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Role of primary care clinician concern during screening for early identification of autism

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Abstract

Objective: To evaluate the added value of primary care clinician (PCC)-indicated concern during primary care universal standardized screening in early identification of autism.

Methods: Toddlers were screened for autism during primary care check-ups (n=7,039, aged 14.24 to 22.43 months) in two studies. Parents completed the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F[1]). For each participant, PCCs indicated whether or not they had autism concerns (optional in one study – before or after viewing screening results, required prior to viewing screen results in the other). Children at high likelihood for autism from screen result and/or PCC concern (n=615) were invited for a diagnostic evaluation; 283 children attended the evaluation.

Results: Rates of PCC-indicated autism concerns were similar whether PCCs were required or encouraged to indicate concerns. High likelihood of autism indication on both screen and PCC concern resulted in the highest Positive Predictive Value (PPV) for autism and PPV for any developmental disorder, as well as the highest evaluation attendance, with no significant difference between positive screen-only or PCC concern-only groups. Although frequency of PCC-indicated autism concern did not differ significantly based on child's cognitive level, PCCs were more likely

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to identify children with more obvious autism characteristics compared to more subtle autism characteristics as having autism.

Conclusion: Findings support the American Academy of Pediatrics' recommendation that both screening and surveillance for autism be incorporated into well-child visits. High likelihood of autism on either screen or PCC concern should trigger a referral for an evaluation.

Keywords

autism; surveillance; toddlers

Pediatric primary care clinicians (PCCs) are often first to identify early signs of autism in young children through the complementary processes of developmental surveillance and universal, standardized screening. Surveillance incorporates caregiver concerns, physician observations, and developmental history in the decision to refer children for diagnostic evaluations.[2,3] Screening uses standardized measures to identify children for further evaluation.[2] Most children who screen positive on autism screeners meet criteria for autism or another developmental delay, although psychometrics vary by screening measure, frequency, and child age.[4–7]

Child presentation, including level of autism characteristics or cognitive delays,[8,9] and PCC knowledge and familiarity with developmental disorders[10,11] can impact surveillance and screening. Supporting PCC surveillance through training can enhance early detection of autism.[10–12] In previous work,[5] children were most likely to receive an autism diagnosis when both the screener and PCC indicated concerns; however, few PCCs chose to indicate whether or not they had concerns.

Screening rates have increased in recent years, but this increase does not translate to higher rates of autism evaluation referrals or attendance.[9,13–16] Wallis and colleagues[16] found that 45% of screen positive cases not already in early intervention (EI) services received at least one referral and only 9% were referred for additional evaluation. In another study, only 31% of screen positive cases were referred to a specialist, and only 59% of those referred attended the evaluation.[9] Findings suggest there is room for examining the role of PCCs in screening and surveillance to improve autism referral rates and evaluation attendance. This study aims to 1) compare rates of PCC indicated concerns when optional versus required, 2) compare positive predictive values (PPVs) of screeners and concerns for autism and any developmental disability (DD), 3) examine evaluation attendance among positive screens, concerns, or both, and 4) examine the likelihood of PCC indicated concern for children with more or less obvious autism characteristics and children with more or less significant cognitive delays.

Methods

Participants

Toddlers. A total of 7,039 toddlers, aged 14.24 – 22.43 months, were screened at well-child visits across two studies (see Table 1). In study 1[4], pediatric PCCs were randomized to screening schedules beginning at 12-, 15-, or 18-month check-ups, with repeat screening at

18, 24, and 36 months. Parents completed the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F[1]) electronically or on paper from 15-month visits onward. Toddlers screened at 12 months (n = 838) completed different screeners but later completed the M-CHAT-R/F or had PCC endorsed concerns. In study 2[17], pediatric PCCs were recruited to screen toddlers for autism during well-child visits at 18 months with repeat screening at 24 months.

Across both studies, any toddlers identified with high likelihood of autism by M-CHAT-R/F or PCC concerns were invited to a diagnostic evaluation (n = 615); 283 toddlers (46%) attended an evaluation. For inclusion in the sample, participants needed to attend a 15- or 18-month well-child visit at a participating practice, complete the M-CHAT-R/F in English or Spanish, and not have a previous autism diagnosis. When the M-CHAT-R/F was completed more than once, only the first screen was used for analyses.

PCCs. In study 1, 129 PCCs, across 28 primary care practices, were recruited. PCCs (92 female, 35 male, 2 PCCs who did not identify their sex; 25 racial or ethnic minority) in these practices had an average of 16.6 years (SD = 4.9 years) of experience. PCCs consisted of 87 pediatricians, 7 family medicine physicians, 26 nurse practitioners, 5 physician assistants, 2 social workers, and 1 public health practitioner; one PCC did not specify specific training background. In study 2, 105 PCCs participated across 19 primary care practices. Information for 11 PCCs was not collected. The remaining 94 PCCs (69 female; 26 racial or ethnic minority) had an average of 18.4 years (SD = 11.8) of experience, and consisted of 66 pediatricians, 17 nurse practitioners, 5 physician assistants, and 1 registered nurse; 5 PCC did not specify training background. Data was not collected on whether PCCs received any additional training in developmental diagnosis, but all PCCs were conducting well child visits as a substantial portion of their practice.

Measures

Modified-Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F)[1]—The M-CHAT-R/F is a two-stage autism screener validated for 16 to 30 months old. Toddlers are scored (range 0–20) on 20 initial items; those who score in the moderate range (score 3–7) complete the structured Follow-Up. Children are classified at high likelihood of autism if initial score is greater than or equal to 8 or Follow-Up is greater than or equal to 2.

Primary Care Clinician Concern—Primary care clinicians were asked to report any autism-related concerns at each well-child visit, indicating whether their concern was due to language, social engagement, restricted or repetitive behaviors (RRB), and/or other. Language-only concerns were not included as autism-specific concerns. In Study 1, indicating concern was encouraged, but not required; PCCs were able to indicate concerns before or after they reviewed screening results. In Study 2, indication of the presence or absence of PCC concerns was required in order for PCCs to view screen results.

Diagnostic Evaluation Measures—Both studies used the Mullen Scales of Early Learning[18] (MSEL) to evaluate receptive language, expressive language, visual reception, and fine motor skills, and the Autism Diagnostic Observation Schedule, 2nd Edition[19] (ADOS-2), a play-based assessment of social communication and RRBs, which generates

a calibrated severity score (CSS). Semi-structured caregiver interviews were completed for adaptive behavior (Vineland Adaptive Behavior Scales—2nd or 3rd edition[20,21]) and autistic traits (Toddler Autism Symptom Inventory[22] or Autism Diagnostic Interview, Revised[23]).

Procedure

M-CHAT-R/F screening for both studies occurred during well-child visits at PCC offices. Parents who completed the form electronically (subset of Study 1, all Study 2) automatically were administered the Follow-Up questions if their child's initial score was in the moderate range. Parents who completed the paper form (subset of Study 1) received Follow-Up later by phone as necessary. PCCs were encouraged to share results with parents.

Screens were offered in English and Spanish, except at one site in Study 1. Families whose child was at high likelihood of autism based on screening and/or PCC concern were invited for a no-cost evaluation for which they provided informed consent. Evaluations occurred at a university site or pediatric office by a team supervised by a licensed psychologist, certified school psychologist, or developmental pediatrician. All measures were administered by research-reliable team members. Clinical diagnoses were provided using the International Classification of Diseases, tenth edition (ICD-10[24]), or the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5[25]). If autism was ruled out, other developmental disabilities (DD) were considered, including Global Developmental Delay or Language Delay; otherwise no diagnosis (ND) was provided. Caregivers received oral and written feedback.

Analytic plan

This is a retrospective cohort study, evaluating how screening and/or surveillance impact outcomes (diagnosis of autism) across two separate studies. To determine if study design impacted PCC rates, rate of PCC autism concerns were compared between those encouraged (Study 1) versus required (Study 2) to enter concerns using a 2×2 chi-squared analysis with prompt type (encouraged/required) by autism concern endorsement (yes/no). If no differences were detected, study samples would be combined to increase power.

Positive predictive value for autism (PPV_{autism}) is the likelihood that a positive result is a true autism case. True Positives (TP_{autism}) are children diagnosed with autism who screened positive and/or had PCC concerns endorsed. False Positive cases (FP_{autism}) are screener- or PCC concern-identified children not diagnosed with autism. To determine whether PPV_{autism} is higher when both screener and PCC concerns indicated high likelihood of autism compared to each individually, a 2×3 chi-squared analysis was conducted with positive case type (TP_{autism} versus FP_{autism}) by endorsement type (screen only, PCC concern only, screen + PCC concern). Effect size was reported for 2×2 (ϕ) and 2×3 chi-squared analyses (Cramer's V).

To examine the impact of screening versus PCC concerns on evaluation attendance a 2×3 chi-squared analysis was conducted with evaluation attendance (yes/no) by endorsement type (screen-only, PCC concern-only, screen + PCC concern). To determine whether PCCs identify autism likelihood more often for children showing more autism characteristics (ADOS CSS > median) or greater developmental delay (MSEL score < 2 standard deviations

from mean), 2×2 chi-squared analyses were conducted with ADOS CSS or MSEL scores (high/low) by endorsement type (screen-only versus combined screen + PCC concern and PCC concern-only). These analyses were repeated examining children diagnosed with autism with low (ADOS CSS 5–7) and high (ADOS CSS 8–10) levels of autism characteristics. PCC concern-only and screen + PCC concern categories were combined for these latter analyses to determine the utility of PCC identification of autism likelihood compared to screening alone. The combined PCC concern group was of particular interest to examine whether factors such as severity of delays and autism symptoms triggered PCC concerns, regardless of screening outcomes. Missing data were excluded from analyses.

Results

Rates of Primary Care Clinician-Indicated Autism Concerns

The percent of PCC-indicated concerns for autism among total children screened did not differ significantly whether PCCs were encouraged (Study 1: 3.11%) versus required to indicate concern (Study 2: 2.64%; X^2 (1, N=7039) = 1.06, p = .35, ϕ = 0.01). Since the difference in study design did not impact PCC indication of autism concern, samples were combined for the remaining analyses.

Positive Predictive Value for Autism for Screening and Concern

Across both samples, 615 children were identified at high likelihood of autism from positive screen (n= 405), PCC concerns (n=67), or both (n=143). Of these children, 283 (46%) attended a diagnostic evaluation and were diagnosed with autism (n=141), DD (n=110), or ND (n=32). There was a significant difference in PPV_{autism} depending on endorsement type (X^2 (2, n=283) = 13.57, p = .001, *Cramer's V* = 0.22; see Table 2A). Pairwise comparison indicated that screen-only PPV_{autism} (.41) was significantly lower than the screen + concern PPV_{autism} (.64; X^2 (1, n=258) = 13.52, p < .001, ϕ = 0.23). PPV_{autism} for concern-only (.52) was not significantly different from the PPV_{autism} for screen + concern (.64; X^2 (1, n=125) = 1.22, p = .27, ϕ = 0.10), or from screen-only (.41; X^2 (1, n=183) = 1.17, p = .28, ϕ = 0.08).

Positive Predictive Value for DD for Screening and Concern

When examining PPV for any developmental disability (PPV_{DD}), which includes autism and DD diagnoses (see Table 2B), there was a significant difference in PPV_{DD} depending on endorsement type (X^2 (2, n=283) = 6.93, p = .03, *Cramer's V* = 0.16). Pairwise comparison indicated that PPV_{DD} for screen + concern (.95) was higher than for screen-only PPV_{DD} (.86; X^2 (1, n=258) = 5.21, p = .02, ϕ = 0.14) and for concern-only PPV_{DD} (.80; X^2 (1, n=125) = 6.11, p = .01, ϕ = 0.22). However, PPV_{DD} for screen-only (.86) was not significantly different from the PPV_{DD} for concern-only (.80; X^2 (1, n=183) = 0.63, p = .43, ϕ = 0.06).

Evaluation Attendance

Of the 615 children for whom the initial visit indicated high likelihood of autism, attendance differed significantly depending on endorsement type (X^2 (2, n=615) = 42.96, p < .001, *Cramer's V* = 0.26). Pairwise comparison indicated that attendance was significantly higher for screen + concern (69.93%) compared to screen-only (39.01%; X^2 (1, n=548) = 40.55, p

< .001, $\phi = 0.27$) or concern-only (37.31%; X^2 (1, n=210) = 20.15, $p < .001$, $\phi = 0.31$). The difference in attendance based on screen-only and concern-only was not significant (X^2 (1, n=472) = 0.07, $p = .79$, $\phi = 0.01$).

Primary Care Clinician Indication of Autism Likelihood Based on Cognitive Level

Of the 283 children who attended an evaluation, 278 had valid MSEL data. The proportion of children with cognitive delay (i.e., MSEL Early Learning Composite < 70) identified by PCC concern did not differ from the proportion of children identified by screen-only (X^2 (1, n=278) = 3.65, $p = .07$, $\phi = .12$; See Figure 1).

Primary Care Clinician Indication of Autism Likelihood Based on Autism Symptom Severity

Of the 283 children who attended an evaluation, 271 had valid ADOS-2 data. Significant differences emerged in the proportion of children identified by PCC concern (with or without screen) and screen-only for children with more or less obvious autism characteristics (X^2 (1, n=271) = 7.12, $p = .01$, $\phi = .16$). PCCs were more likely to indicate concern for children with higher ADOS CCS scores than lower (62.71% vs. 37.29%), whereas the screen-only more evenly identified children with both higher and lower ADOS CCS scores (46.41% vs. 53.59%; see Figure 2). This was also true for the subgroup of children diagnosed with autism ($n = 136$), as PCCs were more likely to indicate concern for those with higher ADOS CSS scores (8–10) compared to the screen-only that identified similar proportions with high and low ADOS CCS scores (X^2 (1, n=136) = 5.53, p=.02, ϕ=.20).

Discussion

Standardized screening and PCC surveillance are both recommended by the AAP as important for early autism identification. Previous work has closely examined these methods of identification,[12,13,26] however, few studies have explored how these methods work together. With high demands for pediatricians, implementing both methods may be burdensome. Pediatricians may also feel noting their concerns is redundant with screening. In this study, the frequency of PCC-reported concerns did not differ between those who were required to note concerns before viewing screen results and those whose response was optional. This suggests that PCCs report their concerns for social development even when not required to do so. Pediatric PCCs successfully integrate aspects of surveillance into their workflow alongside screening.

Evidence from this study also indicates that both screening and surveillance are essential for detecting as many autism cases as possible, since there were very few PCC concern-only cases identified. Children identified by both screening and surveillance were more likely to have autism diagnoses than those identified by screening only. Furthermore, a higher PPV for a diagnosis of any developmental delay, including autism, was observed for children identified across both compared to screening or surveillance alone. As such, screening and surveillance together can more accurately identify children with high likelihood of autism and a broader range of children in need of early intervention services. Of note, children identified by both modalities were also more likely to attend an evaluation. Parents may be

more likely to attend an evaluation after a positive screen if the PCC also shares a concern. However, more than half of the children diagnosed with autism were *not* identified by both methods, indicating that there are individual and complementary contributions of these two strategies.[27] In our sample, 64 children diagnosed with autism were identified only by the screener (along with 94 false positives in the screen-only group), and 13 were identified only by PCC concern (along with 12 false positives in the concern-only group). This suggests that high likelihood for autism identified either by the caregiver-report screener or by PCCs should be cause for further evaluation. Caregivers possess extensive and accurate knowledge about their child's behavior,[28,29] whereas PCCs possess expert knowledge on child development. Findings also confirm that PCCs should refer children for evaluation when screeners indicate concerns, *even if they do not have clear autism concern from surveillance*, since screeners alone detected nearly half of the autism cases in this study. Furthermore, children identified by any method benefit from referrals for further evaluation or early intervention services.

Children's cognitive levels did not differ among groups identified by concerns versus screeners-only, with both modalities identifying children with greater cognitive impairment. This could mean that both surveillance and screeners perform equally well at indicating autism likelihood among children with cognitive delays. However, it is also possible that children with autism who do not have significant delays may be more difficult to detect at this young age. In addition, while the difference was not statistically different, there is a trend of cognitive level differences based on concern modality and therefore future studies need to explore PCC-indicated concern for children with more or less significant cognitive delays with larger samples. Children's level of autism characteristics, on the other hand, varied based on identification by concerns versus screeners-only. Specifically, PCCs concerns were more likely among children with more significant autism characteristics, whereas screen results identified cases across the spectrum of severity. These findings suggest that children may need to show more obvious characteristics to exceed the threshold for surveillance detection during a brief pediatric visit, or for PCCs to have sufficient confidence in surveillance.

Results from this study indicate that PCC surveillance and screening both play important and complementary roles in the identification of children; when implemented together, they maximize detection of autism. Pediatricians identify some children through surveillance when caregivers do not endorse items on screeners, potentially due to the caregiver's lack of knowledge about development, or perhaps caregivers' lack of readiness to endorse autistic behaviors. Conversely, caregiver reports on screeners identify children with less obvious presentations of autism symptoms that may not be readily apparent in a brief check-up.

When both surveillance and screening indicate high likelihood of autism, families are more likely to seek evaluation. Considering that 69% of families attended an evaluation following high likelihood of autism identification on both modalities compared to 37–39% on either modality alone, it is important to include both methods in well-child visits. Having multiple sources of information regarding a child's potential likelihood for DD may help families decide to pursue further evaluation. Of note, there are many systemic barriers in many community settings that families face in pursuing evaluations for autism, including access,

long waitlists, and high costs.[30] Although these were mitigated in our study, there are also individual barriers including stigma, lack of understanding of need for immediate action, cultural factors, as well as disagreement regarding concern,[31–33] which may delay pursual of an evaluation. Combining surveillance and screening is critical in facilitating conversations that PCCs have with families to communicate the concerns and discuss next steps. Future studies may explore what types of behaviors contribute to PCCs' concerns that can augment screening results, especially since families may be less likely to attend an evaluation if their pediatric PCC does not indicate concern for autism, which may lead to delayed diagnosis and impede access to early intervention. Following children who did not attend an evaluation may be helpful for tracking later diagnoses and understanding caregivers' perceptions about early autism evaluations.

Limitations

Several limitations are important to consider. Notably, only 46% of children who were identified by screeners or PCC concern as being at high likelihood of autism attended an evaluation; the diagnostic status of children who did not attend an evaluation is unknown, potentially biasing the PPV. In some cases, PCCs did not note lack of concern, meaning that it was unclear whether they did not have a concern, forgot to fill out their concerns, or left it blank for another reason. However, PCCs appeared to note concerns when they had them, as suggested by the similar frequency in concerns when required versus when encouraged. Additionally, while PCCs in the community have been shown to refer for evaluations at low rates[9] due to many contributing factors, including lack of available evaluation or therapy services,[34] study personnel managed incoming referrals and families were promptly scheduled for diagnostic evaluations. A barrier to referral from PCC may be the long waitlist for evaluation in the community, which is important to consider. Lastly, future research should explore how child comorbidities, such as existing delays, prematurity, or other medical conditions may influence PCC surveillance.

Conclusion

In summary, these findings indicate that both PCC-noted concerns and standardized screening are helpful for identifying children at high likelihood of autism as well as a broader range of DDs. True positive rates were far higher for children with any DDs compared to those for autistic children. Additionally, evaluation attendance was higher when both screening and surveillance indicated high likelihood for autism, suggesting stronger motivation to attend an evaluation compared to when only one modality indicated high likelihood for autism. Identifying a broader range of children with DDs means that more children will be referred for evaluation and thus gain access to early intervention services sooner. The role that each early detection modality plays in identifying children at high likelihood of autism may be unique and complementary, emphasizing the importance of integrating both in the context of well-child visits.

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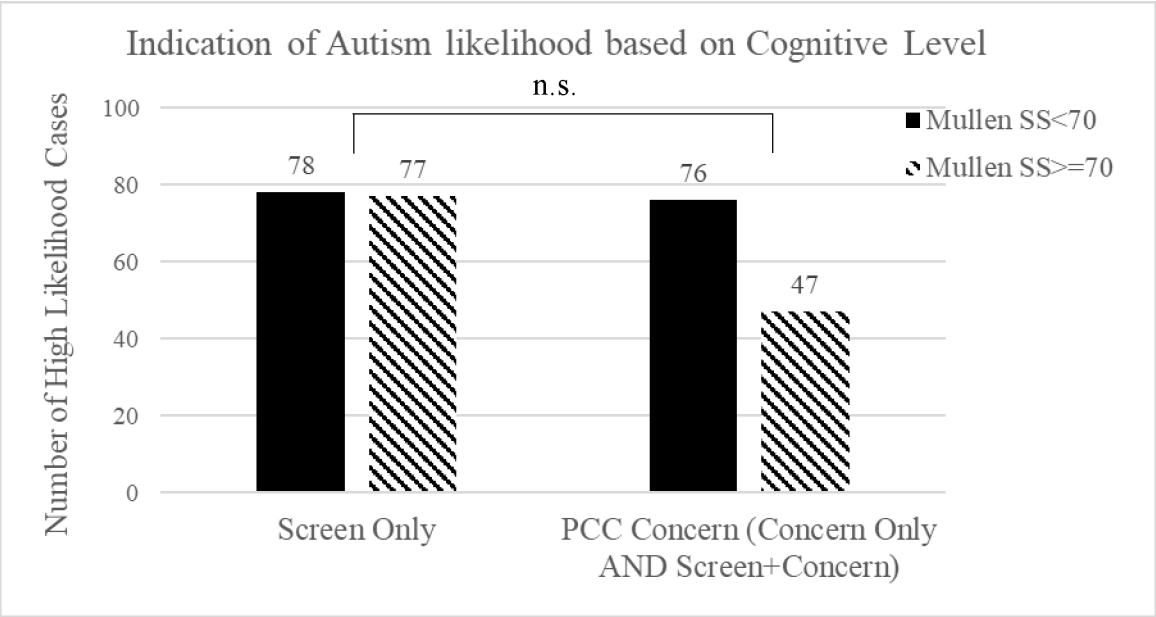

Figure 1.

Indication of autism likelihood based on cognitive level measured by MSEL for screener only and for PCC concern, combining concern-only cases and cases where both PCC concern and screener indicated high likelihood of autism. n.s. = non significant

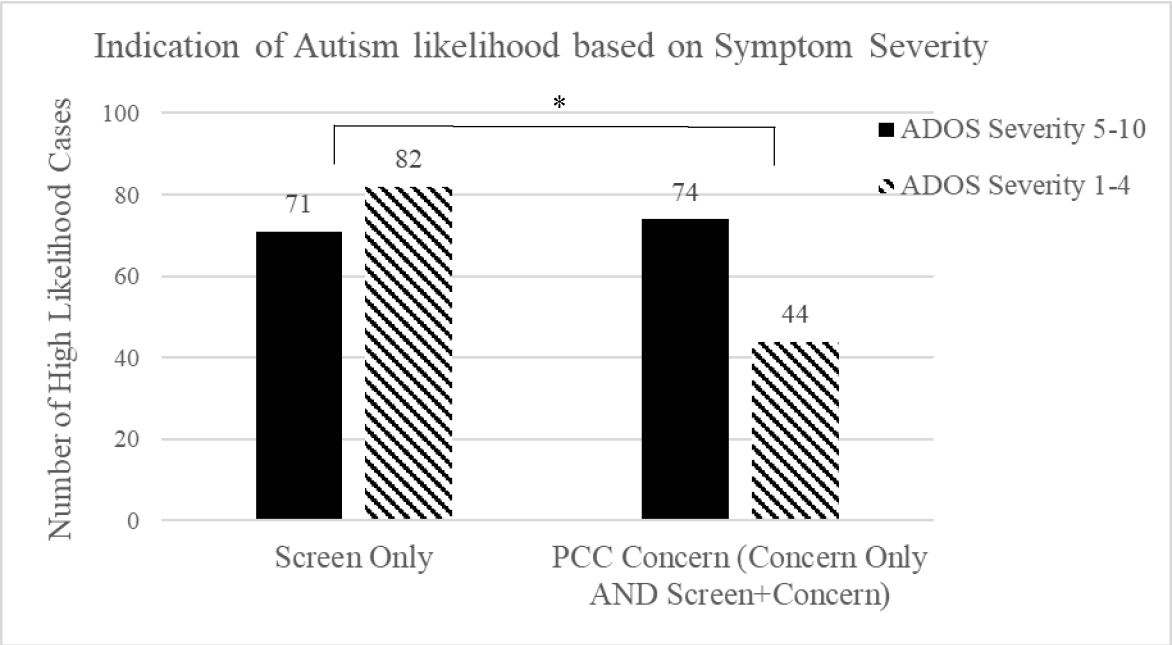

Figure 2.

Indication of autism likelihood based on autism symptom severity measured by the ADOS-2 for screener only and for PCC concern, combining concern-only cases and cases where both PCC concern and screener indicated autism likelihood. * p=.01

Table 1

Sample Demographic Characteristics

	Screening Sample		Evaluation
	Children screened in Study 1 (*n* = 5,110)	**Children screened in Study 2 (*n* =1,929)**	**Children evaluated across Studies 1 & 2 *n* = 283***
Age (*M*, (*SD*))			
Age Screened (months)	17.96 (1.64)	18.52 (0.87)	18.42 (1.66)
Age Evaluated (months)	-	-	21.09 (3.40)
Sex (*N*, (%))			
Male	2570 (50.29%)	1014 (52.57%)	192 (67.84%)
Female	2463 (48.20%)	915 (47.43%)	91 (32.16%)
Not reported	77 (1.51%)	0	0
Race (*N*, (%))			
White/Caucasian	3052 (59.73%)	1157 (59.98%)	132 (46.64%)
Black/African American	865 (16.93%)	246 (12.75%)	66 (23.32%)
Asian	222 (4.34%)	162 (8.40%)	22 (7.77%)
Native Hawaiian/Other Pacific Islander	6 (0.12%)	8 (0.41%)	2 (0.71%)
American Indian/Alaska Native	17 (0.33%)	3 (0.16%)	3 (1.06%)
Bi- or multiracial	399 (7.81%)	231 (11.98%)	22 (7.77%)
Other	127 (2.49%)	72 (3.73%)	16 (5.65%)
Unknown	422 (8.26%)	50 (2.59%)	20 (7.07%)
Ethnicity (*N*, (%))			
Hispanic/Latine	739 (14.46%)	277 (14.36%)	72 (25.44%)
Non-Hispanic/Latine	3252 (63.64%)	1563 (81.03%)	171 (60.42%)
Unknown	1119 (21.90%)	89 (4.61%)	40 (14.13%)
Final Diagnoses (N, (%))			
Autism	-	-	141 (49.82%)
Developmental Delay	-	-	110 (38.87%)
No Diagnosis	-	-	32 (11.31%)

Note.

*283 children attended an evaluation after positive screen or concern at any timepoint. Of these children, 265 children attended the evaluation after high autism likelihood was indicated at the initial visit (number used for the attendance analyses), and 18 attended after high autism likelihood was indicated during a repeat visit. Out of the 283 children, 5 were missing the MSEL score, and 12 were missing the ADOS-2 score.

Table 2

PPV for Autism (A) and DD (B) based on Autism Likelihood Indication

A.			
Likelihood Indication	**True Positive Autism Cases**	**False Positive Cases**	**PPVautism**
Screen Only (*n* (%))	64 (40.51%)	94 (59.49%)	.41
Concern Only (*n* (%))	13 (52.00%)	12 (48.00%)	.52
Screen + Concern (*n* (%))	64 (64.00%)	36 (36.00%)	.64
Total (*n* (%))	141 (49.82%)	142 (50.18%)	.50
B.			
Likelihood Indication	**True Positive Autism +DD Cases**	**False Positive Cases**	**PPV_{DD}***
Screen Only (*n* (%))	136 (86.08%)	22 (13.92%)	.86
Concern Only (*n* (%))	20 (80.00%)	5 (20.00%)	.80
Screen + Concern (*n* (%))	95 (95.00%)	5 (5.00%)	.95
Total (*n* (%))	251 (88.69%)	32 (11.31%)	.89

Note

* PPV_{DD} refers to PPV for any developmental disability, which includes autism and other DD diagnoses