

Hi, I'm a developmental Pediatrician and professor of pediatrics at OHSU. I have been the healthcare representative on the Oregon Commission on Autism Spectrum Disorder (OCASD) and am still a member of 2 of its committees, the Screening Identification and Assessment (SIA) committee and the Healthcare committee. I'm writing to discuss SB 365 and now SB 696 and the wording as to who can make the diagnosis of autism (I will use the term autism spectrum disorder or ASD). I have discussed this issue at some length with members of the Screening Assessment and Identification committee of the OCASD and Paul Terdahl, parent and advocate.

The current law says:

(2) A health benefit plan shall provide coverage of:

(a) The screening for and diagnosis of autism spectrum disorder by a licensed neurologist, pediatric neurologist, developmental pediatrician, psychiatrist or psychologist, who has experience or training in the diagnosis of autism spectrum disorder; and

(5) Coverage under this section may be subject to utilization controls that are reasonable in the context of individual determinations of medical necessity. An insurer may require:

(a) An autism spectrum disorder diagnosis by a professional described in subsection (2)(a) of this section if the original diagnosis was not made by a professional described in subsection (2)(a) of this section.

The term "screening" should not be part of the statement. The statement should be specific for diagnosis. Screening refers to the use of a brief tool to identify children at high risk for a developmental disorder including autism. The Oregon Pediatric Society, myself, and others have worked for several years to train primary care physicians, public health nurses, child care providers and others around the state in the regular use of appropriate screening tools. A child who fails a screening test does not have a diagnosis but rather a red flag that he or she needs to be referred for further evaluation to make a diagnosis.

The current list of approved professionals who can make a diagnosis is counter to the recommendations of the Oregon Commission on ASD and national and international experts on the diagnosis and treatment of young children with ASD. I am currently attending the

International Meeting for Autism Research (IMFAR) in Salt Lake City, and it was once again emphasized at this meeting that an accurate diagnosis depends on evaluation by an interdisciplinary team. The OCASD also recommends a diagnostic evaluation by an experienced interdisciplinary team. Evaluation by a single discipline has a high rate of error especially for children with ASD who do not have an associated overall developmental delay or intellectual disability. Several of the professionals listed in the current statement, e.g., neurology, child neurology and psychiatry rarely see children with ASD in their offices and are very likely not up to date on appropriate evaluation procedures.

The potential downside of requiring an interdisciplinary team evaluation is the long wait lists for evaluation by an experience medically-based team such as the one at OHSU. I am currently medical consultant to a Maternal and Child Health funded project to create and support community-based interdisciplinary teams to identify young children with ASD. We are currently working in 8 and soon to be 9 communities. Our teams include a pediatrician, a mental health provider, the educational staff who are currently doing autism eligibility evaluations for Early Interventions and schools, and a parent advocate. Our goal for these teams is to provide a comprehensive, valid and timely diagnosis of young children in or close to their home community. The mental health provider on several of our teams sees all of the kids referred to the team and in others they evaluate children only on referral from other team members. OHSU staff provide initial training to team members and on-going support through every other month webinars, development of materials, identification of resources, and a newly formed online discussion group. The teams do need to follow the OARs for the timeline to complete the educational evaluation. Capacity is an issue for a few of the sites such as Salem and Medford and we are currently addressing that by training additional health and mental health care providers for the teams. I would be happy to provide further details on request. In short, our teams provide a model for timely interdisciplinary evaluations that could be expanded to address the problem with wait lists at medical centers. The SIA committee has endorsed the process we are following with these teams.

The following language has been approved by the SIA committee of the OCASD to replace the current statement on who can make the diagnosis:

“The diagnosis of an autism spectrum disorder is best determined by an interdisciplinary team following a diagnostic process as described in the administrative rules; or by a developmental pediatrician, pediatrician, child psychiatrist, psychiatrist, pediatric neurologist, neurologist, internist or clinical psychologist who has had prior training and experience and demonstrated competence in the diagnosis of autism spectrum disorder.”

This statement does allow for the diagnosis by a single discipline as an alternative but one who has had prior training and has demonstrated competence. To me this is an acceptable compromise. Pediatricians such as Debra Koutnik in Ashland who are not boarded in developmental pediatrics but do have exceptional skills, knowledge and experience with children with developmental disorders including ASD should be included in the statement as to who can make a diagnosis.

I would be happy to discuss this issue further and provide details about our community-based autism identification teams on request.

Robert Nickel, MD

Developmental Pediatrician

Professor of Pediatrics

OHSU