The purpose of this letter is to request permission to recruit and interview parents in the Santa Barbara County Education region that receive or previously received preschool special education services through SBCEO. The study requires parents to meet certain demographic in order to voluntarily participate in the interview and surveys. For example, parents need to have a child that meets the educational criteria or clinical diagnosis for Autism. In addition, their child needs to have received special education services in preschool through the Santa Barbara County Education Services from 2014-21. The family needs to identify as Latino/Hispanic and use Spanish or Mixteco as one of their primary home languages.
The target size of the study is 5-8 families that reside in Santa Barbara County. The results of the study will be disseminated to parents and to SBCSELPA in order to help improve current special education referral practices and supports. The interviews will be completed in the parent’s primary home language with the researcher. Surveys completed by parents and any audio or video recordings obtained during the parent interview will be maintained confidential and identifying information will be removed to protect parent’s privacy.

The location of the interviews were scheduled at a school or county office or on zoom, based on parent preference. The duration of the survey and parent interview is expected to last 60-90 minutes over two sessions. Flyers will be distributed to parents that may be eligible to participate. The researcher will follow-up with families that are referred by school staff or interested in participating. The researcher will follow up with families who have expressed interest in participating, are referred by school staff, or who have previously worked with the researcher and experienced delays.

My IRB approval letter, consent letter for parents in Spanish/English and the recruitment flyer are attached to this email for your reference. If you would like additional information such as interview questions for parents, please let me know. *Written consent is also in the process of being obtained from SBCSELPA, Lompoc Unified School District and Santa Maria Bonita School District for the study.*

Should you agree to participate in this research, please sign the “Agreement to Participate” form below. If you have questions regarding the study, please contact Ivan D. Alvarez at (805) 293-1898 or ivan.alvarez@mail.missouri.edu. I look forward to hearing from you. Thank you for your time!

Alvarez, Ivan

SBCEO Parent Participation Consent Form, Page 2
Sincerely,

Ivan D. Alvarez, MA, LEP,
Bilingual School Psychologist,
Santa Barbara County Education Office
Doctoral Candidate,
University of Missouri at Columbia

---

**Agreement to Participate**

This is to affirm that SBCEO is providing permission for parents that receive special education services from the Santa Barbara County Education Office to voluntarily participate in the dissertation study by Ivan D. Alvarez, focused on *Socio-Cultural and School Barriers that Latino Spanish-speaking and Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California* (IRB Study# 2080962). The study is expected to initiate during December 2021 and is expected to conclude by Summer 2022 or Fall 2022. The recruitment of families will begin as soon as consent is provided.

Signature of Kirsten Escobedo,
Assistant Superintendent, Special Education Division,
Santa Barbara County Education Office (SBCEO)
Lompoc Unified School District

DocuSign Envelope ID: 305515E2-36C1-4721-8C7A-02B10C7F4076

Brian Jaramillo
Director, Special Education & Auxiliary Support Services Department
Lompoc Unified School District
Jaramillo.brian@lusd.org

December 11th, 2021

Dear Mr. Jaramillo,

I am currently a Bilingual School Psychologist at the Santa Barbara County Education Office and a doctoral candidate in the Educational Leadership and Policy Analysis department at the University of Missouri at Columbia. The title of my study for my doctoral dissertation is Socio-Cultural and School Barriers that Latino Spanish-Speaking and Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California. Dr. Ray Avila, SBCSELPA Director and Dr. Florene Bednersh, Retired Special Education Assistant Superintendent of Santa Barbara County Education Office are on my dissertation committee. My study received IRB approval (#2080962) from the University of Missouri on December 10th, 2021.

The purpose of this letter is to request permission to recruit and interview parents in the Lompoc Unified School District region that receive or previously received preschool special education services through SBCEO from 2014-present. The study requires parents to meet certain demographic in order to voluntarily participate in the interview and surveys. For example, parents need to have a child that meets the educational criteria or clinical diagnosis for Autism. The family needs to identify as Latino/Hispanic and have Spanish or Mixteco as one of their primary home languages. The target size of the study is 5-8 students that reside in Santa Barbara County.
The results of the study will be disseminated to parents and to SBCSELPA in order to help improve current special education referral practices and supports. The interviews will be completed in the parent’s primary home language with the researcher. Surveys completed by parents and any audio or video recordings obtained during the parent interview will be maintained confidential and identifying information will be removed to protect the parent’s privacy.

The location of the interviews will be scheduled at a school or county office or on zoom, based on parent preference. The duration of the survey and parent interview is expected to last 60-90 minutes over two sessions. Flyers will be distributed to parents that may be eligible to participate. The researcher will follow-up with families that have expressed interest in participating, who are referred by school staff or who have worked with the researcher previously and experienced delays.

My IRB approval letter, consent letter for parents in Spanish/English and the recruitment flyer are attached to this email for your reference. If you would like additional information such as interview questions for parents, please let me know.

*Written consent is in the process of being obtained from SBCSELPA, SBCEO and Santa Maria-Bonita School District for the study.*

Should you agree to participate in this research, please sign the “Agreement to Participate” form below. If you have questions regarding the study, please contact me at (805) 293-1898 or ivan.alvarez@mail.missouri.edu I look forward to hearing from you.

Alvarez, Ivan Lompoc Unified Parent Participation Consent Form, Page 2
Sincerely,

Ivan D. Alvarez, MA, LEP,
Bilingual School Psychologist,
Santa Barbara County Education Office
Doctoral Candidate,
University of Missouri at Columbia

______________________________
________________________________________
Agreement to Participate

This is to affirm that Lompoc Unified School District is providing permission for parents within the school district that meet the criteria to voluntarily participate in the dissertation study by Ivan D. Alvarez, titled *Socio-Cultural and School Barriers that Latino Spanish-speaking or Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California* (IRB Study# 2080962). The study is expected to initiate during December 2021 and is expected to conclude by Summer 2022 or Fall 2022. The recruitment of families will begin as soon as consent is provided.

Signature of Brian Jaramillo,
Date
Director, Special Education & Auxiliary Support Services,
Lompoc Unified School District
Santa Maria-Bonita School District

Erik Thompson
Director, Special Education Services Department
Santa Maria-Bonita School District
ethompson@smbsd.net

December 11th, 2021

Dear Mr. Thompson,

I am currently a Bilingual School Psychologist at the Santa Barbara County Education Office and a doctoral candidate in the Educational Leadership and Policy Analysis department at the University of Missouri at Columbia. The title of my study for my doctoral dissertation is *Socio-Cultural and School Barriers that Latino Spanish-Speaking and Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California*. My study received IRB approval (#2080962) from the University of Missouri on December 10th, 2021.

The purpose of this letter is to request permission to recruit and interview parents in the Santa Maria-Bonita School District region that receive or previously received preschool special education services through SBCEO from 2014-present. The study requires parents to meet certain demographic in order to voluntarily participate in the interview and surveys. For example, parents need to have a child that meets the educational criteria or clinical diagnosis for Autism. The family needs to identify as Latino/Hispanic and have Spanish or Mixteco as one of their primary home languages. The target size of the study is 5-8 students that reside in Santa Barbara County.

The results of the study will be disseminated to parents and to SBCSELPA in order to help improve current special education referral practices and supports.
The interviews will be completed in the parent’s primary home language with the researcher. Surveys completed by parents and any audio or video recordings obtained during the parent interview will be maintained confidential and identifying information will be removed to protect parent’s privacy.

The location of the interviews were scheduled at a school or county office or on zoom, based on parent preference. The survey and parent interview duration is expected to last 60-90 minutes over two sessions. Flyers will be distributed to parents that may be eligible to participate. The researcher will follow up with families that are have expressed interested in participating, who are referred by school staff or who have worked with the researcher previously and experienced delays.

My IRB approval letter, consent letter for parents in Spanish/English and the recruitment flyer are attached to this email for your reference. If you would like additional information such as interview questions for parents, please let me know. Written consent is in the process of being obtained from SBCSELPA, SBCEO and Lompoc Unified for the study.

Should you agree to participate in this research, please sign the “Agreement to Participate” form below. If you have questions regarding the study, please contact Ivan D. Alvarez at (805) 293-1898 or ivan.alvarez@mail.missouri.edu I look forward to hearing from you.

Alvarez, Ivan
Sincerely,

Ivan D. Alvarez, MA, LEP,
Bilingual School Psychologist,
Santa Barbara County Education Office
Doctoral Candidate,
University of Missouri at Columbia

---

**Agreement to Participate**

This is to affirm that Santa Maria-Bonita School District is providing permission for parents within the school district that meet criteria to voluntarily participate in the dissertation study by Ivan D. Alvarez, titled *Socio-Cultural and School Barriers that Latino Spanish-speaking or Mixteco-speaking families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California* (IRB Study# 2080962). The study is expected to initiate during December 2021 and is expected to conclude by Summer 2022 or Fall 2022. The recruitment of families will begin as soon as consent is provided.

**Signature of Erik Thompson, Date**

Director, Special Education Services,
Santa Maria-Bonita School District

12/13/2021
Appendix H: Parent Form to Participate in a Research Study in English

PARENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Researcher’s Name: Ivan D. Alvarez
IRB Project Number: 2080962

Project Title: Socio-Cultural and School Barriers that Latino Spanish-speaking and Mixteco-speaking Families with a Preschool Child with Autism Experienced in the Special Education Referral Process and for Obtaining a Diagnosis in Santa Barbara County, California

INTRODUCTION
This consent may contain words that you do not understand. Please ask the investigator or the study staff to explain any words or information that you do not clearly understand.

You are being asked to participate in a research study. This research is being conducted to study the experiences of predominately Spanish-speaking and Mixteco-speaking Latino families with obtaining a special education referral, special education services, and obtaining a diagnosis for children with Autism. When you are invited to participate in research, you have the right to be informed about the study procedures to decide whether you want to consent to participation. This form may contain words that you do not know. Please ask the researcher to explain any terms or information you do not understand.

You have the right to know what you were asked to do to decide whether or not to be in the study. Your participation is voluntary. You do not have to be in the study if you do not want to. You may refuse to be in the research, and nothing will happen. If you do not want to continue to be in the study, you may stop at any time without penalty or loss of special education services to which you are otherwise entitled. If you would like to discontinue the study, please inform the researcher as soon as possible by email or phone.

WHY IS THIS STUDY BEING DONE?
This research aims to understand the barriers that families experience and positive experiences in the special education referral process, for obtaining special education services, and with obtaining a clinical diagnosis of Autism. The goal is to share the study results with organizations involved to reduce barriers for families.

HOW MANY PEOPLE WERE IN THE STUDY?
The goal is for 5-8 families that meet the criteria to participate in the study.

WHAT AM I BEING ASKED TO DO?
You were asked to first participate in a survey with the researcher. Once it is determined that you can participate in the study, you will be contacted to schedule a face-to-face interview with the researcher (using COVID protocols) or via zoom based on your
preference. In-person interviews will be audio or video recorded for interviews conducted on zoom or phone. No identifiable information will be released outside of the research team. The interview and survey will consist of questions related to your experiences by your family during the special education referral process and for obtaining special education services and for obtaining a clinical diagnosis of Autism for your child.

**HOW LONG WILL I BE IN THE STUDY?**
This study will take 60-90 minutes over 1 or 2 sessions. You can stop participating at any time without penalty.

**WHAT ARE THE BENEFITS OF BEING IN THE STUDY?**
Your participation will potentially benefit other parents, local school districts, the county office of education, special education administrators, and school psychologists to help reduce barriers that parents face during the referral process and obtain special education services and a clinical diagnosis.

**WHAT ARE THE RISKS OF BEING IN THE STUDY?**
There may be some discomfort if you had difficulties with the special education process or obtaining a clinical diagnosis. There are no other risks that can be foreseen with participating in the study. You may discontinue answering any questions or participating in the study at any time.

**WHAT ARE THE COSTS OF BEING IN THE STUDY?**
There is no cost to you.

**WHAT OTHER OPTIONS ARE THERE?**
You have the option of not participating in this study, and will not be penalized for your decision.

**CONFIDENTIALITY**
Information produced by this study will be stored in the investigator’s file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.
In addition, audiotapes taken during the study that could identify you require you to provide special written permission for their use. In that case, you will be given the opportunity to view or listen, as applicable, to the audiotapes before you give your permission for their use if you so request. Your responses were included in the study without identifying information from your family or child.

**WILL I BE COMPENSATED FOR PARTICIPATING IN THE STUDY?**
You will receive no payment for taking part in this study.

**WHAT ARE MY RIGHTS AS A PARTICIPANT?**
Participation in this study is voluntary. You do not have to participate in this study.
You will also be informed of any new information discovered during the course of this study that might influence your health, welfare, or willingness to be in this study.

**WHO DO I CONTACT IF I HAVE QUESTIONS, CONCERNS, OR COMPLAINTS?**
Please contact Ivan Alvarez, Doctoral Candidate at the University of Missouri at Columbia if you have questions about the research. Additionally, you may ask questions voice concerns or complaints to the researcher or to his supervisors, Dr. Bret Cormier or Dr. Timothy Wall.

**WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?**
You may contact the University of Missouri Institutional Review Board (IRB) if you have any questions about your rights as a study participant, want to report any problems or complaints, or feel under any pressure to take part or stay in this study. The IRB is a group of people who review research studies to make sure the rights of participants are protected. You can reach them at 573-882-3181 or muresearchirb@missouri.edu. If you want to talk privately about your rights or any issues related to your participation in this study, you can contact the University of Missouri Research Participant Advocacy by calling 888-280-5002 (a free call), or emailing MUResearchRPA@missouri.edu.

You may ask more questions about the study at any time. For questions about the study, contact Ivan Alvarez at (805) 741-7668 or ivan.alvarez@mail.missouri.edu, Dr. Bret Cormier at (401) 865-2803 or bcormier@providence.edu or Dr. Timothy Wall at (660) 562-1179 or timwall@nwmissouri.edu

A copy of this Informed Consent form and a translated copy in Spanish will be provided to you before you participate in the research. The questions will also be administered in your preferred home language (Spanish or English).
Appendix I: Parent Form to Participate in a Research Study in Spanish

FORMULARIO DE CONSENTIMIENTO DE LOS PADRES PARA PARTICIPAR EN UN ESTUDIO DE INVESTIGACIÓN EN ESPAÑOL

Nombre del investigador:  Ivan D. Alvarez
Número del proyecto:  2080962
Título del proyecto:  Barreras socioculturales y escolares que las familias latinas que hablan Español con un niño en edad preescolar con autismo experimentaron en el proceso de referencia de educación especial y para obtener un diagnóstico en el condado de Santa Bárbara, California

INTRODUCCIÓN
Este consentimiento puede contener palabras que usted no entiende. Favor de pedirle al investigador o al personal del estudio que expliquen cualquier palabra o información que no entienda claramente.

Se le pide que participe en un estudio de investigación. Esta investigación se está llevando a cabo para estudiar las experiencias de las familias latinas predominantemente que hablan Español o Mixteco en obtener una referencia de educación especial, servicios de educación especial y de obtener un diagnóstico de autismo para su hijo/a. Cuando se le invita a participar en la investigación, tiene derecho a ser informado sobre los procedimientos del estudio para que pueda decidir si desea dar su consentimiento a la participación. Este formulario puede contener palabras que usted no conoce. Favor de pedir al investigador que explique cualquier palabra o información que no entienda.

Tiene derecho a saber lo que se le pedirá que haga para que pueda decidir si desea o no participar en el estudio. Su participación es voluntaria. No tienes que estar en el estudio si no quieres. Usted puede negarse a estar en el estudio y no pasará nada. Si no desea continuar en el estudio, puede detenerse en cualquier momento sin penalización o pérdida de los servicios de educación especial a los que tiene derecho. Si desea interrumpir el estudio, informe al investigador lo antes posible por correo electrónico o por teléfono.

¿POR QUÉ SE ESTÁ HACIENDO ESTE ESTUDIO?
El propósito de esta investigación es comprender las barreras que son experimentados por las familias y las experiencias positivas en el proceso de referencia de educación especial, para obtener servicios de educación especial y para obtener un diagnóstico clínico de autismo. El objetivo es compartir los resultados del estudio con las organizaciones involucradas con el fin de reducir las barreras para las familias.

¿CUÁNTAS PERSONAS ESTARÁN EN EL ESTUDIO?
El objetivo es que de 5 a 8 familias que cumplan con el criterio que participen en el estudio.

¿QUÉ SE ME PIDE QUE HAGA?
Se le pedirá que primero participe en una encuesta a través de una encuesta en papel, según sus preferencias. Una vez que se determine que puede participar en el estudio, se le contactará para programar una entrevista cara a cara con el investigador (utilizando
protocolos COVID) o a través de zoom o teléfono según su preferencia. Las entrevistas en persona serán grabadas en audio o video para entrevistas realizadas por zoom o teléfono. No se divulgará información identificable fuera del equipo de investigación. La entrevista y la encuesta consistirán en preguntas relacionadas con sus experiencias por parte de su familia durante el proceso de referencia de educación especial y para obtener servicios de educación especial y para obtener un diagnóstico clínico de autismo para su hijo/a.

¿CUÁNTO TIEMPO ESTARÉ EN EL ESTUDIO?
Este estudio tomará de 60 a 90 minutos durante 1 o 2 sesiones para completarse. Puedes dejar de participar en cualquier momento sin penalización.

¿CUÁLES SON LOS BENEFICIOS DE ESTAR EN EL ESTUDIO?
Su participación beneficiará potencialmente a otros padres, distritos escolares locales, la oficina de educación del condado, administradores de educación especial y psicólogos escolares para ayudar a reducir las barreras que enfrentan los padres durante el proceso de referencia y con la obtención de servicios de educación especial y un diagnóstico clínico.

¿CUÁLES SON LOS RIESGOS DE ESTAR EN EL ESTUDIO?
Puede haber alguna molestia si tuvo algunas dificultades con el proceso de educación especial o con la obtención de un diagnóstico clínico. No hay otros riesgos que se puedan prever con la participación en el estudio.

¿CUÁLES SON LOS COSTOS DE ESTAR EN EL ESTUDIO?
No hay costo para usted.

¿QUÉ OTRAS OPCIONES HAY?
Usted tiene la opción de no participar en este estudio, y no será penalizado por su decisión.

CONFIDENCIALIDAD

La información producida por este estudio se almacenará en el archivo del investigador y se identificará solo con un número de código, como encuestas en papel completadas y notas del investigador. La clave de código que conecta su nombre con información específica sobre usted se mantendrá en una ubicación separada y segura. La información contenida en sus registros no puede ser entregada a nadie no afiliado al estudio en una forma que pueda identificarlo sin su consentimiento por escrito, excepto según lo exija la ley.

Además, las cintas de audio, el audio digital, las sesiones de zoom grabadas y el video digital tomado durante el estudio que podrían identificarlo, requieren que proporcione un permiso especial por escrito para su uso. En ese caso, se le dará la oportunidad de ver o escuchar, según corresponda, las cintas de audio antes de dar su permiso para su uso si así lo solicita. Sus respuestas se incluirán en el estudio sin ninguna información de identificación de su familia o hijo/a.
¿SE ME COMPENSARÁ POR PARTICIPAR EN EL ESTUDIO?
No recibirá ningún pago por participar en este estudio.

¿CUÁLES SON MIS DERECHOS COMO PARTICIPANTE?
Su participación en este estudio es voluntaria. Usted no tiene que participar en este estudio.
También se le informará de cualquier nueva información descubierta durante el curso de este estudio que pueda influir en su salud, bienestar o voluntad de participar en este estudio.

¿CON QUIÉN ME COMUNICO SI TENGO PREGUNTAS, INQUIETUDES O QUEJAS?
Póngase en contacto con Ivan Alvarez, candidato doctorado en la Universidad de Missouri en Columbia si tiene preguntas sobre la investigación. Además, puede hacer preguntas, expresar inquietudes o quejas al investigador o a sus supervisores, el Dr. Bret Cormier o el Dr. Timothy Wall.

¿A QUIÉN LLAMO SI TENGO PREGUNTAS O PROBLEMAS?
Puede comunicarse con la Junta de Revisión Institucional (IRB) de la Universidad de Missouri si tiene alguna pregunta sobre sus derechos como participante del estudio, desea informar cualquier problema o queja, o se siente bajo alguna presión para participar o permanecer en este estudio. El IRB es un grupo de personas que revisan los estudios de investigación para asegurarse de que los derechos de los participantes estén protegidos. Puede comunicarse con ellos al 573-882-3181 o muresearchirb@missouri.edu. Si desea hablar en privado sobre sus derechos o cualquier problema relacionado con su participación en este estudio, puede comunicarse con University of Missouri Research Participant Advocacy llamando al 888-280-5002 (una llamada gratuita) o enviando un correo electrónico a MUREsearchRPA@missouri.edu.

Para preguntas sobre el estudio, comuníquese con Ivan Alvarez al (805) 741-7668 o ivan.alvarez@mail.missouri.edu, el Dr. Bret Cormier al (401) 865-2803 o bcormier@providence.edu o el Dr. Timothy Wall al (660) 562-1179 o timwall@nwmissouri.edu
Se le entregará una copia de este formulario de Consentimiento Informado y una copia traducida en español antes de participar en la investigación. Las preguntas también se administrarán en su idioma preferido del hogar (español o inglés).
**Appendix J: Santa Barbara County Education Office PRIM Meeting Form**

**PRE-REFERRAL INFORMATION MEETING**

**PRIM TEAM TODAY INCLUDES:**

**TODAYS DATE:**

**REFERRED BY:**

**NAME OF STUDENT:**

**DATE/PLACE OF BIRTH:**

**SEX/ETHNICITY:**

**PARENT(INFORMANTS) NAMES:**

**BEST WAY TO CONTACT YOU:**

**HOME LANGUAGE/LANGUAGE CHILD SPEAKS:**

**CHILD ATTENDS PRESCHOOL/DAYCARE:**

**WHO LIVES AT HOME:**

**ANY CURRENT DIAGNOSIS:**

**ANY AGENCY/PROGRAM CURRENTLY WORKING WITH CHILD:**

**ANY FAMILY HISTORY OF LEARNING/BEHAVIOR CHALLENGES:**

**WHAT ARE YOUR CONCERNS:**

**BIRTH HISTORY CHALLENGES:**

**CURRENT HEALTH CHALLENGES AND MEDICATIONS:**

**SPEECH/LANGUAGE CONCERNS:**

**BEHAVIORAL CONCERNS (ODD/ACTIVITY LEVEL)**

**SOCIAL-EMOTIONAL CONCERNS:**

**GROSS/FINE MOTOR CONCERNS**

**SELF-HELP SKILLS CONCERNS (TOILET TRAINED, ASSIST IN DRESSING):**

**WHAT ARE CHILD’S STRENGTHS:**
NOTES:_______________________________________________________

ACTION: (NO ASSESSMENT, SPEECH/LANGUAGE ASSESSMENT/ TEAM ASSESSMENT)
Appendix K: Consultation Process for SLPs with Psychologists
(For students receiving speech therapy services with an active IEP)

Revised 3/18/2022

- The SLP will complete the psych consult form along with 6-weeks of therapy notes on the student and send an email to the Psychologist’s and Coordinator (put ‘Team Referral’ as the subject) attaching the consult form and therapy notes.

- The Psychologist will consult with the treating SLP regarding concerns for the student and determine possible dates to hold an Amendment IEP. The IEP will allow for a discussion of students' overall concerns and enable an opportunity for the Psychologist to observe the student informally.

- SLP will contact the parent to schedule the IEP.

- SLP will touch base with the Psychologist to confirm the IEP date.

- At the IEP, the team will make a recommendation and document the outcome in the notes (i.e., team assessment or not).

- If a team assessment is recommended, the Psychologist will then contact the Director of Special Education to assign a psychologist and team.

- The assigned Psychologist will create an AP and send it to the parent to sign.
Appendix L: Santa Barbara County Education Office Psychologist Consultation Form

<table>
<thead>
<tr>
<th>Request for School Psychologist Consultation for Preschool Students with IEPs</th>
<th>Date Received</th>
<th>Psych Assigned</th>
<th>Date of observation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child's Name</strong></td>
<td></td>
<td>Parent's Name(s)</td>
<td></td>
</tr>
<tr>
<td><strong>DOB/Age</strong></td>
<td></td>
<td>Address</td>
<td></td>
</tr>
<tr>
<td><strong>Date of last IEP</strong></td>
<td></td>
<td>Phone Numbers</td>
<td></td>
</tr>
<tr>
<td><strong>Date of last evaluation</strong></td>
<td></td>
<td>Interpreter needed?</td>
<td></td>
</tr>
<tr>
<td><strong>Speech/Language Specialist</strong></td>
<td></td>
<td>Contact information</td>
<td></td>
</tr>
<tr>
<td><strong>Location and days/times to observe</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current Goals (please check the heart)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>💚 Articulation</td>
<td>💚 Social Skills</td>
<td>💚 PreAcademic</td>
<td>💚 Other:</td>
</tr>
<tr>
<td>💚 Receptive Language</td>
<td>💚 Executive functioning</td>
<td>💚 Fine Motor:</td>
<td>💚 Other:</td>
</tr>
<tr>
<td>💚 Expressive Language</td>
<td>💚 Self Help</td>
<td>💚 Gross Motor:</td>
<td>💚 Other:</td>
</tr>
<tr>
<td><strong>Your Current Concerns (please check the stop sign)</strong></td>
<td><strong>Describe: What does it look like?</strong></td>
<td><strong>Describe: When does it happen?</strong></td>
<td><strong>Interventions Tried</strong></td>
</tr>
<tr>
<td>🚫 Behavior</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>🚫 Stereotypic/unusual Behavior</td>
<td></td>
<td></td>
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<tr>
<td>🚫 Failure to progress</td>
<td></td>
<td></td>
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<tr>
<td>🚫 Motor skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>🚫 Sensory sensitivities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>🚫 Other (describe):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Others' Current Concerns</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have parents or others expressed similar concerns?</td>
<td>Yes</td>
<td>No</td>
<td>Does the student receive any IEP services other than your services?</td>
</tr>
<tr>
<td>Have parents been contacted regarding these concerns?</td>
<td>Yes</td>
<td>No</td>
<td>If yes, specify other services and contacts</td>
</tr>
<tr>
<td><strong>Other Available Supports</strong></td>
<td><strong>Contact Name</strong></td>
<td><strong>Contact Phone</strong></td>
<td><strong>Contact Email</strong></td>
</tr>
<tr>
<td>Tri Counties Regional Center</td>
<td></td>
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<tr>
<td>CCS</td>
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<tr>
<td>Private Behavioral Services</td>
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<tr>
<td>CADA</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
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</tr>
</tbody>
</table>
VITA

Ivan Alvarez has been a Bilingual School Psychologist for the Santa Barbara County Education Office since 2014. He has worked in K-12 schools as a School Psychologist since 2012. He is also a credentialed school counselor in California. Ivan is currently a Doctoral Candidate in the Department of Educational Leadership and Policy Analysis at the University of Missouri, Columbia. He was selected as the new Region VIII Representative for the California Association of School Psychologists in August 2021. He is currently serving on the Board of Directors for the Children and Family Resource Services in Santa Barbara County. Ivan previously served as a Board Member, President, and Past-President for the Central Coast Association of School Psychologists from 2017-2020. He has a passion for working with diverse families and underrepresented populations, particularly students with disabilities.

Ivan was initially inspired to pursue a career in school psychology in high school due to a positive interaction I had with an exceptional bilingual school psychologist. Although Ivan did not work directly with the bilingual school psychologist, he observed the significant difference he made in the lives of students and families in the school and community. He interned with the same bilingual school psychologist in graduate school, and he served as his mentor during his practicum years until the present.

Before his career in school psychology, Ivan previously held positions as a Disability Resources Tutor in college and Substitute Teacher for K-12 schools for three years. He noticed that his passion was working with students in special education and committed to pursuing a career as a school psychologist. The field is rewarding due to the vast
opportunities that school psychologists have to assist students, school staff, and the community.

Ivan’s favorite part of his position is working with preschool students during their transition from infant to preschool-related services. He enjoys working closely with families and providers to determine a student’s areas of strength, areas of need, and potential benefits during this initial process with the IEP team. He finds it rewarding to conduct Kindergarten transitions as part of the assessment team and measure a student’s growth.

It is refreshing when he can inform families that their child is demonstrating age-appropriate skills and no longer require the same level of special education services during their transition to Kindergarten. This outcome is made possible when our IEP team members and families work diligently throughout the year so that all children make short-term and long-term progress on their IEPs.