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Mary Troxel, Keri Linas, Diane Jacobstein, Matthew Biel, Sandra H. Soto, Isabella Lorenzo-Hubert, Soraya Dos-Santos, Rocio Mendez, and Bruno J. Anthony

Abstract

While Autism Spectrum Disorder (ASD) and other developmental disabilities are being diagnosed at increasing rates, there is strong evidence of disparities in rates of identification and utilization of services by Latino children as compared to non-Latino children. Attempts to reduce these disparities include culturally-informed early screening for ASD risk. In preparation for initiation of a screening program in a primary care setting serving primarily Latino children, focus groups and interviews were conducted with Latino parents (N=31), medical staff (N=15), health care providers (N=4) to better understand the barriers and facilitators to engagement around developmental concerns that contribute to the low identification and service use for Latino children with autism. Using a thematic analysis approach, focus group and interview data revealed themes organized around three issues impacting engagement of Latino parents in screening for ASD: 1) information exchange, 2) culture, and 3) structure. In particular, parents and providers, felt that it was important to connect on the importance of developmental issues, address health literacy, acknowledge differences in language, beliefs, and values, and address structural barriers, like length of patient/provider interaction. Information obtained through this qualitative study informed the intervention, *Supported Screening*, to facilitate screening and referral for ASD at primary care sites that serve predominantly Latino families.

KEYWORDS: delayed diagnosis; primary care screening; developmental disorders; autism spectrum disorder; Latino

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ABSTRACT

While Autism Spectrum Disorder (ASD) and other developmental disabilities are being diagnosed at increasing rates, there is strong evidence of disparities in rates of identification and utilization of services by Latino children as compared to non-Latino children. Attempts to reduce these disparities include culturally-informed early screening for ASD risk. In preparation for initiation of a screening program in a primary care setting serving primarily Latino children, focus groups and interviews were conducted with Latino parents (N=31), medical staff (N=15), health care providers (N=4) to better understand the barriers and facilitators to engagement around developmental concerns that contribute to the low identification and service use for Latino children with autism. Using a thematic analysis approach, focus group and interview data revealed themes organized around three issues impacting engagement of Latino parents in screening for ASD: 1) information exchange, 2) culture, and 3) structure. In particular, parents and providers, felt that it was important to connect on the importance of developmental issues, address health literacy, acknowledge differences in language, beliefs, and values, and address structural barriers, like length of patient/provider interaction. Information obtained through this qualitative study informed the intervention, Supported Screening, to facilitate screening and referral for ASD at primary care sites that serve predominantly Latino families.

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INTRODUCTION

While Autism Spectrum Disorder (ASD) and other developmental disabilities are being diagnosed at increasing rates, there is strong evidence of disparities in rates of diagnosis and utilization of services by Latino children as compared to non-Latino children (Mandell et al., 2009; Christensen et al., 2012). Data from the National Health Interview Survey of 2014-2016 reported that Hispanic children are significantly less likely to be diagnosed with any developmental disability (4.69%) as compared to non-Hispanic white children (7.04%), non-Hispanic black children (6.20%), and non-Hispanic other children (6.16%) (Zablotsky, Black & Blumberg, 2017).

A recent study estimated the cost of supporting children with ASD, in the absence of intervention, is \$2.4 million over the life span of the child (Buescher, Cidav, Knapp, & Mandell, 2014). Although a report from the United States Preventative Services Task Force (McPheeters et al., 2016) felt that more research was needed on the effectiveness of early universal screening, there is growing evidence that early detection of ASD is facilitated by standardized developmental surveillance in primary care (Zwaigenbaum et al., 2015). The American Academy of Pediatrics (AAP) advises elicitation of parents' developmental concerns at every pediatric visit throughout the first 5 years of life and beyond, and screening for ASD at 18 and 24 months (Myers & Johnson, 2007). Moreover, it recommends that children identified through ASD-specific screening should be immediately referred for diagnostic evaluation and appropriate intervention, since the potential benefits of a positive screen will be realized only if followed by consistent referral and timely access to specialized assessment and intervention services.

The extent to which parents of young children receive developmental surveillance has been shown to vary based on family and child demographic factors such as race/ethnicity and primary language spoken in the home. Evidence strongly suggests that families, for whom Spanish is the primary language, experience disparities in evaluation, diagnosis and treatment of developmental disorders as compared to families for whom English is the primary language (Guerrero, Rodriguez, & Flores, 2011; Zuckerman et al., 2013). In the 2007 National Survey of Children's Health, Latino parents, particularly those who spoke a non-English primary language, were significantly less likely than white parents to report provider elicitation of developmental concerns (Guerrero, Rodriguez, & Flores, 2011).

There may be many reasons for disparities in developmental surveillance; however engagement of providers and primary care sites is likely an important element in reducing these disparities (Cooper-Patrick et al, 1999; Bird & Cohen-Cole, 1990). Latino parents have shown difficulties building relationships with health providers (Stevens & Shi, 2002) and tend to not receive family centered care sensitive to cultural values and customs (Coker, Rodriguez & Flores, 2010). They also experience difficulties using services because of communication problems with providers (Flores & Ngui, 2006; Weech-Maldonado, Morales, Spritzer, Elliott, & Hays, 2001). Understanding the mechanisms through which Latino culture influences patient engagement, and ultimately health outcomes, will inform the tailoring and targeting of interventions to improve the rate of appropriate identification and evaluation of developmental concerns.

We report here the results of focus groups that were conducted with medical staff and Latino parents, and structured interviews that were conducted with physicians/nurse practitioners. The purpose of the study was to: 1) investigate parent and provider perspectives through focus groups and interviews in order to understand barriers to engagement around development concerns, and 2) use the information derived from this work to inform a multi-component

intervention, called *Supported Screening*, for use in primary care setting to both enhance parent engagement around development issues and facilitate the identification of ASD in Latino toddlers. The following paper primarily describes the qualitative results of the focus groups and interviews, and the *Supported Screening* intervention will be more extensively detailed in a subsequent paper.

METHOD

Community Health Partner

Unity Health Center is the largest primary care center in the District of Columbia (DC), with 30 service sites throughout DC. The Upper Cardozo Health Center (UCHC) is the largest clinical site of Unity Health Care, with 17,000 pediatrics visits/year, 30% of which are for 1-2 year olds. Approximately 65% of visits at UCHC involve Latino families, primarily from Central America, and a large percentage of parents are monolingual Spanish speaking. UCHC became concerned that very few young children were being identified as at risk for or diagnosed with ASD, given new data on ASD prevalence. Discussions with local psychiatrists providing services at UCHC led to a collaboration to increase their providers' capacity to engage Latino families in exploring developmental concerns, carry out effective screening and monitoring for ASD/DD, and enhance the success of appropriate referrals for further evaluation and intervention.

Participants

Medical providers and staff. The Chief of Pediatrics at UCHC recruited medical providers and staff via email, describing the study and inviting participation. Interested individuals responded directly to a member of the research team. Key informant interviews were conducted with four UCHC medical providers, representing the range of professionals treating young children: a family medicine physician; a nurse practitioner; and 2 pediatricians. The number of 1- to 3-year-old patients seen by each provider ranged from 100-500, representing from 10-50% of their caseload. Two 60-minute focus groups were held with 15 members of UCHC medical staff, including care managers, medical assistants, a case manager, a nutrition counselor and a lactation consultant. Participants were asked to write in their race/ethnicity, which resulted in 10 identifying as Latino, 3 as African American, and 1 as Ethiopian. One participant did not provide a response.

Family members. Caregivers were recruited through flyer distribution and word of mouth at the following three family and health resource centers serving Latino families in DC: a Head Start/Early Head Start Center, a comprehensive primary care health center, and a family health center. The center directors, coordinators, and staff at each location facilitated recruitment by speaking individually with families and providing information about the groups. A bilingual family outreach coordinator on the research team followed up with a phone call to potential participants to ensure eligibility and to confirm participation. Parents were recruited through family and health resource centers but did not have to be a patient, or parent of a patient, at UCHC to be a participant. The only inclusion criteria were: Hispanic origin, parent of a child 18-60 months old, and had previously taken their child to a primary care or health center visit.

Four 90-minute focus groups were conducted with 32 parents of children between the ages of 18-60 months. Parents described their experiences in a variety of health clinics across the District of Columbia, including UCHC. Parent focus groups (n=32) included parents of typically developing children, and parents of children with developmental delay. All parents were monolingual Spanish speakers and natives of Central America (El Salvador: n=23; Honduras: n=2; Guatemala: n=2; Nicaragua: n=1); or Mexico (n=4). Parents were between the ages of 20-41 years

old and all were mothers except for one father and one grandparent. They reported having resided in the U.S. from 0-14 years, although the majority had lived in the U.S. for 5-9 years.

Procedure

Protocol Development. Focus group and structured interview format and questions were developed by the research team, consisting of 4 clinicians (3 clinical psychologists and 1 child psychiatrist). Two of the clinicians were fluent in Spanish and worked extensively with Spanish speaking families with young children with developmental or behavioral challenges, one was a bilingual expert in qualitative data analysis with a master's degree in public health and one was a bilingual/bicultural health educator. The team met regularly to review and determine: what information was critical and needed to be addressed, what would be the most beneficial to the project, and what was currently available and did not need to be included. The team developed a preliminary list of questions and obtained feedback from two key consultants on the project, a child psychiatrist with extensive experience in formative research in primary care sites and the director of a non-profit organization designed to reduce bias and discrimination, as well as from the two bilingual/bicultural family navigators on the project, one with a master's degree in special education, with a certification in Autism and Applied Behavior Analysis. We then revised and refined the list using the feedback obtained, focusing on questions that were short and to the point, would not evoke embarrassment, and involved unambiguous wording. The protocols were translated into Spanish and back-translated to ensure that the intended meaning of the content was appropriately conveyed.

Questions asked of participants in focus groups and key informant interviews fell into several categories: awareness and knowledge about child development and ASD, patient/provider communication, developmental screening, barriers to care, cultural issues affecting access, and post-screening services. These questions are provided in Appendix A.

Key informant interviews with medical providers. A child and adolescent psychiatrist on the research team with expertise in autism and developmental disabilities carried out the in-person, key informant interviews with providers that lasted approximately 60-minutes.

Focus groups with medical staff. A human rights educator, two psychologists, one of whom was bilingual, and a bilingual special educator conducted the two medical staff focus group sessions, which were held at UCHC during lunch hour.

Focus groups with parents. Three bilingual and bicultural members of the research team, one of whom was raising a child with autism and was receiving care at UCHC, conducted the four family focus groups in Spanish. Two groups (n=11) consisted of parents raising a typically developing child and two groups (n=21) consisted of parents raising a child with a developmental delay. Given the nature of focus group research, it is important to bring together individuals who share characteristics important to the research questions (e.g., Umana-Taylor & Bamaca, 2004). Since we were interested in part in parents' beliefs about developmental disabilities, we felt it best to convene separate groups of parents with and without a child with developmental disabilities to enhance the flow of discussion given their different personal experiences. Homogeneity can be key to maximizing disclosure among focus group participants, therefore groups of parents with and without a child with a developmental delay were formed. No other factors determined parent assignment to a particular focus group and parents were encouraged to choose the day and location that was most convenient for their schedules.

All written documentation including consent was carefully explained and discussed in Spanish or English with the participants, based on their preference. All participants received financial compensation for their time and/or to cover the costs of childcare and transportation. Study procedures were approved and monitored by the research team's Institutional Review Board.

Data Analysis

All interviews and focus groups were digitally recorded, professionally translated (if in Spanish) and transcribed for analysis. In order to minimize the loss of meaning during the translation process, we employed an approach recommended by van Nes and colleagues (2010) that the "researcher operates as a moderator in cooperation with a professional translator" throughout the translation process. Thus, translation was reviewed by two members of the research team proficient in Spanish, one a native speaker. In addition, the translator integrated notes and impressions made by one of the focus group facilitators to further understand participants' comments.

Analysis of the transcribed interviews and focus groups employed a framework approach using thematic analysis and procedures (Gale, Heath, Cameron, Rashid & Redwood, 2013; Miles and Huberman, 1984), which included data reduction, data display, and conclusion drawing and verification. Data reduction involved selecting, focusing, and simplifying the data in such a way that themes and conclusions could be eventually drawn from it (Nelson, Kocos, Lytle & Perry, 2009). For this step, two investigators worked independently to establish criteria for data inclusion and reduction, carefully reviewing the transcripts of each session and applying a paraphrase or label (a 'code') which described what they have identified in the passage as important. Following the independent reviews, findings were discussed, and consensus was established. Next, data was organized in such a way that themes and relevant concepts could be easily seen and extracted. For this step, three investigators independently reviewed quotes to generate a list of themes using combined inductive and deductive approaches that drew on participants' views and experiences raised in the interviews that might be relevant from as many different perspectives as possible, as well as, a priori issues and questions from the protocol. Additional themes around communication and decision making were coded as they emerged. Investigators then presented their independently generated themes and established consensus through discussion. Focus group data is not presented by parent group (i.e. separated into perspectives of parents of children with developmental delay and parents of typically developing children) because no consistent or meaningful differences emerged between parent groups during data analysis.

RESULTS

Analyses of focus group data were carried out separately for each group. However cross-cutting themes between groups emerged, and therefore the results section is organized by theme instead of by group. Data analysis revealed three main themes that impact engagement of Latino parents: information exchange, cultural factors, and structural factors. Table 1 below summarizes the barriers and facilitators of effective screening for developmental delays identified from the focus groups and key informant interviews. Within themes, multiple subthemes emerged and are included to facilitate the presentation of results.

Table 1: Barriers and facilitators to effective screening				
Factors	Barriers		Facilitators	
	Family	Provider	Family	Provider
Information Exchange	<ul style="list-style-type: none"> - Apparent provider lack of interest in development issues - Limited awareness of developmental milestones and ASD - Limited awareness of supports/service systems - Provider minimization of parent's concerns 	<ul style="list-style-type: none"> - Perception of family lack of interest in development - Recommendations around developmental issues not always followed by family - Limited knowledge of local and community resources - Gaps in knowledge about development, ASD and screening 	<ul style="list-style-type: none"> - Interest in raising developmental concerns - Willing to talk with provider about anything - In-person communication with providers 	<ul style="list-style-type: none"> - Providers raises developmental concerns - Provider has knowledge of development, screening protocols and resources - Desire to participate in training
Cultural Factors	<ul style="list-style-type: none"> - Views of disability and its source - Stigma/embarrassment over developmental problems - Lack of consideration or cultural understanding by providers and staff 	<ul style="list-style-type: none"> - Misunderstanding of family beliefs and needs - Stigma/embarrassment - Language barriers between staff/providers and families - Lack of positive interaction with families 	<ul style="list-style-type: none"> - Developmental information presented in Spanish with strong visual content - Respectful and pleasant reception by front office staff - Support from providers, community members in navigating health systems/resources 	<ul style="list-style-type: none"> - Consideration and acknowledgement of language, culture, beliefs and values different from own
Structural Factors	<ul style="list-style-type: none"> - Short time with providers - Restricted focus of visit - Immigration status - Inconsistent medical provider 	<ul style="list-style-type: none"> - Not enough time in session - Restricted focus of visit - Increased time to investigate behavioral issues 	<ul style="list-style-type: none"> - Availability of a translator - Alternative information sources (e.g. "charlas") - Face-to-face interaction - Trust in provider 	<ul style="list-style-type: none"> - Verbal explanations

Information Exchange

Respondents focused on two areas of information exchange that could impact effective screening: connecting on the importance of development and health literacy, particularly lack of information related to ASD and associated systems of care.

Connection around Developmental Issues. Both health providers and parents reported that it was important to discuss developmental issues during primary care visits. Parents generally viewed providers as more informative than outside sources of information and reported that they were comfortable approaching their doctor with a problem. However, parents perceived providers as lacking interest in exploring developmental concerns. A majority of parents reported that they wished to ask pediatricians about development and behavior during well-child visits but perceived the doctor's priority to be on physical health and growth. Several parents reported they wanted more details about their child's behavior but were often met with what they perceived as a dismissive response to their questions, such as, "don't worry."

So, I talked to her doctor, but sometimes doctors pay more attention to sickness than to the emotional and social development of children. So her pediatrician told me, "Oh, that's a normal situation. She will change." We need to present to them a serious problem to be taken seriously.

Many parents said they had to "insist" in order for concerns around development to be heard.

Providers presented a parallel perspective, but in reverse, reporting that parents often seemed more concerned about physical health and reluctant to focus on development or behavioral health.

They [parents] are very quick to point out a little tiny white spot on their son's face... I rarely have had a parent every say, "I'm worried about his speech."

Providers reported finding it difficult to focus on developmental questions when the priority of the family is on an immediate health concern.

I try to make my 18 month well-check have a really heavy development focus and to be honest, if someone's got a cold...[development] is rarely going to be the focus...I try and meet the parents where they are and if that's not what's important to them, it's hard to continue on that agenda.

Often, providers reported that parents wait until problems have been observed in other settings, like in school by the child's teacher, before seeking guidance on their child's behavior or development.

Health Literacy. Each category of respondent reported gaps in knowledge about autism and related services. Some parents had heard of autism, but many had not, and many of those who had did not possess an understanding of what behaviors it entails, the neurodevelopmental implications or needed supports. One mother described her growing awareness of the word *autismo* [autism].

Now I understand what they are talking about. Before I would hear it (autism) and I didn't understand. I would confuse it with a church called [Baptist]. Now that I know what it is, I can find information.

Some described a child with autism as "not hearing very well" or "hyperactive" or with other conditions.

I've heard about it but, according to what I've heard, an autistic child is someone whose bones are [deformed/disordered].

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Latinos among the medical staff added that some people in their community believe autism may be caused by poor nutrition or neglect in pregnancy or during early childhood.

Parents with a child with a disability reported that they require help to understand and navigate the service system. Several parents reported relying on bilingual and bicultural coordinators.

I feel comfortable when my clinical coordinator helps me find the places to take my child, she goes with me and explains what I have to do, I couldn't do it without her.

Providers were aware of parents' limited information regarding developmental delays and thought that it affects follow-through on recommendations for further assessment and intervention. They reported few conversations with parents about their concerns specifically related to autism. Providers also recognized that developmental delays may have unclear significance to Latino parents and thus they may be less likely to follow through on referrals without external support.

If I said: I think your child might have some delays; here is this free program (early intervention); go ahead and call; they wouldn't call. I have tried and they don't call because they don't see the problem and they feel weird asking for something that they don't see as a problem. So just giving the phone number doesn't work. We try to make appointments for all of our patients.

Primary care providers also reported gaps in their own knowledge about screening and services. Some expressed discomfort with autism-specific screening, relying on developmental observation, particularly for autism. More commonly, many described limited knowledge of local resources, including the early intervention systems.

What are the autism services from the early intervention? I don't even know.

Providers stated they access professional organizational websites and electronic databases but seldom rely on resources from advocacy organizations. Medical and administrative staff also had questions about autism and resources and stated a desire for training.

Cultural factors

Although respondents acknowledged that increasing health literacy around developmental delays should be an important part of primary care visits, their comments made it clear that such communication was affected by issues of language and culture. In particular, culturally-related views of disability and acceptance in the health setting likely impacts engagement in conversations about disability and involvement in screening initiatives.

Stigmatization of autism and disability. Parents' responses indicated that strong cultural beliefs and sensitivities influence their views of child development which may not be evident to or considered by the provider and may impede disclosure of problems. First, the majority of parents reported that in their home cultures, a disability implies no future for a child and that families struggle with involving their child in the community.

There's a kid with autism in my family [in my country]. His mom keeps him inside the house, that's something like...hiding him from the world.

Second, parents may often be blamed for developmental problems. For instance, some parents reported that they had heard that autism might be related to parents not taking good care of themselves during pregnancy. As one mother put it: *Well, they say it's because one wasn't careful when one was pregnant, or that one wasn't eating well.*

Third, disability may be viewed as a gift or punishment from God or attributed to a parent's wrongdoing or experiences: *...maybe God wanted the child to be born that way. I think God gives kids like them, special kids, to special parents. They say it is a punishment from God.*

Members among the medical staff, particularly those who were Latino, reinforced some of the parent reports of stigma associated with autism. They reported that children with "invisible" disabilities like autism can be perceived as "bad," whereas people have more compassion for children whose disability is more obvious (e.g., Downs Syndrome). Staff discussed that culturally-related views of autism and disability weigh heavily on parents and likely interfere with identification and referral. They reported that families might not believe the diagnosis of autism and might discontinue treatment because of the stigma associated with autism and disability.

Communication as influenced by language and culture in medical settings. Cultural and language issues also influenced parents' willingness to disclose developmental concerns with medical staff. Bilingual staff were important in helping them more fully understand messages from physicians. When they could not interact with individuals who spoke Spanish, parents reported feelings of alienation and sought new health care options.

...there wasn't anybody who spoke Spanish and sometimes when I went there [to the clinic], there was one of those girls they put in front of the desk, and I asked her something and maybe she couldn't understand me, so she got all mad and I felt really uncomfortable because there were times when she even laughed, and I used to say "she's laughing at me because I don't speak English." And the doctors didn't speak Spanish either.

Families appreciated the presence of an interpreter; however, some reported that such resources were only called upon when discussion of complicated issues was anticipated. Additionally, parents noted that the presence of staff from their own culture did not always lead to feelings of inclusion.

I think there has to be communication, so we can feel welcome in a place. I don't understand why that happens in places where there's Latin people, like us. They are our own people, and they treat each other bad. I think it shouldn't be that way. It should be the other way around and [we should] support each other. We feel discriminated by other Latino people.

Providers were aware that often their own language limitations can impede disclosure of information by Latino families. Most reported attempting to speak Spanish with the caregiver even though their language skills may be limited. As one provider put it:

I think I speak Spanish but I speak basic Spanish, so I think sometimes there are nuances I probably miss.

They also stated that their style of communication and approach to gathering information might not always facilitate sharing or accurate disclosures.

Even in terms of asking the questions about developmental milestones and things like that, I mean, sometimes, I don't know, parents [might] just tell me yes because maybe they don't completely understand the question or maybe they sort of think their child is doing it but aren't actually sure themselves, so I'm sure I miss some.

Structural Factors

Interaction format and structure. Certain parameters of the usual primary care visit were identified by providers and parents as affecting the kinds of conversations needed to build trust and engagement which is necessary for disclosure about developmental concerns. In general, Latino families indicated a preference for discussing their children's development through face-

to-face interaction rather than through written materials. For some, hearing the provider's recommendations helped them to assess the validity of the guidance.

I think that it's better to attend and be there when it comes to getting information about the child, because if they're telling you something that is not true, you would know if they're telling you lies or the truth. So, I prefer them to tell me face to face, and not through the phone or written on paper.

Parents also described situations when they were told they can't speak about concerns outside of the stated reason for the visit. One parent said she could no longer take her child to a clinic because she was told by staff: *the reason why you're here is this, not that.*

Time. The greater likelihood of disclosure in face-to-face meetings is countered by their report of being "rushed" during the office visit with limited or no opportunity to address concerns.

I wish we could have more time, more relaxing time, and that the doctors were relaxed as well.

Providers also reported that their routine appointment schedule did not afford the time for the caregiver's to integrate the presented concern with the goal of the well visit (i.e. assessment of developmental milestones and current functioning). Lack of time affects opportunities for meaningful engagement with families around problems relating to the child's development or behavior. With inadequate time, providers recognized an increased likelihood of missed information.

It's a rush. You have fifteen minutes to see a patient on a well-check, especially the younger ages...the screaming kid...there are four siblings in the room...I don't think I always go through it extremely detailed... So I really need to do a lot more digging on my part to get things out.

Most of the medical staff cited instances in which parents will come to them asking for further explanation of what was discussed in the visit because there was not enough time for the primary care provider to address all of the parent's questions or concerns.

DISCUSSION

We gathered the perspectives of Latino parents, UCHC primary care providers, and medical staff about their knowledge of autism, comfort discussing developmental problems and factors inhibiting and promoting communication between providers and parents about concerns related to child development and autism. Below, we provide a summary of the results grouped by theme, and describe recommendations for implementing autism screening for children from diverse populations. The *Supported Screening* intervention is a product of these recommendations and is briefly described at the end of the discussion section.

Information exchange

Providers and parents described missed opportunities for discussing developmental and behavioral concerns. Parents reported a desire to speak with their child's doctor about developmental and behavioral concerns but stated that providers were more focused on physical health than on the social emotional health of their child. Latinos among the medical staff suggested that unfamiliarity of autism is a problem in their Latino community, and both parents of children with a developmental delay and parents of typically developing children reported very little or no knowledge of autism. In a qualitative investigation by Zuckerman and colleagues (2014), Latino parents, with a child diagnosed with autism, reported that prior to the diagnosis, they did not know

the indicators or risks associated with autism, the types of questions they could ask their pediatrician, or when to raise concerns.

Parents in our study reported that even when they tried to raise concerns about their child's behavior, their worries were sometimes minimized by primary care staff. This finding is consistent with the experiences of Latinos and other people of color described in qualitative studies of family-medical provider communication (Zuckerman et al., 2014; Jimenez, Barg, Guevara, Gerdes & Fiks, 2012). Others have also found that families of color, particularly families with limited English, receive less anticipatory guidance and family centered care (Bethell, Reuland, Halfon & Schor, 2004; Flores & Tomany-Korman, 2008).

In contrast, providers perceived parents as lacking interest in exploring developmental concerns, particularly those with younger children. Latino parents perceived lack of interest may result in part from a limited knowledge of child development (Rowe, Denmark, Harden & Stapleton, 2016). Providers were convinced that limited health literacy affected parental understanding of autism and follow-through on recommendations. In addition, previous work suggests that Latinos evince a greater reluctance to seek advice for mental health concerns from medical professionals (Hough et al., 2002); rather, they look to family or community contacts for assistance (McMiller & Weisz, 1996).

Recommendations to Promote Information Exchange

The implementation of new screening and referral procedures in primary care needs to be sensitive to the literacy needs of the community and be informed by an understanding of social networks through which health information is exchanged. Primary care providers may need to take the initiative to explicitly raise developmental topics with Latino families to demonstrate that this is an important part of the visit. In our *Supported Screening* intervention, information for providers in developmental and autism screening emphasize techniques to engage families, whose language and culture differed from their own. We found that focus groups and brief individual interviews with parents helped to identify parent knowledge, beliefs, and skills in accessing health services and systems as well as their preferences in communication methods with the provider.

Cultural Factors

Parents and medical staff described cultural beliefs and stigma associated with disability that may not always be immediately evident when parents participate in the well-child visit with the child's provider.

Parents in our study described the social implications of a disability, like autism, in their native cultures. Like experiences described by Latino parents in other primary care contexts (Zuckerman et al., 2014), as well as in cross cultural investigations of autism (Kim, 2012), they reported that disability in their home cultures can bring shame and worry about the child's future. They described examples of how parents are often blamed for having a child with a disability. It is important for providers to recognize that the beliefs about the causes or course of autism may affect parents ease of asking questions, the types of treatment they choose, and their willingness to follow through on recommendations (Mandell & Novak, 2005). A recent qualitative study found that while White mothers felt a sense of relief upon their child receiving an ASD diagnosis, Latino mothers reported an increased sense of guilt upon diagnosis (Lopez, Magaña, Xu & Guzman, 2018). Furthermore, Latino mothers indicated that their extended family members were less supportive in regard to their child's diagnosis, as compared to White mothers. The impact of these cultural differences on the disclosure and follow-up of developmental concerns suggests that

providers and interventions should focus on creating a non-judgmental, supportive and informative atmosphere that acknowledges the unique perspective and experience of each parent.

In our study, Latino parents who reported more familiarity and understanding of developmental delay and autism still found it difficult to independently navigate health systems and they underscored the need for input from a trusted community member to assist families with accessing services, including finding phone numbers and calling to make or change appointment times.

Recommendations to promote engagement across cultures

Culturally sensitive and competent interactions need to begin at the front desk as a team effort otherwise families can feel that they are being treated rudely or feel undervalued, which will undermine their trust in their child's provider and their desire to engage with health systems (Bronheim, 2004; Barrett, Puryear & Westpheling, 2008). Written organizational policy is needed to assure that all clinical staff, including the reception desk, receive clear guidance on cultural readiness, like how to determine a family's need for language access or reading support. Organizational self-assessment tools have been used with success (Goode, 1989). Ongoing cultural readiness training, informed by and understanding of shared definitions rather than a single annual workshop can offer practice and feedback. Providers should feel comfortable routinely exploring parents' and the community's attitudes on developmental expectations, understanding of atypical development, and disability (Ravindran & Myers, 2012). Parents beliefs about the causes of disability will play a role in the family's comfort and willingness to follow through on referrals and seek evaluation and treatment.

We recently pointed out that a reasonable adaptation process of an ASD screening tool in a new cultural and linguistic setting should go beyond translation (Soto et al., 2015) by, for example, adding specific culturally relevant indicators of ASD, changing wording to avoid misinterpretation because of cultural norms related to non-verbal and social communication, adding examples to avoid confusion over item meaning, and altering the format of the tools to align with response styles of respondents.

Finally, families from diverse backgrounds may need targeted outreach. In our screening intervention, we found that family navigators who were bilingual, bicultural and part of the community were a tremendous support to families and providers, providing a source for information, collaborating in the interview screening process and acting as a liaison between the health system, family system, and community agencies. The family navigation model has been shown to successfully reduce disparities in diagnosis and increase access to treatment for low-resourced and minority patients (e.g., Godoy et al., 2017; Sprecher et al., 2018). For example, Latino and African American parents have reported that when accessing parent peer support centers for families of children with a disability, they appreciated connecting to a peer parent who also had a child with a disability. Interacting with a parent who also had a child with a special health care need and who spoke Spanish may have helped Latino families trust the information they received, thereby spurring them into action for their child (Bronheim, Can & Anthony, 2015; Bronheim, Soto, Anthony, 2015).

Structural Factors

Providers, parents, and medical staff reported on the structural barriers preventing the kinds of conversations they would like to have with each other about child development, with length of visit identified as a primary barrier to engagement. A short visit time with the provider has been

identified as a burden or source of dissatisfaction from both provider (Dosreis, Weiner, Johnson & Newschaffer, 2006) and parent perspectives (Halfon, Inkelas, Mistry & Olson, 2004). Limited interaction interfered with addressing development related issues that were outside of the stated reason for the visit and led to missed information. In addition, providers reported that time barriers prevented investigation of and interaction with key community resources (e.g., early intervention) to facilitate services for identified developmental delays.

Recommendations to Reduce the Impact of Structural Barriers

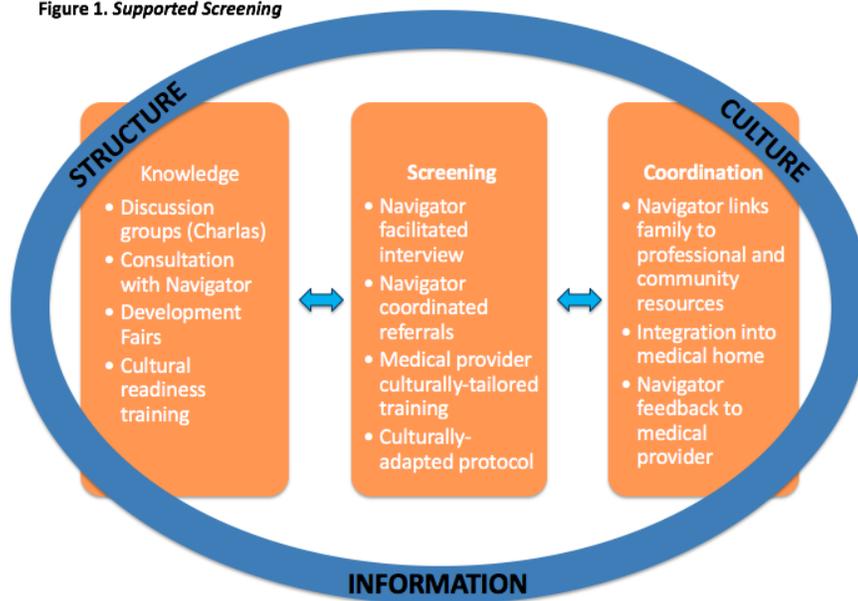
Parents and medical staff offered suggestions for reducing the impact of short visits and enhancing information sharing. Parents in our study reported they would be comfortable sharing and receiving information about their child in a group format. Thus, in *Supported Screening* (Biel et al., 2017), we institute culturally-tailored, patient-centered initiatives to provide information for Latino parents (Elder et al., 2009) led by family navigators who are from the targeted community and are schooled in appropriate messages. These include individual consultation, discussion groups (e.g., Kaphingst et al., 2011) or “charlas,” in which parents of young children can come together to discuss mutual concerns, answer questions and increase parents’ awareness of how to identify concerns and convey them to their physician. It also includes “development fairs” in which organizations both within (e.g., WIC) and outside (e.g., early intervention) of the primary care practice provide information on their services facilitated by family navigators and other staff.

In *Supported Screening*, family navigators also help bridge the gap between families, external services and the primary care providers. They support linkage to appropriate referral following a positive screen, including informing the family on the reason for referral and supporting efforts to confirm appointments and attend evaluation. In addition, they work to promote effective feedback of external evaluations back to the primary care site, facilitate links to other needed services and integrate with other components of the medical home.

Supported Screening Intervention

By using information gathered in the focus groups and interviews, we modified the implementation of the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001), creating the *Supported Screening* intervention. The intervention was created in order to expedite the translation of research to practice, which on average takes 17 years (Green, Ottoson, Garcia & Hiatt, 2009). It is now being used to guide the implementation of autism screening in an urban primary care center that serves a large percentage of Latino children and families. Figure 1 provides a summary of the components of *Supported Screening* (Biel et al., 2017).

Figure 1. Supported Screening



CONCLUSION

Parents and providers offered detailed insights about their experiences with and perceptions of primary care in regard to developmental issues, exposing barriers to diagnosis and treatment. Families from Latino backgrounds may have different beliefs, cultural practices and expectations around developmental issues which impact the trajectory of their care with providers. While not exhaustive, our findings identify distinct gaps and missed opportunities in the provision of services to Latino families in the primary care setting.

Understanding and identifying the mechanisms through which race and ethnicity influence patient engagement informs the tailoring and targeting of interventions and encourages consideration of these factors in assessing outcomes (Grinker et al., 2015). Ultimately, to reduce disparities in diagnosis and treatment of developmental disabilities in Latino populations, implementation of system-level supports, like *Supported Screening*, for providers are critical. Then providers can initiate thoughtful and culturally sensitive conversations about development and behavior with parents, provide them with comprehensible information, and support their access to and reception of services. Some of the provider's responses in this study suggested a lack of perspective or narrow insight into cultural issues that affect Latino children and families. Community health-promotion practitioners working with diverse communities must start with a thorough knowledge of their audience, e.g., the sociocultural, economic, linguistic, and other characteristics of the members of that community. Specific variables to which practitioners should attend include country of origin, generation and acculturation, socioeconomic and legal status, and the interaction between the broader community or region.

Limitations

We provided all of the demographic information that we asked from participants: caregiver age, caregiver role, language, country of origin, and length of residence in the US. We did not collect more demographic information from the participants because of concerns voiced by the

organizations helping with recruitment that requiring personal information could discourage participation. For instance, we were able to avoid asking for information to provide incentive payments since documentation issues may cause concerns for participants. In the future it would be useful to obtain information such as, parent education level, socioeconomic status, and marital status, in order to determine how these factors effect parent experiences.

The individuals participating in the parent focus groups were primarily mothers from Central America. Latino families of other national origins may have different experiences than the parents participating in our study. Likewise, experiences may vary for Latino parents living outside of the District of Columbia. Consequently, the findings may not be generalizable to other Latino populations in other states or other caregiver roles.

Responses were not analyzed by participant country of origin because groups were significantly unequal in size. Seventy-two percent of participants were from El Salvador and other countries of origin made up between 12.5% and 3% of the sample, making it difficult to draw meaningful comparisons between groups. Future research should investigate cultural differences in experiences and beliefs between Hispanic parents based on their country of origin, as this would serve to further support the specific needs of individual parents.

Recommended approaches were used in the translation of interviews and focus groups carried out in Spanish. While all efforts were made to preserve the insights discussed by participants, it is possible that some of the original meaning was lost during the translation process.

Finally, as with most qualitative research, our sample size was relatively small. In particular, the provider interviews took place only within UCHC and with a small number of pediatricians and nurse practitioners, although they provided a significant portion of the care for target population. While the concerns and opinions raised by parents and providers may vary somewhat in other contexts, many of our findings are consistent with results from previous studies and have important implications for the implementation of screening for Latino populations in primary care visits and may be useful to guide future research and to improve the provision of services to Latino families.

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