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# An Environmental Scan of Diagnostic Practices for Children with Disabilities in El Paso

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AN ENVIRONMENTAL SCAN OF DIAGNOSTIC PRACTICES FOR  
CHILDREN WITH DISABILITIES IN EL PASO

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Master's Program in Speech- Language Pathology

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Charles Ambler, Ph.D.  
Dean of the Graduate School

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Alezandra Martinez

2017

AN ENVIRONMENTAL SCAN OF DIAGNOSTIC PRACTICES FOR  
CHILDREN WITH DISABILITIES IN EL PASO

by

ALEZANDRA MARTINEZ

THESIS

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## **Abstract**

With the prevalence of developmental disabilities in the rise in the United States, it is important that these children are identified and diagnosed as soon as possible so that they may receive appropriate medical treatment and intervention. However, research suggests that there are several factors that influence screening, referral, and diagnostic practices. This study aimed to analyze key themes that arose when parents of children with disabilities and pediatric healthcare providers discussed screening, referral, and diagnostic practices for children in El Paso, a medically underserved community. Researchers conducted a 2- phase study that employed both quantitative and qualitative methodology. Results indicated that there were both similarities and differences in how parents and professionals discuss screening, referral, and diagnostic practices in El Paso. Key themes that parents and professional discussed included (1) hassles for parents, (2) lack of understanding/ empathy, and (3) a shortage of professionals. Future research should aim to minimize the gap between these views and improve healthcare practices for children with disabilities.

*Keywords:* developmental disabilities, screening and referral practices, early childhood intervention (ECI), racial/ ethnic healthcare disparities, socioeconomic disparities

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## **Introduction**

### **Developmental Disabilities**

The Center for Disease Control and Prevention (CDC) defines a developmental disability as a condition that can impact an individual's physical, learning, language, or behavioral capacities. These conditions appear early in life, affect daily living, and last throughout the individual's lifetime (CDC 2015). Developmental disorders include Autism Spectrum Disorder (ASD), Attention Deficit/ Hyperactivity Disorder (ADHD), Cerebral Palsy (CP), Intellectual Disability (ID), among many more. Developmental disabilities can range in severity, from mild to severe. The most recent study that analyzed the prevalence of developmental disabilities found that one in six children in the United States have a developmental disability (Boyle et al. 2011). This study also found that the prevalence of developmental disabilities in the United States has increased from 12.84% to 15.04% over 12 years. It is important that with this increase in prevalence, pediatric healthcare providers are adequately screening children for developmental disabilities when there are concerns about a child's development and are making appropriate referrals when necessary. These steps are crucial in receiving a diagnosis as early as possible.

### **Developmental Screening Tools**

Developmental screenings are short assessments that are used to evaluate whether a child is developing basic skills when he or she should, or whether there are potential delays or disabilities (CDC, 2016.) There are several different types of developmental screening tools. The most common screening tools that are used in early childhood development are standardized parent questionnaires. These questionnaires are favored due to their cost- effectiveness and parental involvement (Squires, Bricker, & Potter, 1997). The American Academy of Pediatrics (AAP)

recommends that pediatricians conduct standardized developmental screenings at 9-, 18, and 30-month visits.

A review of existing literature regarding the effectiveness of developmental screening yielded mixed findings. A retrospective study by Dearlove & Kearney (1990) found that a developmental screening performed by healthcare professionals had a sensitivity of only 45%, and a preschool developmental screening tool had a sensitivity of 56% for children who were later identified as having a disability. In this case, specificity is the number of children who are identified as being developmentally at-risk and who truly are. Specificity is the number of children who are identified as being typically developing and who truly are. These numbers mean that about half of the children who were identified as having a disability truly had one, and that about half of the children who were identified as typically developing were truly doing so. A study conducted by Crais et al. (2014) found that interpersonal issues, procedural processes, contextual issues, tool design, and ethical/ moral dilemmas were all factors that influenced pediatric healthcare professionals' Autism Spectrum Disorders (ASD) screening practices.

On the other hand, screening practices can be effective in identifying children with developmental delays, referral to ECI services, and eligibility for ECI services in urban settings with high-risk children (Guevara 2013). Glascoe (1997) found that parents' concerns about their child's development could be used as a screening tool, with a sensitivity of up to 79% and a specificity of 72% when compared to a child's score on the Woodcock- Johnson Test of Cognitive Abilities. There are also several developmental screening tools with adequate psychometric properties and reasonable feasibility that can be used in low- and middle- income settings, such as the Guide for Monitoring Child Development, Disability Screening Test, and the Ten Questions Questionnaire (Fischer et al. 2014).

## **Early Identification Practices**

Under part C of the Individuals with Disabilities Education Act (IDEA), Early Childhood Intervention (ECI) services were made available for infants and toddlers from birth to 35 months of age who display any developmental delays (U.S. Department of Education, 2015). ECI services are effective in improving motor function, language development, social/ emotional health, and decreasing family stress for children with various developmental disabilities (Eikseth, 2009; Reichow & Wolery, 2008; Reithmuller, Jones, & Okley, 2009; Remington et al., 2007; Hill, Brooks- Gunn, J, & Waldfogel, 2003; Yoshinaga- Itano, C., 2003; Dawson et al. 2010). In order to receive ECI services, children with developmental delays and disabilities must be identified as soon as possible. If children are not identified as soon as possible, they must wait to receive services that they need in order to do well in social and educational settings until they enter the school system (CDC, 2016). This is often the case for children with more mild disabilities. However, early detection efforts, such as screenings and referrals, vary greatly in practice (Macy, Marks, & Towel, 2014). In many cases, there is a lack of coordination between pediatric health care professionals that leads to delayed identification of delays and disorders in these children.

Grant and Isakson (2013) found a discrepancy in the number of children who were identified as developmentally at-risk and the number of children enrolled in intervention services, particularly in the south region of the United States. Lack of appropriate referral services has been identified as a barrier in receiving intervention services among mothers of children with developmental disabilities (Hendrickson, Baldwin, & Allred, 2000). Macy et al. (2014) found that many referrals to ECI agencies fall between the cracks of the system, due to a lack of coordination between health care professionals. A study conducted by Peterson et al. (2013) also found that 33% of children identified with a developmental risk before age 3 continued to display these delays

and did not receive any ECI services. Shevell, Majnemer, Rosenbaum, and Abrahamowicz (2001) found a mean delay of 15.5 months between a parent's initial concern about their child's development and a comprehensive assessment.

### **Special Considerations for Low- Socioeconomic Status and Minority Groups**

Early detection of children with developmental disabilities is even further complicated in areas with a high concentration of low- socioeconomic status and minority families. Low- income has been associated with a higher risk of developmental disabilities (Boyle et al., 2011). There is also evidence that suggests that there is a disparity in the age of diagnosis in children with ASD, with Hispanic children receiving a diagnosis one year later than non- Hispanic white children. (Magaña, Lopez, Aguinaga, & Morton, 2013). Mandell et al. (2009) found that children with ASD who were Black or Hispanic were less likely to have a documented ASD diagnosis on their medical records than White children with ASD. Magaña et al. (2013) also found that Latino children with developmental disabilities are less likely to receive ECI services when compared to non- Hispanic White children with developmental disabilities. Moreover, Hispanic children with developmental disabilities in this study were found to have received fewer services than non- Hispanic White children, and have more needs that go unmet. Peacock and Lin (2012) found that non- English speaking families encountered more challenges in accessing diagnosis and intervention services than others (Magaña et al., 2013). Heejoo et al. (2015) found that among children with mild/moderate ASD, the prevalence disparity between non- Hispanic white children and Hispanic children aged 5- 17 years was much larger than the same ethnic groups with severe ASD, suggesting a potential under-identification of Latino children with mild/moderate ASD.

Moreover, many standardized developmental screening tools are not normed on children from culturally and linguistically diverse backgrounds, and therefore should not be used to

compare these children to others of their age. Direct translations of standardized developmental screening tools are often inadequate and use words that do not coincide with the different dialects of Spanish spoken in different parts of the world (Harris, Barton, & Albert, 2014). Indeed, Harris, Barton and Albert (2014) found that many of the screening tools used for ASD did not have any adaptations that can be used with CLD populations.

### **Demography of El Paso, Texas**

According to the United States Census Bureau (2015), the population of El Paso, Texas is predominately Hispanic/Latino (81.3%) and 23.4% of the population lives below the poverty level. These percentages are both higher than the national averages (17.4% Hispanic/ Latino; 15.4% below poverty level). El Paso is also a medically underserved area, with a pediatrician to child ratio of 1- 3532, compared to the national ratio of 1- 1769 (Johnson, 2007). Parish et al. (2012) found that Latino children with ASD and other developmental disabilities had consistent patterns of worse healthcare when compared to White children. Hispanic parents also report the most barriers in regards to accessing healthcare services when compared to non- Hispanic White parents and Black parents (Young & Rabiner, 2015). Thus, it might be the case that the children in El Paso are not getting identified with developmental delays and disabilities soon enough. As a result, these children may be missing out on valuable intervention services that they could benefit from.

### **Environmental Scans**

Considering the unique makeup of El Paso, potential solutions for improving early identification of children with disabilities must be specific to this community. Environmental scans are used in the healthcare field to bring together various stakeholders in the community. Participants can discuss the state of current healthcare practices, as well as plan how these practices can be improved. Environmental scans are recognized as a valuable tool in healthcare decision

making (Graham, Evitts, & Thomas- MacLean, 2008). An environmental scan was recently conducted in Canada regarding services for children with Fetal Alcohol Spectrum Disorder (Naumann, Reynolds, McColl, & Smith, 2013). As a result of this environmental scan, researchers were able to identify gaps in screening procedures and service delivery, as well as devise potential solutions. Peacock and Lin (2012) had similar success when conducting an environmental scan regarding services for children with ASD. A benefit of environmental scans is the diverse viewpoints that can be obtained from the different stakeholders who participate (Graham et al., 2008). In these cases, parents of children with disabilities, professionals who work with children with disabilities, academic partners in related fields, as well as individuals with disabilities were able to come together to discuss areas of concern regarding healthcare services in their community, as well as potential solutions. Using the environmental scan model, researchers were able to obtain a much more comprehensive overview of what the community was in need of in terms of healthcare services for children with developmental disabilities.

Clearly, there is much work to be done in improving early detection practices for children with developmental disabilities. With the unique demographics that make up El Paso, solutions that are specific to the makeup of this community are needed. For this reason, a team of researchers designed and conducted an environmental scan to assess how people in our community view early detection practices.

## **Purpose**

The purpose of the present study was to evaluate how parents and professionals view screening, referral, and diagnostic practices for children with disabilities in El Paso. This 2- phase study aimed to answer the following questions:

1. What are the key themes that parents and professionals discuss regarding screening, referral, and diagnostic practices for children with disabilities in El Paso?
2. Is there a difference between how parents and professionals view screening, referral, and diagnostic practices for children with disabilities in El Paso?

## **Methods**

### **Study Design**

This 2- phase study employed both qualitative and quantitative methodology to assess how parents and professionals view screening, referral, and diagnostic practices for children with disabilities in the El Paso region. The study procedures were approved by the Institutional Review Board at the University of Texas at El Paso

### **Phase 1- Survey**

**Participants.** The participants who completed phase 1 of the current study were part of a larger study conducted by the children with disabilities team of the Community and Academic Partnership for Health Sciences Research (CAPHSR) program at the University of Texas at El Paso (UTEP). The intent was to recruit a wide range of professionals who are involved in the screening, referral, and diagnostic practices for children with disabilities, as well as an equal number of parents. Researchers recruited participants via an email sent to the El Paso Speech Language and Hearing Association (EPSHA), lead speech- language pathologists at various schools and clinics, off- site practicum coordinators in the speech- language pathology, occupational therapy, and physical therapy programs at UTEP, and several community organizations whose main focus is children's healthcare. A graduate research assistant also recruited participants at several parenting classes for parents of children with disabilities at a community center. Researchers employed a convenience sampling strategy, in which participants are recruited due to their availability (Hedge, 2003).

Sixty parents of children with developmental disabilities, 5 individuals with developmental disabilities, and 43 professionals who work with children with developmental disabilities participated in this phase. Two participants did not answer the question regarding whether they

were a parent, professional, or an individual with disabilities (N= 110). A detailed description of phase 1 participants can be found in Table 1, and total household income information can be found in Table 2.

Table 1  
*Phase 1 Participants by Profession*

Profession	Number
Parent	60
Individual with Disabilities	5
Pediatrician	1
Social Worker	9
Counselor	1
Speech- Language Pathologist	5
Physical Therapist	1
Nurse	10
Special Education Teacher	10
Other	8
Total	110

Table 2

*Phase 1 Participants by Total Household Income*

Total Household Income	Number
Less than \$10,000	17
\$10,000- \$19,999	12
\$20,000- \$29,999	16
\$30,000- \$39,999	9
\$40,000- \$49,999	12
\$50,000- \$59,999	10
\$60,000- \$69,999	5
\$70,000- \$79,999	3
\$80,000- \$89,999	4
\$90,000- \$99,999	5
\$100,000- \$149,999	6
\$150,000 or more	5
Incomplete	6
Total	110

**Measure.** The team for children with disabilities of the CAPHSR program at UTEP designed a short survey to distribute to participants. Team members included two speech- language pathology faculty members, one social work faculty member, and three community partners who work with children with disabilities. The survey was created using Qualtrics software (2015). The aim of the survey was to gather preliminary data in regards to how parents and professionals view various services for children with disabilities in El Paso. Creating the survey with both academic and community partners followed the collaborative survey design proposed by Flicker et al. (2010). The Toronto Teen Study (TSS) conducted by Flicker and colleagues was a community-based participatory research study whose aim was to gather information regarding healthcare in

their specific community. Researchers collaborated with both community stakeholders and local teens to create a survey that was able to gather the most accurate information and that would make sense to the target audience.

The initial question on the current survey identified whether the participant was a parent, professional, or an individual with a disability. After the initial question, the survey differed slightly in order to best gather information. The common questions in the survey consisted of two demographic questions, a Likert scale question in which participants were asked to rate the effectiveness of various services for children with disabilities, including screening, referral, and diagnostic processes, and open-ended questions that allowed participants to make further comments about the services that they rated. A detailed description of the survey can be found in Table 3.

Due to the high percentage of monolingual Spanish-speakers in El Paso, the survey was available in both English and Spanish. A graduate research assistant who is fluent in Spanish translated the survey. Two different graduate research assistants who are also fluent in Spanish reviewed the survey to ensure the translated survey was grammatically correct and that the vocabulary used was concurrent with the Spanish dialect used in the area. The survey was then piloted on members of the UTEP speech-language pathology faculty who were not involved in creating the survey, as well as several parents. If any question was found to be ambiguous or confusing to the target audience, researchers revised the question and piloted the survey again.

Table 3

*Phase 1 Survey*

Question	Both parents and professionals	Parents only	Professionals only
	I am		
1.	<ul style="list-style-type: none"> <li>a. A parent of a child with a developmental disability</li> <li>b. Professional who works with children with a developmental disability</li> <li>c. An individual with a developmental disability</li> </ul>		
2.	What is your total household income?		
3.			What is your profession?
4.		Are you (individual with developmental disability)/ is your child younger than 21 years of age?	
5.	Please rate the effectiveness of services being provided to a child with developmental disabilities in the El Paso region (screenings, referrals, diagnostic/ evaluation process, medical care, collaboration of professionals, speech- language pathology services, occupational therapy services, physical therapy services, mental health/ behavioral services, parent support?		
6.		What services do you need but are not available to you?	
7.	What is working well in the El Paso region in meeting the needs of children with developmental disabilities?		
8.	What is not working well in the El Paso region in meeting the needs of children with developmental disabilities?		
9.		What barriers or difficulties do you experience in receiving services?	
10.			What are the gaps in services that you see?

**Procedures.** Researchers distributed the survey via email to different parents, professionals, and individuals with disabilities beginning in July 2015. Several parents also completed the survey via hard copy at the Paso Del Norte Children’s Development Center.

**Analysis.** Analysis of the phase 1 data included both qualitative and quantitative measures. Researchers conducted a 1- way ANOVA to compare the ratings of the Likert- scale questions. A 1- way ANOVA is a statistical analysis that is used to determine whether there are statistically significant differences between the means of two or more groups. The independent variable in this analysis was the group (parent or professional), and the dependent variable was the average rating of each service. The third group, individuals with disabilities, was not included in this analysis due to how few participants belonged to that group when compared to the other two. A content analysis was used to qualitatively analyze the open- ended questions. A graduate and an undergraduate research assistant independently coded the open- ended questions based on subject matter in order to conduct a content analysis to identify recurring themes that participants discussed. Once coded, the two research assistants compared results and discussed any discrepancies that arose.

## **Phase 2- Summit**

**Participants.** All participants from phase 1 of the study were invited to participate in phase 2 via email. Researchers and community partners recruited additional participants via flyers distributed at the UTEP Speech, Language, and Hearing Clinic, several community centers, as well as at several parenting classes at the Paso Del Norte Children's Development Center. A total of 53 participants (31 parents, 27 professionals, 5 both parent and professional) attended the summit.

**Procedures.** During the second phase of the study, researchers held the El Paso Summit for Children with Special Needs. The summit took place at a community center at the end of October 2015 and included a free lunch for all participants. All materials for the summit were available in English and Spanish. Two sign language interpreters and a simultaneous English-Spanish translator were hired to accommodate the needs of all attendees present. The summit used an adapted version of the World Café model, which is a format for hosting large group discussion

(The World Café, 2008). This model begins by establishing the context in which participants will discuss matters, encourages participants to ask meaningful questions, connect diverse perspectives and discover patterns in the content of the conversation. Members of the team for children with disabilities introduced the project and explained the aims of the summit during the first hour. There were ten tables at the summit that participants could choose to sit at. Each table was assigned a theme that was identified as problematic regarding services for children with disabilities using data from phase 1. Themes included (1) access to services, (2) community awareness, (3) collaboration of professionals (4) communication with parents, (5) diagnostic process, (6) financial barriers, (7) follow up/ referrals (8) mental health services, (9) transition services, and (10) an open discussion table. Participants sat at a table of their choosing, according to which theme they wanted to discuss. During the second hour, participants had fifteen minutes at a table to discuss each theme. Both graduate and undergraduate volunteers from the speech- language pathology and social work programs at UTEP sat at each table to act as scribes during these sessions, as well as to facilitate the discussion. All discussions were also recorded using digital voice recorders. At the end of fifteen minutes, participants were asked to move to a different table. This process was repeated for a total of three times. The final fifteen minutes consisted of concluding remarks by members of the children with disabilities research team.

**Analysis.** Following the summit, each of the breakout sessions were transcribed by both graduate and undergraduate bilingual research assistants. Once transcribed, two researchers independently coded and analyzed the transcripts using Nvivo (2010) software. Nvivo software is commonly used in evaluating qualitative data and explaining social phenomena in the fields of social sciences and healthcare (Nvivo, 2010). The transcripts were analyzed using a grounded theory approach, which is a methodology that is used to identify common themes that emerge from

the data as well as postulate theories about said themes (Faggiolani, 2011). Each coder identified recurring themes and subthemes that participants discussed regarding screening, referral, and diagnostic practices.

## Results

The purpose of the present 2- phase study was to analyze how parents and pediatric healthcare professionals view screening, referral, and diagnostic practices for children with disabilities in El Paso. Both quantitative and qualitative analyses were conducted in order to best analyze the data collected. Results from phase 1 and phase 2 are presented below.

### Phase 1

Overall, participants rated screening practices an average 3.14 out of 5. Participants rated referral practices similarly, with a rating of 3.16. Participants rated diagnostic practices highest of the three services, with a rating of 3.27. Parents consistently rated screening, referral, and diagnostic practices lower than professionals. Mean ratings between parents and professionals regarding referrals [ $F(1,64) = 2.402, p = .030$ ] and diagnostic practices [ $F(1,75) = 4.874, p = .034$ ] both reached statistical significance. Although there was a difference between parents' and professionals' ratings of screenings, this difference did not reach statistical significance ( $F(1,75) = 4.695, p = .126$ ). A detailed listing of results can be found in table 4.

Table 4

*Ratings of Services*

Service	Overall Rating	Parent Rating	Professional Rating	<i>p</i> value
Screenings	3.14	2.91	3.39	.126
Referrals	3.16	2.87*	3.46*	.030*
Diagnostic Practices	3.27	2.98*	3.60*	.034*

A qualitative content analysis of the open-ended questions from the survey yielded several themes that were discussed repeatedly by participants.

**What services do you need but are not available to you?** A majority of the parents expressed that the lack of specialists in the area was problematic in accessing healthcare for their children with disabilities. Parents also voiced that there is a lack of transitional support and resources available for children transitioning out of the school system.

**What is working well in the community in meeting the needs of children with disabilities?** Both parents and professionals overwhelmingly stated that ECI services were working well for children. Parents also found community organizations to be very helpful in navigating different obstacles that they came across. Some professionals expressed that their communication with parents was also a strength in the community in meeting the needs of children.

**What is not working well in the community in meeting the needs of children with disabilities?** Parents reported a lack of pediatric healthcare specialists as being problematic in meeting the needs of children. Factors associated with the lack of specialists included long wait times for appointments and poor follow-up care. School systems, follow-up care and referrals, and diagnostic practices were also repeatedly reported as areas of weaknesses. Parents also reported a lack of knowledge about the services available for their children. Interestingly, some professionals also stated that collaboration and communication among professionals as a weakness in the community.

**What barriers do you experience in receiving services?** Parents reported financial and insurance obstacles as barriers in receiving services, as well as a lack of the knowledge of services available. Parents also reported a lack of specialists and long wait times for appointments as barriers.

**What are the gaps in services that you see?** Professionals most often reported a lack of communication and collaboration among professionals as a gap in service delivery. Access to services, doctors, and a shortage of professionals were also reported as gaps in services.

## **Phase 2**

A grounded theory analysis (Faggiolani, 2011) yielded 3 main themes that emerged from the discussion during the breakout sessions at the summit. These themes included (1) hassles for

parents, (2) a lack of understanding/ empathy, and (3) a shortage of professionals. Within each of the main themes, several subthemes also emerged. Since the sessions were not videotaped, there was no possible way to know for certain which participants were professionals and which were parents when transcribing and analyzing the data. However, many times it could be inferred based on the content of the conversation. Each topic, along with illustrative quotes that better describe the nature of the barrier are provided in Table 5.

**Hassles for parents.** Participants reported several obstacles they face when obtaining services for children with disabilities. Among these, the two main subthemes that reoccurred were the lack of coordination and collaboration among professionals and a lack of guidance.

*Lack of coordination and collaboration among professionals.* Within this subtheme, both parents and professionals reported a lack of communication as a barrier in receiving an initial diagnosis and services. Parents often felt that it was difficult to obtain a referral for services that their child needed or for a doctor they needed to see. Participants also stated that there is often a lack of coordination between professionals that lead to the child missing out on services. For example, one parent made the following statement, “If I take my child to one specialist and he says one thing, the second specialist I see will refuse to treat my child if I comply with what the first specialist says.” Another parent stated that doctors often do not speak to each other, and “rely on the parents to relay information.” Parents and professionals discussed the importance of a case manager for these children. As one parent described, “Someone who is not necessarily providing the service that the child needs... but someone who is overseeing how that child accesses those services. Have they fallen out of the appointment schedule? Maybe the family has moved. Maybe they know they can still get services, and a case manager is going to be that one who is going to reach out to find that family and help them get reconnected to the services they need.”

***Lack of guidance.*** The second subtheme under hassles for parents was a lack of guidance from professionals to parents. Parents reported that navigating the healthcare system is no easy feat, and healthcare providers seldom take measures to help parents take the next steps. For example, one parent reported, “When you’re diagnosed, that’s it. They give you a little paper, tell you good luck, and that’s it.” Many parents discussed how they were not aware of the services available for their children, and only found out about them through other parents who had already gone through the process. Although participants reported a lack of guidance, they also discussed the benefits of community organizations and non- profit agencies. Many participants discussed how Paso del Norte Children’s Development Center was immensely helpful in finding resources for their children.

***Lack of understanding and empathy.*** The second main theme that was discussed at the summit was a lack of understanding and empathy from professionals, as well as the community. Parents often felt that the doctors who were seeing their children were often disconnected personally, and did not make an effort to form a personal relationship with their child. Participants also discussed the public’s lack of awareness of different disabilities. Parents discussed different hardships that arise in raising a child with a disability, such as getting disapproving looks from onlookers when their child is throwing a tantrum in a public setting. Many times these tantrums are due to sensory overload, and parents expressed they would appreciate a helping hand when these events took place.

***Shortage of professionals.*** The most discussed barrier in the diagnostic process for children at the summit was the shortage of professionals in our community. Participants discussed two potential solutions for alleviating this issue.

**Personnel Training.** Many participants discussed that training more people in the signs and symptoms of developmental disabilities would greatly facilitate reaching a diagnosis for these children. Wait times for appointments with a specialist are often months long in our community. Therefore, parents discussed the benefits of having more personnel trained to pick up on signs and symptoms of disabilities. The sooner the child is identified as possibly having a disability, the sooner the parents can set up an appointment and ultimately reach a diagnosis. People such as teachers and day care providers are ideal candidates for this type of training.

**University Curriculum.** Many parents expressed that proper training for service delivery in pediatrics begins with the curriculum at universities. Parents felt like graduate students in professional programs, such as speech- language pathology, occupational therapy, and physical therapy, do not obtain enough clinical experience with children with disabilities throughout their coursework. Parents also felt that professionals such as nurses and teachers should also receive additional training in how to provide quality healthcare for children with disabilities. If everyone who is involved for caring for these children had a better understanding of disabilities, not only would the child benefit immensely, but also the families.

**Table 5**

*Issues in the diagnostic process for children with disabilities*

Theme	Illustrative quote
<b>1. Hassles for parents</b>	
a) Lack of coordination among professionals	<p>“With my daughter, I think it’s difficult because... if one [professional] tells me one thing and I go with [a different professional] and [say] ‘well, he’s telling me this,’ this one is probably going be [different]. I mean, there’s been times when they’re like ‘if you want to do what he tells you, I cannot see you.’”</p> <p>“As a mom and as a professional... families call me and [say] ‘you told me to come here but this one’s not working with me because I’m doing this’”</p>
b) Lack of guidance	<p>“When you’re diagnosed, that’s it. They give you a little paper, tell you good luck, and that’s it.”</p>

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“Our son was 11 months when he got [injured], and we were so focused on the trauma of what happened to him. Nobody came to us to tell us about the [services available].”

**2. Lack of understanding/ empathy**

“I need somebody that understands me as a parent. And as a parent with a child with a disability, as it is, when we’re out into society, they treat him bad as it is. So we want somebody to be compassionate, we want someone to be understanding, we want somebody to say “ok, I may not know what it is to be a parent with a child with a disability but I feel your need, your needs, I feel your pain, I feel... you see?”

“One of the things we’ve struggled with was the daycare we were leaving her at. Within one week, they wanted to get rid of her, and we didn’t even know she had autism at that point. But they were just like, “no, your child needs to be somewhere else,” but didn’t really tell us where that somewhere else was.”

**3. Shortage of professionals**

a) Curriculum

“I think it starts at [the university]. I don’t think you all get nearly enough clinical experience out there.”

b) Training

“What if there was better training for all pediatricians? maybe a summit that could provide at least some basics. It wouldn’t be at the level of specialist, but at least get them a little more up to speed, because from what I hear from parents, even the basics are often not there. You were saying they aren’t screening for the social and behavior things... I’ve been reading about places where they’re using paraprofessionals or social workers in clinics to do some of that screening in the pediatrics office so that the kids are getting screened when they come through their well child checkups.”

“Toda la gente que está en contacto con nuestros hijos conozcan también de los signos que hay de cómo pueden darles cuenta si está teniendo un problema, si está desarrollando algo que no es normal de la edad, que no es normal de su etapa de vida.”

(translated from Spanish)

*“All of the people who are in contact with our children should be familiar with the red flags so that they can tell parents when there is something to be concerned about, if something is not normal for their stage of development or age.”*

## **Discussion**

Research has found that the prevalence of developmental disabilities in the United States has increased, affecting about one in every six children. For this reason, it is important that healthcare providers are screening children for developmental delays and disabilities, and making appropriate referrals when necessary. These first steps are crucial in reaching a diagnosis as early as possible. However, there is great variability in screening and referral practices. Discrepancies in these practices ultimately lead to delayed identification of developmental disabilities in children. Many studies have identified inadequate referral practices as a barrier in receiving an initial diagnosis, as well as subsequent intervention services. There is also ample evidence that suggests that minority children and children who come from low socioeconomic homes are identified with developmental disabilities at a later age, receive fewer services, and have more needs that go unmet (Magaña et al, 2013; Mandell et al, 2009).

El Paso, Texas and the surrounding area has a higher concentration of minorities and individuals living below the poverty level when compared to the U.S. as a whole. It is also a medically underserved area. For this reason, along with others previously mentioned, children with disabilities in the El Paso region may be at a high risk of not getting identified early enough and are missing out on valuable services.

The purpose of the present study was to evaluate how parents and pediatric healthcare providers view screening, referral, and diagnostic practices in El Paso. Specifically, this study aimed to determine the key themes that emerged when parents and professionals discussed these practices, as well as whether there are differences between how parents and professionals view these practices in the region.

### **Themes**

The first research question aimed to determine what key themes arose when parents and professionals discussed the screening, referral, and diagnostic practices for children in El Paso. Using qualitative analysis, several themes were identified. These included (1) hassles for parents, (2) lack of understanding/ empathy and (3) shortage of professionals. Participants also identified follow up care/ referrals as an area of weakness in El Paso, and expressed the need for a case manager for children so that they do not fall through the cracks and get left behind.

The first over-arching theme that was identified entailed hassles for parents. These included a lack of coordination among pediatric healthcare professionals, as well as a lack of guidance after the initial diagnosis. These findings are similar to findings of Young & Rabiner (2015), who identified the importance of strengthening relationships between pediatric healthcare providers and parents as a crucial step in eliminating barriers to accessing services for children with disabilities.

A lack of understanding and empathy from healthcare professionals was the second major theme that was discussed. Parents felt as if both healthcare providers and the general public did not express as much empathy as they would hope people would. Professionals expressed a similar concern, expressing that the public, in general, was not aware of many disabilities. More community education and awareness is needed so that children with disabilities and their families can be better understood.

The final overarching theme was concerned with a shortage of professionals in our community. With El Paso traditionally being a medically underserved community, it was not surprising that many participants voiced concerns that the community has a huge shortage of specialists that can meet the needs of children. To alleviate the issues that arise from the shortage of professionals in the area, parents felt that more people that are in contact with children should

be familiar with developmental milestones and red flags so that these children can be identified as early as possible.

### **Parents and Professionals**

The second research question aimed to determine whether parents and professionals view screening, diagnostic, and referral practices differently. Overall, parents rated the effectiveness of all three practices lower than professionals, with the difference between referral and diagnostic practices reaching statistical significance. It is possible that the discrepancy between how parents and professionals view screening, referral, and diagnostic practices can be attributed to a lack of communication between healthcare professionals, as well as a lack of communication between parents and professionals. This argument is concurrent with existing literature that has found that there is often times a lack of coordination and communication among healthcare professionals who work with children with developmental disabilities (Macy et al., 2014). This lack of coordination is often the reason that children with developmental disabilities are not identified as early as they should be.

Another possible explanation for the discrepancy in these ratings could be the fact that there were far fewer pediatricians and nurses who completed the survey than parents. Pediatricians and nurses have been identified as the primary personnel who conduct developmental screenings (Crais et al., 2014). The overwhelming number of parent participants compared to pediatricians and nurses could have masked the views of the pediatricians and nurses. Pediatricians in the El Paso area have also reported that they use both standardized global developmental screenings and autism screenings on all children by at least 18 months of age and refer to ECI services when a child fails an initial developmental screening (Gonzalez et al., 2015). Crais et al. (2014) also identified that pediatric healthcare providers often times feel overwhelmed by large caseloads.

Pediatricians in El Paso might have much larger caseloads when compared to other communities due to the fact that there are fewer pediatricians to serve the community. While pediatric healthcare professionals with limited time and large caseloads strive to be as efficient and effective, parents of children with disabilities may perceive their practices as ineffective. Future studies should aim to identify factors that may contribute to the discrepancy in how parents and professionals perceive the effectiveness of screening, referral, and diagnostic practices.

An interesting point to note is that minority status or language spoken was not once mentioned by any participant as a barrier in reaching a diagnosis or receiving services, a contradicting finding to current research (Parish et al, 2012). This could be due to the fact that the overwhelming majority of El Paso is made up of Hispanics, many of whom speak both English and Spanish. People in this border community might not experience differences between minority groups as much as people living in other communities in the United States. Traditionally, research has shown that Hispanic parents are less likely to voice their concerns regarding their children's development and are more likely to view healthcare providers as authoritative figures whose opinions should not be questioned (Magaña et al., 2013). However, parent's concerns about their child's development has been shown to be an effective screening tool in children with developmental disabilities (Glascoe, 1997). Future studies should aim to create potential strategies to improve the communication between pediatric healthcare providers and parents, specifically with culturally and linguistically diverse populations.

### **Room for Growth**

It should be noted that while there were differences in how parents and professionals rated these practices differently, there is much room for improvement in all areas that were surveyed. Ratings ranged from 2.91- 3.60 out of 5, which translate to about a "neutral" view of these

practices. The medical community in El Paso clearly has some work to do in order to improve the way that both parent and professionals view screening, referral, and diagnostic practices for children with disabilities.

### **Limitations**

There are limitations to the present study that should be addressed. The sample in both phases of this study raises the question of whether the participants in this study were truly representative of the population. There were also considerable differences in the variety of professionals who work with children with disabilities. There were considerably more social workers and special education teachers who participated in phase 1 of the study than any other profession. Results of phase 1 may be biased toward the views of these professions. During phase 2, there were more parents and individuals with disabilities than professionals. This may have influenced the way in which screening, referral, and diagnostic practices were discussed, limiting the viewpoint to only that of the parents.

A final limitation is that of a sampling bias. Many of the parents involved in this study were parents that were already active participants in the community and advocates for children with disabilities. It is possible that there are a vast number of parents of children with disabilities who have been overwhelmed with information and who did not participate in the study. Despite these limitations, future researchers should use the findings of the current study to further analyze factors that affect how individuals in the community view screening and referral practices. Solutions to improve these practices in El Paso should also be explored.

### **Future Directions**

The environmental scan that was conducted in this study is only the first step in improving healthcare services for children in our community. Future research should aim to analyze specific

barriers to healthcare in our community and ways in which they can be minimized in order for healthcare services to be more accessible for all children with disabilities and their families.

Following this study, members of the CAPHSR team created both an executive summary and a policy brief using results from the study to give to various members of the community. Both documents are intended to spread awareness of the challenges that parents face when accessing healthcare services for their children with special needs, as well as to give specific recommendations as to how these challenges can be minimized. The executive summary should be used by other professionals to guide future research in our community and to write grants proposals to fund this research. The policy brief is a document that was created for legislators and policy makers in our community to use as a tool in guiding policy making to improve healthcare in our community. Specific recommendations for our community that address these challenges include creating long- term incentives to increase retention of pediatric specialists in El Paso, increasing insurance coverage for all services for children with disabilities in both private and managed care programs, and increase collaboration among stakeholders to consolidate medical and/ or therapeutic resources to one location. With the help from various stakeholders and policy makers in our community, we can make these recommendations a reality to improve our healthcare services.

## **Conclusion**

Results of this 2- phase study provide a unique look at the state of screening, referral, and diagnostic practices for children with disabilities in the El Paso region. The collaborative effort of community and academic partners in the development of the methods of this study allowed for researchers to obtain a comprehensive overview of how different people in the community perceived the effectiveness of screening and referral practices. Results of this study yielded

findings that were unique to the target community, which is comparable to outcomes of other environmental scans (Naumann, 2013; Peacock & Lin, 2012). Both pediatric healthcare providers and parents were able to come together to discuss areas of concern and were able to identify weaknesses in screening, referral, and diagnostic practices. Potential solutions to improve these practices were also discussed.

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