

**Title:** Cultural Influences on Family Experiences with Early Screening for Autism Spectrum Disorder

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**Introduction:** Research has shown positive effects of early diagnosis and intervention on improving the developmental trajectory for individuals with autism spectrum disorder (ASD) (Elder et al., 2017). While the American Academy of Pediatrics recommends universal ASD screening at the 18- and 24-month well-child pediatrician visits, a 2016 United States Preventive Services Task Force (USPSTF) report highlighted several research gaps regarding universal screening, such as its potential harms and benefits for families of children who do not receive an ASD diagnosis after comprehensive evaluation (i.e. a false-positive screen), and the lack of cultural and sociodemographic diversity in ASD research samples (Siu et. al., 2016). Perceptions of child development, developmental delays, and milestones vary by culture (Bernier et. al., 2010), and this variation may pose different challenges for diverse groups, particularly for immigrant families who are navigating through a healthcare system that they are not familiar with. Little is known about immigrant families' interactions with their pediatricians, and experiences with the developmental evaluation process. The current project explores cultural influences on views of child development, communication with pediatric providers, experiences navigating the developmental evaluation process, and perceived harms and benefits of universal ASD screening.

**Method:** Twenty-six racially and ethnically diverse parents (56% US-born, 44% immigrant) whose children received a false-positive ASD screen and completed the developmental evaluation process in Boston, Philadelphia, or New Haven participated in semi-structured, in-person interviews. Interviews were conducted in Spanish or English according to parents' preference. Parents were asked to reflect on their experiences with (1) ASD screening, (2) communication with their pediatric providers, (3) the developmental assessment process in which they made several visits to a specialty clinic for further evaluation. Data were transcribed verbatim, systematically coded, and analyzed using applied thematic analysis (Guest et al., 2011). Parents were stratified into two groups, US-born and immigrant, to examine the similarities and differences between their experiences during the developmental evaluation process, and the ways in which different perceptions of child development impact parent experiences in healthcare settings.

**Results:** All parents reported that they found the screening and evaluation process helpful in getting their children the services they needed. Group differences emerged in how US-born and immigrant parents described their expectations for typical child development. While US-born parents expressed that they had expectations of their children reaching certain developmental milestones at certain ages, immigrant parents viewed child development as a unique process that unfolds differently for each child. For immigrant parents, there was a mismatch between the US system of imposing a universal timeline for certain behaviors, and their own perception of each child developing at their own pace and having their unique developmental trajectory. This mismatch impacted the way parents communicated with their pediatric providers and the manner initial concerns were raised. Most US-born parents reported that they had identified developmental concerns prior to initial screening. In contrast, there was more variability in how immigrant parents initially became concerned about their child's development. Many immigrant parents reported that they did not have concerns prior to the routine developmental screening at their well-child visit. When immigrant parents did have concerns before the pediatrician, they explained that these concerns stemmed from their previous experiences with developmental testing with an older sibling with autism or developmental delays. Many immigrant parents also reported that the developmental evaluation process was the first time they had heard the word "autism," and they described a greater need for explanation on how child development is monitored in the US, as well as what behaviors and developmental milestones they need to look out for in order to identify developmental concerns.

**Discussion:** Current findings indicate that cultural factors influence families' experiences and child outcomes across the developmental evaluation process, thus highlighting the importance of including diverse perspectives in ASD research in order to identify and meet the needs of different populations. Regarding universal screening, findings from this sample suggest that children of immigrant families may be at higher risk of being overlooked if they do not receive screening at their well-child pediatrician visits, because their families are not familiar with the ways child development is viewed in the United States. Universal screening

could be an important way of integrating immigrant families into the culture of monitoring child development in the United States both through identifying at-risk children earlier in their developmental trajectory and by giving parents and pediatricians common terminology through which to discuss child development.

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