**Symposium Title:** Informing the Evidence Gaps in Autism Screening and Diagnosis in Culturally and Linguistically Diverse Populations

**Chair:** Jenna Sandler Eilenberg¹

**Discussant:** Lisa Ibañez²

**Overview:** Autism spectrum disorder (ASD) affects 1 in 59 individuals in the United States (Baio et al., 2018), and early diagnosis of ASD is critical for optimizing long-term outcomes (Remington et al., 2007). As a result, the American Academy of Pediatrics has developed guidelines for screening all children at 18 and 24-month well-child pediatric visits (Johnson & Myers, 2007). The recommended autism-specific screening tool called the Modified Checklist for Autism in Toddlers, Revised with Follow Up (MCHAT R/F) is designed to identify children with ASD as early as 18 months; however, only about 50% of children who screen positive on the MCHAT R/F receive an ASD diagnosis after a comprehensive evaluation (Robins, Casagrande, Barton, Chen, Dumon-Mathieu, & Fein, 2014). In 2016, the United States Preventive Services Task Force issued a report stating that there was insufficient evidence to recommend universal ASD screening in pediatric primary care. The report cited a number of research gaps as a reason for their conclusion, including: (1) lack of information about the balance of benefits and harms of screening, (2) lack of evidence to determine if certain factors, such as child age, gender, or family characteristics, affect the performance characteristics of ASD screening tools, and (3) lack of studies that include low-income and racial/ethnic minority populations (Siu et al., 2016). Each presentation in this symposium will describe research designed to address these evidence gaps.

The first paper describes the perceived benefits and harms of universal autism screening from the perspective of racially and ethnically diverse families whose child received a false positive ASD screen. The second paper presents data from developmental and behavioral pediatricians about their own biases in diagnosing ASD, highlighting the importance of objective measures. The third paper uses data from a randomized multisite trial to predict which families are most likely to follow up on a positive ASD screen and which children are most likely to receive an ASD diagnosis after a positive screen. Finally, the fourth paper presents a novel screening tool designed to identify developmental concerns at younger ages in low-income, ethnically diverse populations. Collectively, these presentations highlight the benefits of universal ASD screening from the perspective of parents and providers, as well as outline strategies for more effectively identifying developmental concerns in low-income and minority populations.

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**Paper 1 of 4**

**Paper Title:** Harms and Benefits of Universal Screening for Autism Spectrum Disorder: Perspectives from Families Whose Child Received A False Positive Autism Screen

**Authors:** Jenna Sandler Eilenberg¹, Anjali Oberoi³, Deniz Kizildag¹, Julia Levinson⁴, Sarabeth Broder-Fingert⁵,⁶, Emily Feinberg⁴,⁵, Kristin Long¹

**Introduction:** In response to the increasing prevalence of autism spectrum disorder (ASD) (Baio, 2014) and the growing body of research that highlights the importance of early ASD identification and treatment (Elder et al., 2017; Estes et al., 2015; Remington et al., 2007), the American Academy of Pediatrics recommends that pediatricians screen all young children using validated ASD-specific screening tools (Johnson & Myers, 2007). However, after an exhaustive literature review, the United States Preventive Services Task Force stated that there was insufficient evidence to recommend universal ASD screening. In their

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2016 report, they cited a lack of evidence about the potential harms and benefits of universal ASD screening as well as a lack of research that includes diverse populations (Siu et al., 2016). To address these gaps, we conducted in-depth qualitative interviews with culturally and linguistically diverse families of children who received a positive ASD screen in primary care followed by a formal developmental evaluation that did not result in an ASD diagnosis (i.e., false positive ASD screen). Aims of the current study were to: 1) learn about families’ perceptions of harms and benefits of universal ASD screening and 2) gather families’ recommendations about the screening and referral process.

Methods: Families were recruited from an ongoing multi-site comparative effectiveness trial aimed at reducing disparities in early ASD diagnosis (Broder-Fingert et al., 2018). Parents were eligible to participate in the current sub-study if their child had a false positive ASD screen. Enrolled families participated in semi-structured interviews that lasted approximately one hour. Interviews were conducted in English and Spanish. To ensure broad representation, a purposive sampling strategy was used to recruit families based on age and gender of the child, presence/absence of parental developmental concerns prior to screening, and race/ethnicity. Data collection continued until thematic saturation was reached. Qualitative data were audio-recorded, transcribed verbatim, and checked for accuracy, and Spanish interviews were translated to English and checked for accuracy. The interview transcripts were entered into NVivo 12 software, coded, and analyzed using applied thematic analysis (Guest, MacQueen, & Namey, 2012).

Results: Twenty-seven racially and ethnically diverse parents participated (56% Black, 7% Asian, 37% other race; 33% Hispanic or Latino). For all study participants, the positive ASD screen triggered a comprehensive developmental evaluation in a specialty pediatrics clinic. Although their children were not diagnosed with ASD, all children received a formal developmental diagnosis after the comprehensive developmental evaluation (59% developmental disorder of speech or language, 18% developmental delay, 11% global developmental delay, 4% fine motor delay, 4% gross motor delay, and 4% disruptive behavior disorder). In terms of benefits of screening, parents explained that going through the process of ASD screening and evaluation increased their knowledge about child development and in some cases helped them identify developmental concerns earlier in younger siblings. Additionally, the ASD screening and evaluation process resulted in connecting their child to Early Intervention services, which parents felt led to improvements in their child’s developmental trajectory. In terms of harms of screening, parents described some anxiety during wait times for the formal developmental assessment. However, all parents expressed that, if given the option, they would repeat the screening and evaluation process again. A majority of parents recommended universal screening for ASD and suggested that screening extend beyond the pediatrician to other settings like daycares and community centers.

Discussion: Parents generally expressed satisfaction with the process of ASD screening, evaluation, and developmental services. 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 recommendations put forth by the American Academy of Pediatrics. These data directly address the US Preventive Services Task Force’s concerns about harms and benefits of ASD screening by suggesting that harms associated with screening are minimal and benefits include access to helpful services regardless of whether or not the child has ASD.

References/Citations:


Page 2 of 6
Paper 2 of 4

Paper Title: Practices Surrounding Autism Over-Diagnosis and Under-Diagnosis: Results from A National Healthcare Provider Survey

Authors: Aniqa Azim7, Carlos Candelaria-Rosario7,8, Rebecca E. Rdesinski7, Randall Phelps7, Katharine Zuckerman7

Introduction: The prevalence of autism spectrum disorder (ASD) increased tenfold in the last 40 years, and disparities have been noted by race/ethnicity and socio-economic status, prompting concern about diagnostic accuracy. Provider perceptions of ASD diagnostic accuracy are not known.

Methods: We conducted a survey of providers who diagnose ASD regarding how non-clinical factors might affect ASD diagnostic rates. A mixed-mode survey was sent to members of the Society of Developmental and Behavioral Pediatrics (SDBP) with clinical interest in ASD (n=400). Respondents used a Likert-type scale to address how often they and their colleagues over- or under-diagnosed ASD. They were also asked how families grouped by race/ethnicity, education, socioeconomic status, and urbanicity, perceived an ASD diagnosis.

Results: 63% of providers completed the survey. 8.7% of providers self-reported that they over-diagnose ASD at least sometimes. However, 58% of providers reported that local colleagues over-diagnose ASD at least sometimes. 7.8% of providers self-reported under-diagnosing ASD at least sometimes, and cited parents not wanting a diagnosis as one of the most common reasons they may under-diagnose. Providers reported that non-White and rural families were more likely to think that ASD diagnosis was “a bad thing” than “a good thing” than White and urban and suburban families, respectively.

Discussion: To our knowledge, this is the first study to report about how non-clinical factors may influence providers in their ASD diagnostic behaviors. Results from our study may help explain disparities in how children with ASD are diagnosed, and may potentially improve the ASD diagnostic process.

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Paper Title: Predicting Receipt of An Autism Spectrum Disorder (ASD) Diagnosis After A Positive ASD-Specific Screen

Authors: Jocelyn L. Kuhn, Julia Levinson, Manisha Udhnani, Kate Wallis, Emily Hickey, Amanda Bennett, Ada M. Fenick, Emily Feinberg, Sarabeth Broder-Fingert

Introduction: Universal ASD-specific screening with consistent diagnostic evaluation referral for those who screen positive is currently considered to be critical for achieving widespread timely and equitable identification and treatment of ASD (Johnson et al., 2007). However, these practices are limited both by lack of follow-through on diagnostic evaluation referrals post-screening and by poor predictive information from the screening tools in diverse populations (Guthrie et al., 2019). Understanding which families are least likely to engage in the diagnostic process can help providers better support parent engagement. Knowing who is most at risk for ASD, based on predictors of true positive ASD screens, can help providers prioritize patient referral - creating more efficient systems of care. Thus, families, service providers, and service systems would all benefit from expanded knowledge regarding the following two questions that this study addresses: 1) after a positive screen on a universally administered ASD-specific screener, who is most likely to follow-through on a recommendation for a diagnostic evaluation; and, 2) of those who screen positive, who is most likely to be diagnosed with ASD?

Methods: This study was a secondary analysis of data collected in a larger NIMH-funded, multi-site randomized controlled trial evaluating the impact of family navigation on diagnostic ascertainment and linkage to treatment. Participants included 310 predominantly low-income and racial/ethnic minority background parent-toddler dyads who screened positive on the MCHAT-R/F (Robins et al., 2014). Data on family factors and child adaptive functioning (ABAS-2 subscales) were collected as part of the baseline assessment, which was conducted at the time of primary care referral for a diagnostic evaluation. Families were followed via electronic medical record review to determine whether they completed a diagnostic evaluation and if so, what diagnoses were conferred. Generalized estimating equations with the logit link function and an independence working correlation structure were used to fit models of predictors for each of the two binary primary diagnostic outcomes: completing the diagnostic evaluation and receiving an ASD diagnosis upon evaluation.

Results: The best-fit model for completing a diagnostic evaluation identified the following significant independent predictors: younger child age at screen, older parent age at screen, lower child communication adaptive functioning, receiving Early Intervention, and non-Hispanic ethnicity. Significant predictors for receiving an ASD diagnosis upon evaluation included: male sex of child, lower child communication adaptive functioning, no use of interpreter for MCHAT-R/F screening, White and non-Hispanic parent race/ethnicity, and no parent history of a depressive or bipolar disorder.

Discussion: Findings from the first model identified children who were least likely to access diagnostic services among a sample of low-income, predominantly ethnic/racial minority families – a group known to be at elevated risk for delayed ASD diagnosis (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Children whose parents were younger or Hispanic, and who are not yet involved in Early Intervention were least likely to access diagnostic services, possibly due to lower awareness of developmental problems or acceptance of referral for developmental assessment/services. Parents of older children with higher communication functioning were also less likely to follow-through on diagnostic care; this may be because parents of such children feel less concerned about their child’s development. Families with these characteristics may benefit from interventions aiming to enhance parent engagement and address barriers to care. Findings regarding sociodemographic predictors of receiving an ASD diagnosis also corroborated prior research indicating problems with MCHAT-R/F accuracy among minority populations (Guthrie et al., 2019).
et al., 2019) and females (Øien et al., 2018). Use of an interpreter for screening predicted decreased likelihood of a true ASD diagnosis, suggesting potential issues with the language interpretation process within parent checklist screening approaches. Finally, lower communication adaptive functioning skills of the toddlers predicted receiving an ASD diagnosis, suggesting that such information may be useful to collect early in the primary care screening and referral process as part of efforts to more effectively triage children and increase efficiency of care for those who need a targeted ASD assessment.

References/Citations:

from the time of the positive IT Checklist screen until the child reached 24 months. The following data were abstracted from the child’s medical record: screening results from the PEDS and the M-CHAT-R/F; developmental diagnoses; referrals for developmental services; notation of parental and provider concerns; and responses to a social determinants of health screening questionnaire. Preliminary data were analyzed descriptively. Once all participants have reached 24 months and charts can be fully abstracted, the kappa statistic will be used to measure agreement between the IT Checklist and the PEDS, the IT Checklist and the M-CHAT-R/F, and the IT Checklist and parental concern. Additionally, multivariable logistic regression will be performed to assess the relative odds of a failed screen, taking into account language, child age, and parental concerns.

Results: 300 children were screened using the IT Checklist; 56% were Black or African American, 23% were Hispanic, 49% were male and 16% of parents/guardians preferred a language other than English to complete the screen. 98 children (33%) scored above the cut off for developmental concern on the IT Checklist. Of these 98, we obtained permission to access the charts of 91 children. Of these 91, 66 (73%) were screened with either the PEDS or the M-CHAT-R/F at the closest proximal well child visit; 15 screened positive and 51 screened negative. 26 had no documentation of routine screening. IT Checklist positive screening results were discordant with M-CHAT-R/F and PEDS results in 77% of proximal screens. Of the 25 children with chart reviews that extended to 24 months of age, 3 received an ASD diagnosis and 6 received at least one other developmental diagnosis.

Discussion: Preliminary results show a higher positive screen rate on the IT checklist than previous studies. This finding is likely due to the higher risk and younger age of participants in this study. The IT Checklist appeared to identify new concerns, not revealed by the clinic’s standard screening tools. Findings suggest that broadband screening may lead to earlier diagnosis of ASD and other communication delays. However, it is also possible that the tool over-identifies very young, low income children. Ongoing chart review and analysis will assess the potential advantage of this screener for identifying developmental delays and ASD. Further, factors associated with a failed IT Checklist screen will be examined.

References/Citations: