



Published in final edited form as:

Acad Pediatr. 2022 March ; 22(2): 279–288. doi:10.1016/j.acap.2021.12.025.

Implications of Universal Autism Screening: Perspectives from Culturally Diverse Families with False Positive Screens

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Abstract

Objectives—The American Academy of Pediatrics (AAP) recommends that pediatricians screen all young children for autism spectrum disorder (ASD). However, the U.S. Preventive Services Task Force stated that there is insufficient evidence about the potential harms and benefits of universal ASD screening. To address this gap, we conducted qualitative interviews with caregivers of children who received a false positive ASD screen to learn about families' perceptions of the harms and benefits of universal ASD screening.

Methods—Culturally-diverse caregivers (N=26) of children with false-positive ASD screens completed qualitative interviews focused on parents' experiences with and recommendations to improve the ASD screening and evaluation process. Interviews were transcribed verbatim, coded, and analyzed using applied thematic analysis.

Results—Parents explained that the ASD screening and evaluation process increased their knowledge about child development and substantiated existing concerns. The ASD screening and evaluation process resulted in connecting their child to services, which parents felt led to improvements in their child's delays. Parents endorsed anxiety during wait times for the formal developmental assessment. However, all parents expressed that, if given the option, they would

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Clinical Trial Registration: This paper uses data from a supplemental study to a larger clinical trial. The clinical trial registration number is [NCT02359084](https://clinicaltrials.gov/ct2/show/study/NCT02359084).

Conflict of Interest Disclosures: The authors have no conflicts of interest relevant to this article to disclose.

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repeat the screening and evaluation process again. Caregivers recommended universal screening for ASD and suggested that screening extend beyond the pediatrician to other settings.

Conclusions—From parents' perspectives, the connection to developmental services and increased knowledge of child development that resulted from the false positive ASD screen outweighed the time-limited emotional distress triggered by a positive ASD screen. Overall, parents' preferences for universal ASD screening align with the AAP's recommendations.

Keywords

Autism spectrum disorder; screening; primary care; young children; health disparities

What's New:

This study explores the harms and benefits of autism screening from the perspective of families who received a false positive autism screen. These data address knowledge gaps identified in the U.S. Preventive Services Task Force 2016 report on autism screening.

Autism spectrum disorder (ASD) is characterized by social and communication impairments and restricted and repetitive behaviors that persist throughout the lifespan.¹ ASD occurs in 1 in 44 children in the United States² and can be reliably diagnosed by two years of age.^{3–8} Children with ASD who are identified and treated before three years of age are more likely to experience persistent gains in adaptive skills and core ASD symptoms than children who are identified and treated later.^{9–19} Despite the importance of early identification and treatment, children from low-income and racial/ethnic minority backgrounds are diagnosed later and have access to fewer specialty services than white and higher-income children.^{20–23} To optimize outcomes for all children with ASD, the American Academy of Pediatrics (AAP) recommends universal ASD screening, in addition to broadband developmental screening, at the 18- and 24-month well-child pediatric visits.^{24–25} Children whose autism screen indicates high likelihood of ASD are referred to Early Intervention (EI) services and to a comprehensive developmental evaluation to diagnose or rule out ASD. Wait times for comprehensive developmental evaluations could be up to a year and may be longer for certain groups of people (e.g., non-English speakers).^{26–28}

In contrast to the AAP's recommendations, the US Preventive Services Task Force (USPSTF) has stated that there is insufficient evidence to recommend universal ASD screening.²⁹ In their 2016 report, they cited a lack of evidence about the harms and benefits of screening. As approximately half of children who screen positive for ASD on the most widely-used screening tool (Modified Checklist for Autism in Toddlers – Revised with Follow-Up (MCHAT-R/F)) do not receive an ASD diagnosis after a comprehensive evaluation,³⁰ the USPSTF noted another key research gap regarding unknown child and family effects of receiving a false positive ASD screen.²⁹ They specifically highlighted the need for research focused on low-income and racial/ethnic minority populations who have poorer access to care and increased risk of delayed diagnosis.²⁹

The USPSTF report also questioned whether universal ASD screening provides additional benefit beyond typical conversations with the pediatrician, which may be guided by parents'

perceptions of their child's development. Regardless of the MCHAT-R/F score, parents vary in their level of concern about their child's development.³¹ In pediatric settings, parents who share a provider's concern about a medical issue are more likely to follow through on the provider's recommendations.³² Therefore, parents who are in agreement with the provider's concerns about the child's development may find more value in the autism diagnostic evaluation process. On the other hand, parents who are less concerned initially may gain knowledge and connections to services that they otherwise would not have pursued. Understanding how families' experiences of the ASD screening and evaluation process differ by level of initial parent concern would shed light on whether ASD screening is more beneficial for certain groups of families.

The current study addresses the USPSTF question about harms and benefits of ASD screening, including whether these harms and benefits differ for certain subgroups, by conducting in-depth qualitative interviews with culturally diverse families of children who received a positive ASD screen in primary care that did not result in an ASD diagnosis (i.e., false positive). This study aims to document families' experiences with developmental screening and related services, perceptions of the harms and benefits of universal ASD screening, and recommendations about the screening and referral process; and examine differences in these themes by level of initial parent concern about their child's development. The study focuses on racial and ethnic minority children who are at highest risk for delays in diagnosis and access to services.

Methods

Sample and recruitment

Families were recruited from Project Early, a clinical trial aiming to reduce disparities in early ASD diagnosis and service engagement.³³ In Project Early, families were randomized to receive either family navigation or conventional care management. Standard care at the Project Early clinical sites included autism-specific screening at the 18- and 24-month well-child visits. English or Spanish-speaking families were eligible to participate in the current sub-study if they had a child with a positive MCHAT-R/F screen at the 18- or 24-month well-child visit and did not receive an ASD diagnosis after a comprehensive developmental evaluation. To ensure broad representation, a purposive sampling strategy was used to recruit families based on child age and gender, extent of parent's concerns about their child's development prior to screening, and race/ethnicity. Enrollment continued until thematic saturation was reached in primary research questions (i.e., when additional interviews did not add new information).³⁴

The research team contacted eligible families to discuss the study and ascertain interest in participation. The research team conducted verbal consent with interested families and scheduled a time to conduct the interview at the family's preferred location (participants' homes (n=23) or other community locations (n=4)). Eight-two percent of families reached by phone or text participated. One family was excluded from analysis because it was later discovered that the child was diagnosed with ASD. Parents were compensated \$50 for participating. The study was approved by the Boston University Medical Campus Institutional Review Board.

Interview description

Parents participated in semi-structured individual interviews (~60 minutes). Interviews were conducted by a research team with expertise in qualitative methods, including bicultural Spanish-speaking researchers. Qualitative interviews probed parents' experiences with and recommendations to improve the ASD screening and evaluation process. After briefly describing their child's developmental functioning, participants responded to open-ended questions about their experiences with developmental screening, following up on pediatrician recommendations, attending the comprehensive developmental assessment, and recommendations regarding ASD screening (Table 1).

Interviews were conducted in Spanish (n=6) and English (n=21). Spanish interviews were translated to English during transcription and checked by bilingual researchers to facilitate coding and analysis by all research team members. Qualitative data were recorded, transcribed verbatim, and checked for accuracy.

Measures

During the Project Early baseline questionnaire, which occurred immediately after the initial MCHAT-R/F screen, parents reported their level of concern about their child's development on a scale from 0 to 10 (0 = not at all concerned; 10 = very concerned). The parental concern variable was dichotomized based on the median level of concern at baseline (6.5).

Data analysis

Interview transcripts were entered into NVivo 12 qualitative data analysis software³⁵ and coded by a team of three graduate students (J.E., A.B., N.C.) and one undergraduate student (D.K.), with close oversight by an experienced qualitative methodologist (K.L.). *A priori* research questions were used to draft the initial coding structure, which included detailed instructions on when to apply each code with exceptions and examples. Six transcripts were coded together by the entire coding team to finalize the coding structure and ensure reliability among coders. While coding these transcripts, revisions to the coding structure were made until no new changes were needed. Once the coding structure was finalized, all transcripts were coded using the finalized coding structure. Twenty percent of transcripts (n=7) were double-coded. Inter-coder concordance was calculated to be 86% by dividing the number of concordant codes by the total number of codes assigned to each transcript. Discrepancies were resolved through group discussion. The coded transcripts were analyzed using applied thematic analysis.³⁶ Data were stratified by level of parental concern at baseline.

Results

Sample

Demographic data for participants are outlined in Table 2. Data from twenty-six culturally-diverse, low-income parents were analyzed. There were no significant differences in demographic characteristics between the high and low concern groups. All study participants' children completed a comprehensive developmental evaluation in a specialty

pediatrics clinic following positive ASD screens. Although not diagnosed with ASD, all children received a formal developmental diagnosis and received EI services.

Perceived benefits of ASD screening and evaluation

When asked explicitly if they would repeat the ASD screening and evaluation process, parents unanimously said yes. Parents indicated that the process ensured that their children received needed services and thus outweighed the time, effort, and emotional toll involved. Parents discussed key benefits in each stage of the screening and evaluation process, outlined below. Table 3 includes a summary of themes and supporting quotes.

Discussing initial concerns at pediatric primary care visit—Parents who reported low concern about their child’s development at screening described receiving messages from family members that all children develop at their own pace and not to worry if their child was not yet completing expected developmental tasks. Low-concern parents found the ASD screening process helpful because it taught them new information about developmental milestones and alerted them to potential developmental concerns. They described the ASD screener as a useful tool for guiding conversations about their child’s development with the pediatrician. Some low-concern parents described how the screening process highlighted concerns that they likely would not have noticed. In some cases, low-concern parents explained that learning about developmental milestones through ASD screening led to earlier identification of concerns in younger siblings.

Parents in both groups described their concerns about their child in terms of challenging behaviors, such as tantrums and aggression. While low-concern parents did not attribute these behaviors to developmental delays, high-concern parents attributed these behaviors explicitly to the child’s inability to communicate his/her needs. High-concern parents described the ASD screening process as helpful in validating these concerns about their child’s communication and initiating services to address the child’s delays.

Completing the comprehensive ASD evaluation—Both low- and high-concern parents discussed the benefit of the developmental evaluation linking them to needed services, such as EI. Parents in the low-concern group emphasized the helpfulness of coordination between EI and the Developmental Behavioral Pediatrics clinic to ensure that the child’s needs were met. Parents in the high-concern group emphasized feeling hopeful about taking the first step to address their child’s delays.

Following up on recommended services such as Early Intervention—No differences emerged between low- and high-concern parents regarding EI services, all of whom expressed high satisfaction with EI. Parents noted that EI involvement led to significant improvements in their children’s development and in their own ability to manage their child’s needs. Parents described learning about child development, including how to recognize signs of developmental delay. EI also was cited as a valuable source of emotional support for parents striving to understand their child’s developmental delays.

Perceived harms of ASD screening and evaluation

Although parents typically said there is nothing they would change about the ASD screening and evaluation process, some parents described aspects of the developmental screening and evaluation process that they found burdensome or unhelpful, outlined below and summarized in Table 3.

Discussing initial concerns at pediatric primary care visit—Parents generally did not indicate negative aspects of the initial visit with the pediatrician, during which they completed the MCHAT-R/F. A subset of low-concern parents described difficulties understanding the instructions or purpose of the MCHAT-R/F and logistical challenges regarding completing the screener while simultaneously supervising their children.

Low-concern parents also described the negative emotional impact of the screening process. They used words like “heartbroken” and “nervous” to describe their experience of learning that their child’s ASD screener indicated developmental risk. Some low-concern parents also expressed feeling defensive after completing the MCHAT-R/F and noted that the screener did not account for contextual factors that may affect child development. High-concern parents did not describe negative aspects of completing the screener or discussing developmental concerns with the pediatrician.

Completing the comprehensive ASD evaluation—Both groups of parents described feeling anxiety during the interval between a positive MCHAT-R/F screen and the comprehensive developmental evaluation. They explained that the uncertainty about ASD elicited worries about their child’s future. High-concern parents expressed mixed emotions during this wait-time. In addition to fear and anxiety about ASD, some high-concern parents reported hopefulness about finding explanations for their child’s delays and receiving services to help their child reach developmental milestones.

In both groups, parents described relief after finding out their child did not meet diagnostic criteria for ASD. A subset of high-concern parents described feeling disappointed that their child would not be eligible for autism-specific services; several of these parents had another family member with ASD and were familiar with ASD specialty services.

Across both groups, those who emphasized negative aspects of the developmental evaluation focused on the emotional impact of the wait time. Although some low-concern parents noted logistical challenges navigating the comprehensive developmental evaluation (e.g., taking time off work, finding childcare, and securing transportation), these challenges were not emphasized. Low-concern parents reported less support from family and friends during the diagnostic process. High-concern parents reported few to no logistical hurdles in scheduling and attending the developmental evaluation.

Following up on recommended services such as Early Intervention—Families in neither group reported harms associated with EI services.

Parent recommendations about ASD screening and referral

No differences emerged between low- and high-concern parents regarding recommendations for ASD screening and referral. When asked to provide recommendations for identifying children with ASD and/or developmental delays (summarized in Table 4), parents indicated that developmental screening should be initiated as early as possible and repeated regularly. Parents preferred initial screening between ages one and two years, with repeated screening every six months to adequately capture developmental changes. Parents explained that early screening might prevent problems from worsening over time.

When asked explicitly about universal screening (all children at certain ages) versus targeted screening (only those children whose parents bring up concerns), parents typically recommended universal screening. Reasons for preferring universal screening included 1) parents may lack knowledge about expected developmental milestones, 2) parents may prioritize other aspects of the child's health (e.g., feeding, sleeping) in conversations with pediatricians, 3) parents may not spontaneously bring up concerns to the pediatrician due to fear that something might be wrong with their child, and 4) parents may be busy with other responsibilities and may not always notice their child's developmental progress.

Other screening recommendations included expanding developmental screening beyond the pediatrician's office to settings like daycares and community centers and providing more information about the purpose of the screening tool when presenting it to parents.

Discussion

In 2016, the USPSTF concluded that there was insufficient evidence to support universal ASD screening for children ages 18–30 months, specifically citing the lack of evidence about the balance of benefits and harms of screening and about the effectiveness of universal screening in diverse populations.²⁹ To explore families' perspectives about universal ASD screening, the current study enrolled culturally- and linguistically-diverse mothers of children who received a false positive ASD screen in primary care. Parents expressed that the benefits of universal ASD screening (i.e., connection to developmental services and increased knowledge of child development) outweighed the time-limited emotional distress and logistical challenges elicited by the positive screening result. All families in this sample emphasized that they would repeat the ASD screening and evaluation process again despite its challenges.

Despite convergence regarding parents' support of universal screening, differences emerged based on the parent's level of concern about the child's development prior to the ASD evaluation process. For parents who expressed low concern about their child's development initially, the ASD screener provided guidance about expected developmental milestones. These "low concern" families represent those who may miss without universal ASD screening because they are unlikely to spontaneously initiate conversations with the pediatrician about developmental delays. Thus, these are children for whom universal ASD screening may result in earlier diagnosis and treatment. Recent evidence supporting this finding suggests that children who are screened with an autism-specific screener reach diagnostic resolution ten months earlier, on average, than children who are not screened.³⁷

Importantly, the developmental screening process led to families identifying developmental concerns earlier in younger siblings, consistent with literature suggesting that benefits of universal ASD screening may extend to other children.³⁸ For families who expressed high concern about their child's development initially, the ASD screener validated parents' existing concerns, thereby empowering the parent and pediatrician to engage in shared decision-making around suspected developmental delays. Pediatricians' low responsiveness to caregivers' worries about their child's development has been shown to perpetuate racial disparities in early diagnosis of developmental delays.³⁹ Thus, the potential for universal ASD screening to substantiate parents' concerns may be particularly beneficial for racial/ethnic minority children who have increased risk for delays in diagnosis and services.

Although they were not diagnosed with ASD, all children in this sample were diagnosed with a developmental delay requiring intervention. This is consistent with the psychometric properties of the MCHAT-R/F; the positive predictive value is 95% for any developmental delay (i.e., 95% of children with a failed screen have a true developmental delay).³⁰ Thus, another benefit of ASD screening was that it triggered a referral to EI, which all families found helpful for both informational and emotional support. Parents largely attributed their child's developmental progress to their involvement in EI services, which reflects the high degree of satisfaction with EI that is documented in the literature.⁴⁰

As hypothesized in the USPSTF report, families discussed negative aspects of the ASD screening and evaluation process, including the negative emotional impact of the screening process, logistical challenges of following through on providers' recommendations, and anxiety while awaiting a comprehensive evaluation. Low-concern families endorsed more logistical challenges and less family support during the ASD screening and diagnostic process. Family navigation or similar interventions may be beneficial in helping these families follow up on the positive ASD screen.⁴¹ Parents emphasized that the harms did not have negative long-term impacts on their well-being. Nevertheless, provider and system-level strategies, such as providing families with information about the purpose of ASD screening and counseling about the need for a developmental diagnosis, may improve families' experiences with the screening and diagnostic process.

Following the initial ASD screen, families in this sample waited an average of 4.5 months for diagnostic resolution. Nearly all parents experienced heightened anxiety during this wait time. Innovative solutions to address the long wait time for ASD diagnostic testing are currently being explored (e.g., training primary care providers to diagnose ASD, using telemedicine formats for diagnostic testing, improving triage systems for children suspected to have an ASD).^{26–28, 42–43} Since these systemic changes take time to widely implement, strategies to better support families during the wait time are needed. Given their positive relationships with families, EI providers may be well-positioned to help families navigate the uncertainty associated with a possible ASD diagnosis, provide helpful developmental services while they are awaiting diagnostic resolution, and report on the child's response to EI services to aid in accurate diagnosis.

Strengths & limitations

A major strength of this study is its focus on low-income, culturally diverse families with highest risk for delays in ASD diagnosis and treatment. The majority of autism research is centered on white families' experiences; therefore, this study's findings offer important context about the experience of non-white families during the ASD screening and evaluation process. In addition, quantitative data from the clinical trial allowed us to stratify the qualitative data by initial level of parent concern about child's development, which contributes information about how subgroups of families may differentially benefit from universal ASD screening. In particular, this study captures the perspectives of the "low concern" group of families whose children's developmental delays may not have been identified through developmental surveillance alone.

Findings should be considered in light of limitations. First, participating families lived in urban areas in the northeastern United States. Therefore, findings may not generalize to children in other geographic areas who may have differential access to services. Similarly, the extent to which findings generalize to other racial and ethnic groups not represented in this sample is unclear. Second, qualitative interviews were conducted months to years after the ASD screening process occurred; thus, parents' reports may be biased by more recent experiences and/or their memories of past events may have faded. Third, families were included in the present analyses only if they completed the developmental evaluation process. As low-concern families may be less likely to follow through on the developmental evaluation process without additional supports, low-concern families who received family navigation were somewhat overrepresented in this sample. Future research should examine the harms and benefits of ASD screening from the perspective of families who did not complete the developmental evaluation process, as these families likely represent a unique subgroup. Finally, the USPSTF report identified several key research gaps that led to their "insufficient evidence" recommendation. Although this study addresses one key research gap (i.e., harms and benefits of false positive screens), it was not designed to fully address the USPSTF's concerns. Future research should continue to fill the evidence gap, such as studies that assess the relationship between universal screening and longer-term developmental outcomes.

Conclusion

Current findings directly address the USPSTF's concerns about harms and benefits of ASD screening by enrolling a culturally-diverse sample and suggesting that 1) harms associated with screening are time-limited and perceived as acceptable to participants, 2) benefits include access to helpful diagnostic and treatment services regardless of the child's ASD status, and 3) universal screening likely identifies children whose parents would not otherwise raise developmental concerns. Parents recommended that universal ASD screening be conducted early and often, and also suggested that providers offer additional support (e.g., information about the purpose of screening, logistical help while completing the screener) during the screening and evaluation process to minimize stress and burden on the family.

Acknowledgements

We thank Andrea Chu, Julia Levinson, and Plyce Fuchu for their help with project management and data collection. We extend special thanks to the families who participated in this study. This study was funded by the National Institute of Mental Health (3R01MH104355-04S3).

Role of Funder/Sponsor: The funder/sponsor did not participate in the work.

Abbreviations:

AAP	American Academy of Pediatrics
ASD	Autism spectrum disorder
EI	Early Intervention
IQ	Intelligence quotient
MCHAT-R/F	Modified Checklist for Autism in Toddlers – Revised with Follow-up
USPSTF	United States Preventive Services Task Force

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Table 1.

Sample Questions from Interview Guide

Topic	Example Questions ^a
Child's developmental functioning	Please start by telling me a little bit about your child's development. Probes: <ul style="list-style-type: none"> • When were developmental concerns first raised? • What <i>specific</i> concerns were raised?
Developmental screening	Please describe your experience talking about your child's development at the pediatrician's office. Tell me about your experience filling out the MCHAT-R/F in the pediatrician's office. How did you feel after concerns were raised about your child's development?
Following up on pediatrician recommendations	What did your pediatrician recommend as next steps? Probes: <ul style="list-style-type: none"> • What was challenging about following through on referrals to other doctors and services? What was easy?
Attending comprehensive developmental assessment	Please describe your experience with the developmental assessment process for your child. Probes: <ul style="list-style-type: none"> • How long did you wait for your first developmental assessment appointment? • What was it like for you during that wait time?
Positive and negative aspects of the false-positive screen	Knowing what you know now, would you still go through the screening and evaluation process? Why or why not? In what ways did the screening result and related services affect your <u>child's</u> ... <ul style="list-style-type: none"> • Development? • Services? In what ways did the screening result and related services affect <u>your</u> ... <ul style="list-style-type: none"> • Work life? • Emotional functioning or mood?
Recommendations regarding screening for ASD	How should we screen children for autism/developmental concerns? One of the questions we have is which children we should be screening. In other words, should we screen all children who come to the pediatrician (universal screening) or only screen the children for whom the parent or pediatrician expresses concern for autism (targeted screening). What are your thoughts about these two approaches?

Abbreviation: MCHAT-R/F, Modified Checklist for Autism in Toddlers-Revised with Follow-up

^aTable does not include the full list of lead questions and probes.

Table 2.

Parent and Child Demographics

Mother Characteristic	Mean or Percentage ^a (SD)		Test Statistic (χ^2 or <i>t</i>)
	Low concern (n = 13)	High concern (n = 13)	High concern vs. low concern
Race			$\chi^2 = 1.82$
Asian	8%	8%	
Black/African-American	77%	54%	
White/Caucasian	0%	0%	
More than one	0%	0%	
Other	15%	39%	
Ethnicity			$\chi^2 = 0.17$
Latina/Hispanic	31%	39%	
Not Latina/Hispanic	69%	62%	
Born outside the United States	39%	54%	$\chi^2 = 0.62$
Language			$\chi^2 = 0.87$
English	85%	69%	
Spanish	15%	31%	
Marital Status			$\chi^2 = 2.64$
Single	54%	31%	
Married	15%	23%	
Living with a partner	15%	39%	
Separated or divorced	15%	8%	
Received Family Navigation	69%	46%	$\chi^2 = 1.42$
Eligible for Public Insurance	100%	85%	$\chi^2 = 2.17$

Child Characteristic	Mean or Percentage (SD)		Test Statistic (χ^2 or <i>t</i>)
	Low concern (n = 13)	High concern (n = 13)	Low concern vs. high concern
Age (years)	3.89 (1.01)	4.49 (0.68)	<i>t</i> = -1.77
Sex			$\chi^2 = 0.72$
Male	62%	77%	
Female	39%	23%	
MCHAT-R/F score	6.69 (2.72)	7.85 (2.73)	<i>t</i> = -1.08
Age at MCHAT-R/F (months)	21.69 (3.57)	21.30 (3.58)	<i>t</i> = 0.28
Days to Diagnostic Resolution	150 (99.29)	118 (134.09)	<i>t</i> = 0.70

Abbreviation: MCHAT-R/F, Modified Checklist for Autism in Toddlers-Revised with Follow-up

^aPercentages may not add up to 100 due to rounding.

Table 3.

Key Themes and Supporting Quotes.

Low parental concern about child development			
Discussing initial concerns at pediatric primary care visit			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> • Learned new information about expected developmental milestones • Alerted parents to potential concerns about their child's development • Helped guide parents' conversations with the pediatrician • Helped parents identify concerns earlier in younger siblings 	<p><i>"You know, honestly, I know most children are different, so what might show signs in one child, [would] be something totally different in another... the things that I wouldn't have looked for were the actual things that the screening had actually picked up, you know, like the pointing and the spinning."</i></p> <p><i>"So, maybe it [ASD screening questionnaire] is like for me...the quick review, that I can say, 'Yeah, I need to discuss with [pediatrician].' Otherwise, I am just blank-minded."</i></p> <p><i>"I just had a baby, she was just growing, but now I'm like watching out for certain things ... she should be doing at a certain age. Like trying to catch things earlier."</i></p>	<ul style="list-style-type: none"> • Expressed difficulties understanding the instructions and purpose of screening tool • Experienced logistical challenges related to filling out the questionnaire while simultaneously supervising children • Felt defensive after being given the MCHAT-R/F to fill out • Noted that screening doesn't account for contextual factors that may affect child development 	<p><i>"They're [ASD screening questionnaires] given to you at every doctor's visit. They don't talk to you first, they just give it to you."</i></p> <p><i>"I'm not gonna lie...when I did the questionnaire, I kind of felt like, 'Why are you guys giving me this?...He doesn't have autism.' Maybe because no one wants the stigma of it. There are children who do have autism, there's nothing wrong with them, but when you become a parent, you become automatically defensive."</i></p> <p><i>"But, I don't feel like them questionnaires is like beneficial if—like at one point she was like experiencing trauma, so that kind of affected...that questionnaire period... Of course she wasn't at her regular state, so I think there's more outside factors that be involved in with them questionnaires really ask. You know, I think they're like too standardized. I think they need to do more like individual at least."</i></p>
Completing the comprehensive ASD evaluation			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> • Coordination between Early Intervention and the Developmental Behavioral Pediatrics clinic helped meet child's needs 	<p><i>"The lady from early intervention that was working with him, his OT, [and the developmental behavioral pediatrician] actually met and had a conversation. So, she was able to join in on our meeting too and be able to add some of her – and figure out some ways to cope with [3-year-old son] as well. So, that was just the next step, to just figure out, 'Okay, so if it's not autism, how do we correct the sleep habits and the behavioral issues.'"</i></p>	<ul style="list-style-type: none"> • Uncertainty about a possible ASD diagnosis brought up worries about child's future • Had limited support from family and friends during the diagnostic process • Experienced logistical challenges associated with completing the developmental evaluation 	<p><i>"At the beginning, I didn't know what the autism was, because in my country I have never heard of that, because I didn't know what kind of disease it was. Was it serious? Was it terminal? I didn't know, and I felt worried because I didn't know if he could be able to talk, if he could explain to me what's what he wants...So it was very worrying."</i></p> <p><i>"My job was giving me a hard way to go. Because I was missing work. I worked in a daycare, so they saw I was putting my daughter first, before I was putting my job first, so they had to let me go."</i></p>
Following up on recommended services such as Early Intervention			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> • EI led to significant improvements in their children's development and in parents' ability to manage their child's needs 	<p><i>"Because just imagine if I would have waited and she would have never been walking. Or she would have [never] been talking, or saying words that she says now. Her speech would have never been on point. All the stuff that she's doing"</i></p>	<ul style="list-style-type: none"> • None reported 	<p>N/A</p>

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Low parental concern about child development			
Discussing initial concerns at pediatric primary care visit			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
	<i>there [EI], she never would have been able to do if I would have waited."</i>		
High parental concern about child development			
Discussing initial concerns at pediatric primary care visit			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> Validated parent concerns and initiated services to help address the child's delays 	<i>"I really felt good about [pediatrician's recommendations] because I knew it was something wrong, and I wanted to help him, and I didn't want to bring him home and don't do nothing because if I didn't do nothing, he would've gotten worse."</i>	<ul style="list-style-type: none"> None reported 	N/A
Completing the comprehensive ASD evaluation			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> Felt hopeful about finding answers to explain their child's developmental delays and receiving services to help their child reach expected developmental milestones. 	<i>"Well, after the appointment with the doctor, the pediatrician, well, I knew they were trying to fix her problem. We have just taken the first step, so it was good."</i>	<ul style="list-style-type: none"> Experienced fear and anxiety about a possible ASD diagnosis Felt unsatisfied with the results of the developmental evaluation and disappointed that their child would not be eligible for additional services 	<i>"At first, it was like very worrying, because I started to think what was going to happen with her, how her future would be."</i> <i>"I wasn't that happy because for my two other children, when they got that diagnosis [ASD], they were getting services. We were not eligible for services. Without the diagnosis, they can't get those services...So, I was shocked. I was disappointed."</i>
Following up on recommended services such as Early Intervention			
Benefits		Harms	
Key themes	Exemplar quotes	Key themes	Exemplar quotes
<ul style="list-style-type: none"> EI led to significant improvements in their children's development and in parents' ability to manage their child's needs 	<i>"As soon as [EI therapist] came in, it was like [4-year old daughter] connected with her so much...and she started talking, working on words, started developing so much more and it was like this whole new person..."</i>	<ul style="list-style-type: none"> None reported 	N/A

Abbreviations: ASD, Autism spectrum disorder; MCHAT-R/F, Modified Checklist for Autism in Toddlers-Revised with Follow-up; EI, Early Intervention

Table 4.

Parent Recommendations and Supporting Quotes.

Parent recommendations	Exemplar quotes
Age of screening	
<ul style="list-style-type: none"> As early as possible, ideally between ages one and two years 	<p><i>"Sometimes parents don't talk out of fear or say: 'well, my child doesn't have anything.' But...you don't lose anything, on the contrary, you gain if you get evaluations soon, because the child can get medical attention soon. If you get it early, I think the child can improve quickly as a child, before starting an evaluation later when the child is already developing more things emotionally."</i></p>
Frequency of screening	
<ul style="list-style-type: none"> Every 6 months 	<p><i>"Every six months. Because kids develop quickly... a year would be forcing it, so much happens in a year. Every six months would keep a steady pace to know what's going on."</i></p>
Strategies for screening	
<ul style="list-style-type: none"> Generally recommended universal screening over targeted screening Expand developmental screening beyond the pediatrician's office to settings like daycares and community centers Provide more information and support to parents when filling out the screening tool 	<p><i>"I don't think [targeted screening] is a good thing, because sometimes parents, they're too busy at work. They don't notice the things, or they're just not the most attentive parent. Which is a bad thing, but those happen."</i></p> <p><i>"I think in our country or maybe every parent is mostly concerned for the kids' like eating or sleeping, not the behavior and skills. I think this tool is good for that."</i></p> <p><i>"I think everybody should be able to fill out [ASD screening questionnaire]. The daycare provider, the parent, and the pediatrician, because the pediatrician is gonna ask you the same questions, but you might answer differently with the pediatrician versus the daycare. The daycare can be like, 'listen, we're not seeing this or we're seeing all of this and you're just not seeing it,' because sometimes kids do act differently at home and outside of home."</i></p> <p><i>"Sometimes we don't understand, we don't really understand the interpretation of the question, because when they asked me some questions...there were a lot that were like the same, but I didn't understand their difference, and how to answer them... Yeah, it would be good to have someone that guides you when you are answering the questions."</i></p>

Abbreviations: ASD, Autism spectrum disorder