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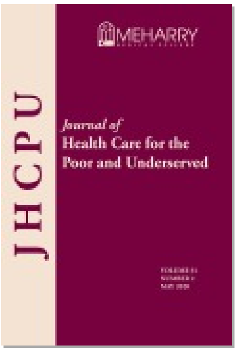

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Journal of Health Care for the Poor and Underserved, Volume 31, Number 2, May 2020, pp. 742-755 (Article)

Published by Johns Hopkins University Press
DOI: https://doi.org/10.1353/hpu.2020.0058

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Abstract: Early identification of children at risk for autism spectrum disorder (ASD) is critical to promote optimal outcomes. However disparities in early recognition of ASD based on race, ethnicity, income, and English proficiency persist. Little is known regarding how parents from these groups describe concerns. The study aim was to understand how parents of children from underserved backgrounds at developmental risk describe concerns about child development and behavior. To address this gap, developmental concerns of 204 parents of children at-risk for ASD from underserved communities were analyzed. In this sample, the number and type of parental concerns differed based on parent primary language but not the presence of ASD or ethnicity. Parents whose primary language was Spanish were less likely to express concerns about their child's development or to express ASD-specific concerns. These findings have implications for how clinicians elicit and interpret developmental concerns from underserved families.

Key words: Autism, underserved, parent concerns, Latino, limited English proficiency.

Early identification of autism spectrum disorder (ASD) expedites access to appropriate intervention and leads to improved functional outcomes.[1–3] There are significant income, racial, and ethnic disparities in the early identification of ASD.[4–7] For example, Latino children receive a diagnosis of ASD later than White, non-Latino children,[5,8] are more likely to receive an alternate diagnosis such as a language disorder,[6,9] and when diagnosed, are more likely to have severe symptoms than White non-Latino children.[6,10,11] Within the Latino population, disparities are especially pronounced for those with limited English proficiency.[12] Reasons for these disparities have not been

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Journal of Health Care for the Poor and Underserved 31 (2020): 742–755.

well-researched and are likely influenced by multiple factors including culture, ASD knowledge, social support, literacy issues,[13] maternal education, number of sources of knowledge about ASD,[8] and mistrust of health care providers.[12]

Disparities in access to diagnosis may also relate to how and when concerns are initially expressed by parents. In a qualitative study of refugee parents, Kroening and colleagues[14] found that parents had limited awareness of developmental milestones and were unlikely to mention concern unless speech or behavioral problems were present. A large-scale study conducted in England among older children (ages 5–10 years) found that parents with higher socioeconomic status (SES) and level of education were more likely to report some degree of concern about their child's emotions, concentration, behavior or social relationships. Although these types of concerns were not specific to ASD, parents of children with ASD reported a greater number of concerns and/or higher intensity of concern.[15]

Little is known regarding the type of concerns that Latino parents or those with limited English proficiency have about their children who are at risk for autism. This may be because Spanish-speaking families who are not also fluent in English may be excluded from research samples entirely[16] or may be included in limited numbers compared with other ethnic groups where education and/or other demographic characteristics may have affected the results.[17] One study found that Latino mothers of children suspected of ASD reported fewer ASD or developmental concerns than non-Latino mothers of at-risk children.[17] In a qualitative study of Latino families of children already diagnosed with ASD, parents reported that primary care providers sometimes dismissed their initial concerns about their child's development or behavior. This, coupled with a diagnostic process that was viewed as cumbersome, led many parents to normalize child behaviors, deny that a problem existed, and lose trust in the medical system.[18] Therefore, it is important to specifically elicit parent concerns as part of early detection of ASD.[19]

Ozonoff elicited developmental concerns from a primarily White group of parents of 243 children enrolled in a longitudinal study from birth to three that included both siblings of children with ASD and those who were not siblings.[19] Concerns were elicited by asking parents, "Do you have any concern about your child's development or behavior at this time?" Responses were grouped into eight categories of concerns by trained coders unaware of risk status of the child. The categories were further collapsed into ASD or non-ASD concerns. Richards applied this same approach to a sample of children at-risk for ASD, but not underserved, and found that most parents reported concerns. Parents of those children subsequently diagnosed with ASD were more likely to report concerns suggestive of ASD (i.e., communication, social, and restricted, repetitive behaviors) whereas parents of children subsequently diagnosed as non-ASD, were more likely to report medical and behavioral concerns.[16] Using a similar approach, Donahue compared the concerns of Black and White parents of children with ASD. The Black parents reported fewer ASD-specific concerns, especially fewer social or restricted and repetitive behavior concerns, despite their children having more severe social symptoms than White children in the study. However, there were no racial differences in parent report of number of non-ASD-specific concerns.[20]

Few studies directly explore how underserved parents of children at risk for ASD describe their concerns regarding their children's development and behavior, particularly parents from low-income Latino backgrounds whose preferred language is Spanish. To address this gap, we conducted content analysis to examine differences in the number and types of concerns among parents of underserved young children at risk of ASD. Our hypotheses are that type and number of concerns will differ by ASD status, ethnicity, and primary language in the home.

Methods

Data source. Data for this study were gathered as part of a larger study being conducted to validate the Developmental Check-In (DCI), an ASD screening tool that is primarily visual in format. It includes images of key communication and social-developmental milestones, as well as red-flag behaviors. The first page of the DCI includes one open-ended question: "Do you have any concerns about your child's development or behavior? Circle: Yes or No. If yes, please describe." Responses to this question were the focus of analysis in this study. Results of the larger study are presented elsewhere.[21]

Participants. The sample included 288 children ages 24 to 60 months old, 211 of whom were seen at an outpatient developmental evaluation program at a pediatric hospital and 77 of whom were seen at federally qualified health centers (FQHCs) located in five medically underserved communities. These children were referred for evaluation due to developmental concerns raised by health care providers or parents, and thus considered high-risk for ASD. Of the sample, 204 (71%) parents listed a response to the open-ended question on their completed DCI forms regarding their concerns about their child's development or behavior.

Procedure. All parents provided informed consent and approval was obtained from Rutgers Biomedical Health Sciences Institutional Review Board (IRB) prior to conduct of this study. Participants recruited from the developmental evaluation clinic were invited to participate in the study when they called to make an evaluation appointment if their child met one or more of the following inclusion criteria: they were insured by Medicaid or were uninsured and/or were non-White and/or were Latino and/or spoke a primary language other than English. Participating FQHCs were asked to refer all children meeting the inclusion criteria for whom parents or health care staff had noted developmental concern. Staff at the FQHCs discussed the study with the parents and arranged an evaluation appointment at the FQHC for those parents who expressed interest.

Full evaluations were provided regardless of scores on screening tools for all children. A packet was mailed to parents to complete and bring with them to the evaluation appointment. All parents were asked to complete the Modified Checklist for Autism in Toddlers—Revised (M-CHAT-R),[22] the Social Communication Questionnaire (SCQ),[23] and the Developmental Check-In (DCI).[21]

The full evaluation appointment consisted of a structured parent interview to gather child and family health information, administration of the Mullen Scales of Early Learning (MSEL)[24] and administration of the Autism Diagnostic Observation Schedule-2 (ADOS-2)[25] and was conducted by a developmental pediatrician, advanced practice nurse, or licensed psychologist. All evaluators were research reliable on the ADOS-2 and experienced in diagnosis of ASD and related disorders. Final ASD diagnosis was informed by the ADOS-2 findings but was based on review of DSM-5 criteria for ASD and clinical judgment of the experienced evaluator who administered the assessment and directly observed the child. Families received a gift card for their participation.

Data analysis. All parent comments were transcribed and entered into a research database. Comments in Spanish were translated into English by certified bilingual translators (authors ML & NG).

All parent concerns were coded using content analysis[26] based on the coding scheme developed by Ozonoff[19] and later adapted by Richards[16] and Donahue.[20] We relied on Ozonoff's original eight categories, which were summed into two broader codes of ASD concerns (speech/language/communication, social, stereotyped behavior, and unspecified ASD) versus non-ASD concerns (motor, medical, behavior/temperament, general development). The ASD concern category aligned with the DSM-5 diagnostic criteria for ASD. If parents described multiple concerns in different categories, all were coded.

All transcripts were coded by two authors (JH & ML) who were blind to ASD diagnosis and demographic characteristics. Discrepancies were resolved through consensus of five of the authors (YJ, JH, CC, ML, and NG).

To test for differences between groups, chi-square analyses and non-parametric Mann Whitney U tests were used. Non-parametric tests were appropriate as equal variances could not be assumed. Results were analyzed using SPSS version 24.[27]

Results

Demographics. Demographic characteristics are presented in Table 1 for the 204 parents who listed a comment and the 84 who did not. Overall, the mean age of the children in the sample was 36 months and 95% were Medicaid-enrolled. Most children were male and Hispanic.

English was the primary language for most parents. Of those parents who reported their education level, 4% reported some type of education beyond high school.

Table 2 indicates number and type of parent concern by child diagnostic category, parent primary language and ethnicity, and site.

Evaluation site. We first conducted chi-square analyses to test for differences between participants seen at DSC vs. FQHC sites regardless of whether parents had listed concerns on the DCI. Children seen at the DSC were more likely than children seen at FQHCs to be female (χ^2=6.32, p<.05), to come from families where English was the primary language spoken at home (χ^2=17.25, p<.01), to have parents with more education (χ^2=23.69, p<.01), and to have concerns listed on the DCI (χ^2 =7.81, p<.01). There were no differences by site in regard to ethnicity or clinical diagnosis of the child.

Presence of parent concerns. We then examined differences between parents who listed concerns versus those who did not. Those whose primary language was English were more likely to list a concern (χ^2 =10.14, p<.01). Parents with a higher reported level of education were also more likely to list concerns (χ^2 =19.31, p<.01).

Among parents who listed concerns, the average number of concerns was 2 (SD= 1.17, range 1–6). The average number of ASD concerns listed was 1.26 (SD=0.84, range 0–4). The average number of non-ASD concerns was 0.81 (SD=0.75, range 0–3).

Table 1.

DEMOGRAPHIC CHARACTERISTICS

	Subjects with comments	Subjects without comments
Total n:	204	84
	n (%)	n (%)
Child ASD	148 (73)	63 (75)
Child Male	150 (73)	62 (74)
Child Black	39 (19)	19 (23)
Child White	83 (41)	20 (24)
Child Other race	44 (22)	14 (17)
Child Multi race	1 (0)	3 (4)
Child race no response	38 (18)	25 (30)
Hispanic	105 (52)[a]	53 (63)[a]
Parent with some education post high school	90 (44)	28 (33)
Parent with high school or less education	99 (49)	45 (54)
Parent education not reported	14 (7)[b]	11 (13)
English as primary language in home	157 (77)	49 (58)
Spanish as primary language in home	47 (23)	35 (42)
Mean Child Age in months	36	36
Child Age 24–36 months	104 (51)	46 (55)
Child Age 37–48 months	85 (42)	29 (35)
Child Age 49- 60 months	15 (7)	9 (11)
Medicaid coverage	194 (95)	80 (95)
Other health insurance coverage	9 (4)	4 (5)
No health insurance coverage	2 (1)	0 (0)

Notes

[a] 2 subjects with parent comments and one parent without comments did not list ethnicity.

[b] 1 subject listed parent education=other.

Primary language of parent. The Mann-Whitney U test was used to examine differences by primary language as equal variances could not be assumed between groups. Parents who spoke English as their primary language had significantly more concerns overall (U= 2854.00, p<.05) and more ASD-specific concerns than Spanish-speaking parents (U= 2992.50, p<.05). Specifically, English-speaking parents expressed significantly more concerns about stereotyped behavior (U=2993.00, p<.01) and social issues (U=3009.00, p<.05) than Spanish-speaking parents. The only difference by primary language for non-ASD concerns was that English-speaking parents expressed more general developmental concerns (U=3204.00, p<.05) than Spanish-speaking parents. No other differences were found by language for type of concern.

ASD status of child. There were also no differences in total number of concerns or

Table 2.

PARENT CONCERN BY CHILD DIAGNOSTIC CATEGORY, PARENT PRIMARY LANGUAGE AND ETHNICITY, AND SITE

	ASD	Non-ASD	Primary language English	Primary language Spanish	Hispanic[a]	Non-Hispanic[a]	FQHC	DSC
Total n:	211	77	206	82	158	127	77	211
Mean # concerns:	2.11	1.93	2.18	1.68	1.92	2.22	1.62	2.19
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Listed any concern	148 (70)	56 (73)	157 (76)	47 (57)	105 (66)	97 (76)	45 (58)	159 (75)
ASD concern	129 (87)	42 (75)	132 (84)	40 (85)	76 (72)	84 (87)	39 (87)	132 (83)
Non-ASD concern	93 (63)	38 (68)	53 (34)	27 (57)	57 (54)	66 (68)	25 (56)	106 (67)
Type of concern								
Speech/language	111 (75)	38 (68)	111 (71)	39 (83)	79 (75)	69 (71)	37 (82)	113 (71)
Social	47 (32)	8 (14)	49 (31)	6 (3)	26 (25)	28 (29)	8 (18)	47 (30)
Stereotyped behavior	36 (24)	11 (20)	43 (27)	4 (9)	19 (18)	28 (29)	1 (2)	46 (29)
Motor	6 (4)	4 (7)	8 (5)	2 (4)	7 (7)	3 (3)	0 (n/a)	10 (6)
Medical	17 (11)	4 (7)	19 (12)	2 (4)	6 (6)	15 (15)	2 (4)	19 (12)
Behavior/temperament	74 (50)	35 (63)	84 (54)	25 (53)	56 (53)	53 (55)	22 (49)	87 (55)
Unspecified autism[b]	5 (3)	1 (2)	6 (4)	0 (n/a)	2 (2)	3 (3)	0 (n/a)	6 (3)
General development	18 (12)	7 (2)	24 (15)	1 (2)	9 (9)	16 (16)	3 (4)	22 (10)

Notes

[a] Three subjects did not indicate ethnicity.

[b] Unspecified autism defined as concerns which referred explicitly or implicitly to autism but did not focus on a specific symptom.

ASD= autism spectrum disorder

FQHC= federally qualified health centers number of non-ASD concerns by diagnosis. Parents of children with ASD, however, had significantly more ASD-specific concerns (U= 3409.00, p<.05).

Gender and ethnicity of child. There were no differences in total number of concerns or number of ASD versus non-ASD concerns by gender or ethnicity, although parents who considered themselves non-Hispanic/Latino were more likely to report medical concerns about their children (U=4596.00, p<0.05).

Age of child. Parent number and type of concerns did not differ by whether the child was older or younger than 36 months of age.

Examples of Concerns. Examples of comments in each category are provided in Table 3.

Concerns about speech/language. Most parents (n=150; 74% of those with comment) described concerns regarding their child's communication regardless of ASD status. Both expressive and receptive communication concerns were expressed by parents with regard to their child's inability to speak and/or to understand spoken language.

The observation that children did not engage in "small talk" was often mentioned among parents who noted a communication concern despite their child using spoken language. One English-speaking parent of a child eventually diagnosed with ASD wrote,

> Doesn't make small talk, tell stories, or have conversations. Does express needs and wants, sings songs, and recites scenes from movies.

Some parents also identified communication concerns about their child's volitional non-communication. For instance, an English-speaking parent of a child not diagnosed with ASD wrote,

> . . . refuse[s] to talk when trying to get him to answer questions.

A Spanish-speaking parent of a child not diagnosed with ASD noted,

> [S]ometimes [he] does not want to talk.

Social concerns. Concern about a child's behavior toward or in relation to an age-peer or adult was captured by this category and was noted by 55 parents (27% of those with comments). As one Spanish-speaking parent of a child with ASD stated,

> He is two years old and still doesn't talk, not even a clear word, doesn't know how to wait, doesn't play with other children, bothered by everyday noises like blender and hair dryer, doesn't share with others.

Overall, when social behavior was mentioned, it was usually in combination with other concerns already captured in other categories. One English-speaking parent of a child not diagnosed with ASD expressed concerns about social behavior, but also communication and behavior:

> He likes to fight his twin brother violently, he doesn't like when I say "no." He will fall out if he doesn't get his way. He does well in school except for speech but everyday common things he seems lost. Have tantrums often. He's a loner; he prefers to be in his room all day while brother and family are outside or doing other activities.

Table 3.

SAMPLE QUOTES BY CATEGORY OF PARENT CONCERN

Category of parent concern	Examples
Speech/language, n=150 (language use, gestures, language comprehension, intention of communication)	*"Still doesn't talk by himself, he repeats or tries to repeat what other say, but that is really the only time"* *"Behind on speech, would like for her to be able to express herself better"* *"Concern because he can't speak in full sentences . . . sometimes communicates by pointing but not often"*
Social, n=55 (engagement, interest in others, reciprocity, social attention including eye contact)	*"Stares at other children and adults he is not familiar with. Will not react when they talk to him or try to play with him".* *"Doesn't play with other children"* *"Plays alone and cries when she sees other kids"*
Stereotyped behavior, n=47 (rigid, repetitive or odd in sensory, motor or object use)	*"Plays with wheels"* *"Lines up his cars and trains and is fixated on them being in a line"* *"OCD—With playing with nail or hand*
Motor, n=10 (motor delays or clumsiness)	*"Delays in fine and gross motor skills"* *"Delays in . . . motor planning"* *"Coordination needs work. Falls a lot and runs into things"*
Medical/regulatory, n=21 (health, or eating, sleeping, toileting)	*"Doesn't sleep for more than 2 hours straight at night"* *"Doesn't like to eat some texture of foods like pears, vegetables and fruits; only eats apple and banana"* *"When hearing noise or anything loud screams and shakes (even with vacuums or lawn mower). Doesn't sleep well, cries and sits straight up in his crib"*
Behavior/temperament, n=109 (activity level, attention, behavior regulation, aggression, impulsivity, compliance, mood, affect, anxious, cranky, stubborn)	*"Gets angry easily, almost all the time and when he does he throws everything that's near him on the floor or hits the tables, etc. Also if I tell him to stop he gets madder and keeps on doing the same things or sometimes hits me or maybe others"* *"Aggressive, very easily frustrated and gets upset when he is not in control of the situation he is in or things happening around him"* *"Very hyper, can't stay still in public places and at home is almost all day on the go"*
Unspecified autism, n=6 (concern mentioning autism)	*"Autism risk"* *"Concerned if it has anything to do with autism and how I can find out"* *"He is showing some signs of autism such as hand flapping and walking on tippy toes. He stares at light, hardly gives eye contact, and twirls a lot . . ."*
General development, n=25 (general developmental concerns, cognitive or self-help concerns, such as late milestones)	*"Does not do what other children [her] age do. Does not self-eat, does not drink the bottle by herself"* *"His learning development is poor, doesn't know his colors, letters, numbers, shapes or body parts. I've tried to teach him but he doesn't seem to understand"* *"Developmental delay"*

Stereotyped behavior. When a concern about a child's stereotyped behavior was expressed (n=47; 23% of those with comments), it was often expressed in the context of playing with toys or repetitive speech/echolalia. As one English-speaking parent of a child with ASD stated,

> Sometimes he makes lines, walks on toes, flaps his hands in excitement. Does not play with toys the way they are intended. Very fussy eater (textures). Makes repetitive noises. Does not seem to know when he plays too roughly, he hurts people. Treats his "blankie" as if it was a real person.

Parents also tended to equate restricted, repetitive behaviors with "OCD" (obsessive-compulsive disorder) as reflected by this English-speaking mother of a child without ASD,

> Has OCD tendencies; flushing toilets, washing hands, hugs, kisses, high-five before leaving. Eats non edible items like: play-doh, dirt, frozen foods, bird feces and toilet paper. Won't wear clothes with buttons and zippers. Clothes have to be "fluffy." Licks the ground, bottom of shoes and different surfaces. Gets very scared with loud noises.

Behavior. Another common concern of parents (n=109; 53% of those with comments) related to behavior, including tantrums or other aggressive externalizing behavior. This category captured a sense of children being irritable and volatile. As one English-speaking parent of a child without ASD expressed it,

> Has a very short fuse, gets upset when he doesn't get his way. If he is having a tantrum, he hits, bites, throws toys and chairs, he runs away and screams.

This category also captured other moodiness, including descriptions of anxiety, as one Spanish-speaking parent of a child with ASD reported,

> Gets scared very easily, not able to be alone in the house.

Other parents shared concerns about their child's low frustration tolerance and/or defiant behavior. An English-speaking parent of a child without ASD said,

> [G]ets angry easily, almost all the time, and when he does he throws everything that's near him on the table and hits the table . . . also when I tell him to stop he gets madder and keeps on doing the same things or sometimes hits me or maybe others . . .

Concerns about aggression also often included mention of hyperactivity as one English-speaking parent of a child without ASD reported,

> [H]yper, some OCD. Hyper—can't sit still to learn or focus. Out of control, hard time settling down to sleep.

Discussion

This study supported our hypothesis that parents whose primary language is English would express more developmental and behavioral concerns and more ASD-specific concerns than those whose primary language is not English. Although the hypothesis that parents of children diagnosed with ASD would have more concerns was not supported, these parents did report more ASD–specific concerns than parents of children not diagnosed with ASD. Ethnicity was unrelated to number or type of concerns in this sample. Our findings provide insight into how underserved families communicate concerns regarding child development and have important implications for pediatric professionals who elicit and attend to these concerns through developmental surveillance and screening.

Families with Spanish as their primary language expressed fewer concerns, and fewer concerns suggesting ASD red flags, even when their child was subsequently diagnosed with ASD. This is similar to findings of Blacher and colleagues[17] in their study of Latino versus Anglo mothers of children suspected of having ASD. This has important implications for pediatric providers. These families often face barriers for accessing primary care delivered in their primary language. Our findings suggest that when Spanish-speaking parents bring their child to a primary care visit, pediatric providers need to make a concerted effort to elicit concerns. Some Latino parents may have less information about ASD relative to non-Latino peers, may struggle to access a same-language provider who listens and understands their concerns, and/or may require significant assistance from providers or other community members to access diagnostic evaluations and therapeutic services when concerns are detected.[13,18,28]

Further building on research that identified disparities in parent knowledge regarding ASD and potential red flags, attention is needed to awareness campaigns that better target underserved communities, especially when the predominantly spoken primary language is not English.[13]

Like Richards,[16] we found no differences between at-risk children diagnosed with ASD versus those not diagnosed with ASD in terms of number of concerns. Unlike Richards, we found no differences based on diagnostic status in this underserved sample in terms of frequency of non-ASD concerns. In the present study, primary language spoken in the home was a more salient distinction among parent concerns than was ASD status. In this sample, English-speaking parents described more concerns in general, more general developmental concerns, and more ASD-specific concerns, particularly more concerns about stereotyped behavior and social issues. Because social issues and stereotyped behaviors are characteristics of ASD, this might indicate a less complete understanding of ASD among Spanish-speaking parents, a cultural difference in the types of concerns that create worry among parents who speak different primary languages, or this may represent a true difference in presentation of these children.

Child communication concerns were the most commonly mentioned parent concern. This finding is consistent with prior research conducted with parents of at-risk toddlers.[16,29] In the current underserved, at-risk sample, concerns about communication did not differ between parents of children later diagnosed with ASD versus those not diagnosed with ASD. Behavioral concerns were frequently mentioned, especially among parents of non-ASD children, but behavioral concerns often involved hyperactivity or aggression rather than stereotyped or repetitive behaviors that are a feature of ASD.

Despite recommendations for ASD-specific screening by pediatric providers serving young children, not all providers are using validated screening tools or following recommended guidelines.[30] Rather, providers may be relying on parent concerns to trigger referral for developmental evaluation. Since parent input is an essential component of ASD screening, it is critical to recognize the methods of evoking parent input commonly used in practice, as well as the content of the input itself, and how it might vary depending on characteristics of the person being queried. Determining patterns of parent concerns associated with an ASD diagnosis may help primary providers in their decision-making process regarding types of evaluation and intervention needed. Given the known disparities in access to screening, diagnosis and assessment, understanding parent concerns may be especially important for children from low income, racial/ethnic minorities and those where English is not the primary language spoken in the home.

This study is subject to certain limitations. It is possible that parents had concerns that they did not list. The open-ended question on the DCI was optional and no effort was made to elicit a response if it was initially left blank. It is also possible that parent interview would have resulted in a different pattern of parental concerns potentially providing an opportunity for further exploration. Racial differences were not examined here because many of the Latino families who responded to the demographic questions did not list race once they responded to ethnicity. The findings are based on a sample of underserved families who either pursued or agreed to and attended a developmental evaluation for their child who had been identified as having some type of developmental concern. It is possible that the findings may not generalize to a broader population. In the future it will be important to follow families to understand their pathways to evaluation, diagnosis, and services, and to determine if that path is influenced by the families' description of their concerns about their children.

Despite these limitations, this study provides insight into the way that underserved families, including families who speak Spanish as a primary language, describe their concerns about their child's development and highlights the need for pediatric providers to actively elicit and attend to parent concerns as part of developmental surveillance and screening. Our findings also underscore the importance of using culturally appropriate, validated screening tools. Further research is needed to explore if similar patterns of parental concerns would be noted in a low-risk sample from similar demographic groups. Research is also needed to determine if number and type of concerns relate to referral and linkage to intervention.

Acknowledgments

The authors thank David Mandell, Rhiannon Luyster and Zuleyha Cidav for their consultation in developing The Developmental Check-In.

Author Contributions. All the authors have contributed in the conceptual, data analysis, writing, and editing process for this manuscript.

Declaration of Conflicting Interests. The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding. This work was supported in part by the New Jersey Governor's Council for Medical Research and Treatment of Autism, New Jersey State Department of Health [grant number CAUT13APS025].

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