Universal Autism Screening for Toddlers: Recommendations at Odds

RUNNING HEAD: Screen Toddlers for Autism

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Letter to the Editor

Universal Autism Screening for Toddlers: Recommendations at Odds

In August 2015, the United States Preventive Services Task Force (USPSTF) released its draft recommendation statement about screening for autism spectrum disorder (ASD) in young children (USPSTF, 2015). They found insufficient evidence to recommend for or against universal ASD screening. However, this recommendation is at odds with the policy statement from the American Academy of Pediatrics (AAP, 2006) and the clinical report that followed (Johnson & Myers, 2007) that recommended a three-pronged approach to developmental surveillance and screening for all children, including autism-specific screening at the 18 and 24 month well-child care visits.

According to the US Census, there are more than 20 million children under the age of 5 in the United States. Using the Centers for Disease Control and Prevention (CDC) prevalence estimates of 1 in 68 children being diagnosed with autism, nearly 300,000 of these children will have autism. Although the USPSTF report found evidence for valid screening tools to detect ASD in toddlers and evidence that early intervention has positive effects on prognosis for children, they concluded that the lack of studies showing long-term outcomes from ASD screening means that there is insufficient evidence for universal toddler screening for ASD. We disagree. It is important to develop a body of research showing long-term health-related outcomes from screening, but waiting until that literature is complete does a disservice to the thousands of toddlers in need of screening and early detection with each passing year.

The most significant concern about the Task Force's conclusion is its over-emphasis on the limited data from treatment studies, in particular, on the observation that published studies have not systematically examined children whose ASD was detected through primary care screening. It is true that the literature lacks large population-based studies of outcomes of children detected through screening and referred to early intervention. However, the majority of the good and fair quality early intervention studies reviewed in the evidence report found improvements in the treatment group; more specifically, children who start treatment earlier have the best outcomes (MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Orinstein et al., 2014), including children receiving intervention in publicly-funded, community-based agencies (Smith, Klorman, & Mruzek, 2015). Children detected through screening are expected to be younger than those detected through other means, which makes it likely that intervention will be even more successful than in older samples. Furthermore, there is no indication that children whose ASD is detected through population-based screening will respond less to early intervention than children who are identified through other means. Indeed, given that recent treatment studies have enrolled younger children, it is possible that one strategy to promote enrollment in treatment research is via primary care screening. Given the evidence that screening detects autism in toddlers, and the growing literature about the effectiveness of early intervention, scientists must consider ethical questions about withholding early detection and intervention from children who are expected to benefit from it. The Task Force's conclusion that it is not possible to generalize from treatment studies of other populations of young children with ASD is overly conservative.

It is promising that this report hopes to promote much needed research to address these gaps in the ASD screening literature. However, the potential for this benefit will be mitigated by the harm this report may do to the well-being of undiagnosed toddlers with ASD in the US today. If

policy makers use this report to decrease efforts to facilitate universal ASD screening, if insurance companies reduce or eliminate payment to physicians/clinicians when they screen patients, or if physicians decrease their efforts to screen for ASD, children with ASD – and perhaps children with other neurodevelopmental issues – will certainly suffer both in the short term and over the lifespan. Given the favorable impact of early intervention services, with minimal to no risk to children who screen positive in primary care, limiting or decreasing universal screening will have deleterious long term effects on children with or at risk for ASD. Additionally, many professionals who work with families and young children are counting on universal screening as a key mechanism for the elimination of existing racial/ethnic and class disparities in the age at ASD diagnosis and start of intervention (e.g., see Herlihy et al., 2014); this recommendation will undermine the work being done by so many to eliminate racial/ethnic and class disparities.

We also are concerned about the wording used at the beginning of the clinical considerations section (and repeated at the end of the discussion), where it states that "This recommendation [of insufficient evidence for ASD screening] applies to **asymptomatic children**… and for whom no concerns of ASD have been raised..." While we understand that the Task Force is differentiating universal population-based screening (referred to as Level 1 screening) from follow-up procedures for children already identified as being at-risk for ASD (also known as Level 2 screening), the language of this statement is less relevant, and perhaps confusing, for a behaviorally-defined disorder that inherently cannot be detected until children are symptomatic. Given the evidence that surveillance strategies do not detect ASD symptoms (e.g., Gabrielsen et al., 2015; Robins et al., 2014), it is crucial to rely on screening to facilitate symptom recognition in previously unidentified children. This is a different process than seeking to detect biomarkers

that may precede symptom recognition. A more accurate statement would be that this recommendation applies to children for whom ASD has "**not previously been recognized.**"

It also is of concern that the USPSTF statement noted that there are few studies of the prevalence of screening for ASD. Five papers in the past decade have surveyed physicians about screening practices (Arunyanart, Fenick, Ukritchon, Imjaijitt, Northrup, & Weitzman, 2012; Dosreis, Weiner, Johnson, & Newschaffer, 2006; Gillis, 2009; Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011; Zuckerman, Mattox, Donelan, Batbayar, Baghee, & Bethell, 2013), and four of these have specifically asked about ASD screening (Arunyanart et al., 2012; Dosreis et al., 2006; Gillis, 2009; Zuckerman et al., 2013). Physicians reported far from universal use of broad developmental screening tools (41-82%) and ASD-specific screening tools (8-59%) during well-child visits. Furthermore, fewer than 20% of physicians reported following the AAP guidelines of ongoing developmental surveillance, broad developmental screening, and ASD-specific screening (Arunyanart et al., 2012); given that no screening tool can have perfect sensitivity and specificity, the combination of screening and surveillance strategies is likely to be the most effective method to detect ASD early. It is unfortunate that the committee did not address these contributions to our understanding of current screening practices.

In conclusion, we are in full agreement that ASD screening is effective in detecting toddlers at risk for ASD. In fact, the task force's evidence report highlights that in primary care screening studies, 50-60% of ASD cases detected through ASD screening were found *before* parents or physicians had any concerns (AHRQ, 2015, page 53); although the screening tools cannot have perfect sensitivity and specificity, children detected through screening are likely to be younger than children detected through other strategies (e.g., see Guevara, et al., 2013). We also agree that additional research, including larger, well-controlled trials of children identified through

screening is needed to fully evaluate the effects of early detection and treatment of ASD and to boost the support for population-based ASD screening. However, we believe strongly that the evidence that ASD can be effectively detected by primary care screening – in many cases before concerns have been identified – coupled with an imperfect but growing and compelling body of evidence demonstrating positive effects of ASD-specific early intervention, is more than sufficient to recommend this practice. Access to early intervention services will be delayed if early screening efforts are decreased as a result of the task force's recommendation. Should there be a reduction in primary-care based screening as a result of the task force report, thousands of children with ASD will experience delays in the diagnosis and initiation of early intervention services that may impose lifelong limitations to their quality of life.

Compliance with Ethical Standards

This is a letter to the editor. It is a commentary, and does not involve any data. Therefore, it does not require Institutional Review Board approval or informed consent. The Author Note, uploaded separately, lists conflicts of interest and funding source. They are not included here in order to keep this document deidentified.

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