

March 23, 2021

U.S. Preventive Services Task Force  
5600 Fishers Lane  
Rockville, MD 20857

## **Request for Public Comment: Autism Spectrum Disorder in Young Children Screening Draft Research Plan**

We are a group of psychologists and physicians who conduct clinical research on autism spectrum disorder related to early identification, screening, and diagnosis. We also provide diagnostic evaluations and ongoing clinical care to children and youth with autism spectrum disorder and other developmental conditions. In reviewing the draft research plan for evaluating “Screening for Autism Spectrum Disorder in Young Children” we have identified several areas to consider, which our prior research highlights as important contributors to early diagnosis and intervention.

- 1. Disparities in screening practices, screening accuracy, referral decisions after a positive screen, and access to autism diagnostic evaluations and interventions may greatly impact diagnosis and functional outcomes.** Our prior work has demonstrated disparities in the accuracy of the most commonly used ASD<sup>1</sup> and in who is referred after a positive ASD screen<sup>2</sup>. These differences undoubtedly contribute to disparities in rates and age of ASD diagnosis and intervention, which will impact the ultimate outcomes of interest. Not accounting for these disparities in the primary analysis and analytic framework will lead to inaccurate estimates of effects. Because disparities currently exist, they should be treated as components of the analytic framework, not secondary to it, and thus should be included as moderators of the primary effects.
- 2. Developmental surveillance also contributes to autism identification and diagnosis.** Our prior work<sup>1</sup> found that 61% of children who completed universal screening in pediatric primary care who were ultimately diagnosed with ASD (n=454) had a negative ASD screen. Many of these children were thus identified by other means, likely in large part through ongoing surveillance efforts in primary care. The recently reissued clinical practice guidelines for ASD<sup>3</sup> emphasized the importance of pairing developmental surveillance with screening. Therefore, inclusion of developmental surveillance in the analytic framework may more accurately reflect real-world practice<sup>4</sup>.
- 3. If screening is not done universally, it is likely driven in large part by level of caregiver concern. Therefore, evaluation of the accuracy of caregiver observations and reporting of ASD-related and general developmental concerns would be important to consider.** Prior work in which we scrutinized electronic medical records to identify documentation of parental concerns found that nearly 15% of children who screened positive and were later diagnosed with ASD had no reported parental concerns by the time of the positive screen (Fleming et al,

unpublished). Without universal screening, these children would otherwise have had delayed or missed diagnoses. Therefore additional evaluation of alternative approaches to universal screening, including relying on caregiver-reported concerns to drive assessment referrals, is an important additional question to consider.

- 4. Referral decisions by clinicians (both aided by screening results and independent of screening results) rely on clinical observations and judgement. If screening is not completed universally, it will be driven in part by clinical decisions, which are shown to be inaccurate.**

Our group has found that clinicians frequently rely on other clinical information when making decisions about when to refer a child for intervention and evaluation, even after a positive screen<sup>2</sup>. However, prior work has found that brief observations (such as those available to a general pediatrician) are inaccurate<sup>5</sup>. Additional information about the role and accuracy of clinical decision-making in ASD identification is needed to determine the value of universal screening.

- 5. Screening for autism spectrum disorder may facilitate the identification of other developmental conditions of concern. The benefit of ASD screening may therefore have benefits beyond those appearing in the proposed analytic framework.** Our group has conducted and contributed to research that has found that the majority of children (72% in Guthrie et al, 2019<sup>1</sup>; 100% in Feinberg et al, 2021<sup>6</sup> and Kuhn et al, 2021<sup>7</sup>) who screen positive for ASD end up with another developmental diagnosis. These also require additional evaluation and intervention, but the benefits accrued to children who are identified with other developmental conditions as a result of a positive ASD screen would not be ascertained in the current proposed analytic framework.

Signed,

Kate E. Wallis, MD, MPH  
Amanda Bennett, MD, MPH  
Marsha Gerdes, PhD  
Whitney Guthrie, PhD.  
Susan E. Levy, MD, MPH  
Judith S. Miller, MD, MPH

## References:

1. Guthrie W, Wallis K, Bennett A, et al. Accuracy of Autism Screening in a Large Pediatric Network. *Pediatrics*. 2019;144(4).
2. Wallis KE, Guthrie W, Bennett AE, et al. Adherence to screening and referral guidelines for autism spectrum disorder in toddlers in pediatric primary care. *PLoS One*. 2020;15(5):e0232335.
3. Hyman SL, Levy SE, Myers SM. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. *Pediatrics*. 2019:e20193447.
4. Wallis KE, Guthrie W. Identifying Autism Spectrum Disorder in Real-World Health Care Settings. *Pediatrics*. 2020:e20201467.
5. Gabrielsen TP, Farley M, Speer L, Villalobos M, Baker CN, Miller J. Identifying autism in a brief observation. *Pediatrics*. 2015;135(2):e330-338.
6. Feinberg E, Augustyn M, Broder-Fingert S, et al. Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet. *JAMA Pediatrics*. 2021;175(3):243-250.
7. Kuhn J, Levinson J, Udhmani MD, et al. What Happens After a Positive Primary Care Autism Screen Among Historically Underserved Families? Predictors of Evaluation and Autism Diagnosis. *Journal of Developmental & Behavioral Pediatrics*. 2021; Publish Ahead of Print.