

August 31, 2015

U.S. Preventive Services Task Force
540 Gaither Road
Rockville, MD 20850

Dear USPSTF Members:

On behalf of the Association of University Centers on Disabilities (AUCD), we write to comment on the draft recommendation statement on screening for autism spectrum disorders (ASD) in young children.

We agree with the need for high quality research to address the gaps identified in the draft recommendation statement, including studies that evaluate the outcomes of children identified through screening. We suggest that the Interagency Autism Coordinating Committee (IACC) should respond to these research gaps; in addition, the National Institutes of Health (NIH) should be sufficiently funded to provide the support needed to ensure that the appropriate studies can be undertaken.

Until this research can be conducted, however, clinicians need clear guidance for practice and we must use the best evidence available to develop this. Based on studies included in the systematic evidence review prepared for the USPSTF, it is known that autism screening with standardized tools is effective, identifies children earlier than parental or clinician concern, and that screened children have earlier ages of referral and diagnosis. Children screened and identified receive higher levels of service than those without a diagnosis. The scientific review found evidence of the benefits of high quality early intensive behavioral and developmental interventions for young children with ASD in clinically-referred samples, some of whom may have potentially been identified through screening. There is evidence suggesting that earlier intervention may result in better outcomes. Further, there may be meaningful outcomes for children and families affected by ASD that are not addressed by the systematic review. The task force concluded that the potential harms of screening and behavioral treatment are no greater than small.

Given the evidence from the systematic review and recognizing its gaps, we have sufficient reason to believe that there are important benefits to universal screening for autism in young children and that these outweigh any potential risks. Hence AUCD continues to support the recommendation for universal autism screening with standardized tools at 18 and 24 months in conjunction with general developmental screening and surveillance, consistent with the American Academy of Pediatrics' Bright Futures Guidelines.

AUCD has serious concerns about unintended negative consequences of this draft recommendation statement for children and families affected by ASD such as the potential for delayed diagnosis and treatment resulting in less than optimal outcomes. In the absence of a clear endorsement for or against screening, we suggest that the task force include a statement in its recommendation that clinicians and other providers who screen young children should look to their professional organizations for guidance on conducting universal autism screening at this time.

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The Association of University Centers on Disabilities (AUCD) advances policies and practices that improve the health, education, social and economic well-being of people with disabilities, their families, and their communities through a national network of university-based centers in every State and territory. Network members consist of 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Intellectual Developmental Disabilities (AIDD), 43 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB), and 15 Developmental Disability Research Centers (IDDRC), most of which are funded by the National Institute for Child Health and Development (NICHD). AUCD member centers are actively engaged in early identification and intervention for children with ASD through training, research, and service delivery.

We appreciate the opportunity to provide comment on this draft recommendation statement. Please do not hesitate to contact Dr. Jamie Perry at 301-588-8252 with questions.

Sincerely,



Andrew J. Imparato, JD
Executive Director, AUCD



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