Oregon Commission on Autism Spectrum Disorder
4506 SE Belmont Street, Suite 101, Portland, OR 97215 - staff@orcommissionasd.org

POSITION PAPER ON ASD EVALUATIONS DURING COVID-19 SOCIAL DISTANCING MEASURES

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1. Introduction. The COVID-19 pandemic has resulted in the imposition of stay at home orders and/or social distancing practices that are currently in effect throughout Oregon. Although some restrictions are being lifted in some parts of the state, social distancing practices could well have to be maintained for a period of several years and greater limitations may have to be reimposed periodically in some areas. This Position Paper was prepared to give ***initial*** guidance on best practices for the evaluation of autism spectrum disorder (ASD) while stay at home/social distancing practices are in effect. It was prepared by an interdisciplinary group of ASD experts on the Commission's Screening, Identification, and Assessment Work Group, including professionals from health care, education, and social services. ***We expect to update this guidance in a few months and periodically thereafter in order to share evolving best practices*** with all of our Oregon stakeholders. Prompt and accurate identification remains a high priority for the Oregon Commission on Autism Spectrum Disorder (OCASD).

2. Summary of Recommendations. Accurate identification of ASD, whether through medical diagnosis or educational eligibility determinations, remains a primary goal in order to ensure that individuals receive services that address their needs. The initial OCASD recommendations for identification of ASD (2010)[1] are relevant and appropriate during the pendency of stay at home/social distancing restrictions. Many elements of an ASD evaluation can be completed remotely. Telehealth/telemedicine assessments, however, cannot reliably substitute for required in-person assessments for ASD. Evaluators should therefore not rely exclusively on remote assessments to determine whether an individual has ASD. Rather, evaluators should complete those portions of the evaluation that can reliably be completed remotely but wait to provide a diagnosis or assign a special education eligibility until a time when the individual can be seen in-person, without extensive use of face masks or other protective equipment that might interfere with the individual's social communication and other behaviors of interest. At this time OCASD recommends against the use of preliminary diagnoses or eligibility determinations using partial or incomplete information.

2. Prior OCASD Evaluation Recommendations

In 2010, OCASD issued recommendations to the Governor of Oregon. The recommendations included the components necessary for an accurate identification of ASD. These components included: (1) an interdisciplinary evaluation with identification of ASD based on current DSM criteria, (2) a diagnostic interview, (3) a standardized observation, using research-based, ASD specific instruments,[2] (4) an observation in an unstructured activity, (5) a developmental assessment using the best available standardized tools,[3] (6) an evaluation of both hearing (if none has been done within the past 6-12 months), and vision, if indicated, and (7) a written document detailing the outcome of the evaluation. The OCASD-recommended evaluation components remain consistent with those recommended by the American Academy of Pediatrics[4]. Most of these elements have also been incorporated into the current special education administrative rules for ASD evaluations.

3. Limitations of Online Testing and Observations

During these unprecedented times, brought about by COVID-19 restrictions on in person, face to face interactions, the ability to complete ASD evaluations has been significantly curtailed. Most activities, whether in education or medicine, are being performed remotely. There is pressure to use remote technology for the identification of ASD as well. **However, OCASD strongly recommends against exclusive reliance on remote assessments** for the following reasons:

a) The identification of ASD requires that evaluators have the opportunity to observe subtle differences in nonverbal communication and reciprocity, as well as repetitive language and body use that may not be readily observable remotely. For example, the position of the camera in relation to the screen distorts interaction and eye contact, even among individuals without ASD or other mental health conditions.

b) Most instruments used in ASD evaluations have not been normed or validated to be used via telehealth or any distance administration.[5]

c) Remote testing that has been validated requires a trained on-site proctor to be in the room with the person being evaluated. At this time, it is rarely possible for a trained on-site proctor to be in an individual's home. Evaluators should adhere to the proctoring requirements for any instruments they administer remotely, and should contact the publisher directly if they are in doubt.

d) Parents or other family members cannot act as proctors. Most standardized tests are designed to be administered with the individual alone with the examiner, and when parents are present, they are not to otherwise engage unless directed by the examiner.

e) The technology involved in telehealth assessments can interfere with the evaluation process. Individuals with ASD may react differently and in unanticipated ways during such evaluations.

Currently, there are several evaluation methods for very young children (under age 3) that are being evaluated for accuracy, reliability, and validity. These include the Systematic Observation of Red Flags through Florida State University and the TELE-ASD-PEDS out of Vanderbilt University. These evaluation methods do not yet have adequate normative information or strong enough evidence of reliability and validity to be used currently, but may be considered for future use. Also, they do not address the evaluation needs of individuals over age 3, who constitute the majority of individuals referred for ASD evaluations.

4. Impact of Stay at Home Orders and Social Distancing on Families. It has been widely reported that stay at home orders and social distancing have created enormous stress and an increase in mental health problems for many people, effects that are expected to outlast stay at home orders for some time. Added stress can affect the behavior and memory of both the individual being evaluated and family members. Evaluators should attempt to understand and consider the impact of stress and other attendant mental health conditions on individuals being evaluated and their families. Compassionate explanation of the reasons for delay may help to reassure individuals and families who are understandably eager to complete the evaluation and obtain services.

5. Recommendations During Pendency of Stay at Home and Social Distancing Restrictions. OCASD is committed to both timely and accurate identification of all individuals suspected of having ASD. The identification of ASD made while stay at home/social distancing restrictions are in place should be as accurate, reliable, and valid as an identification of ASD made at any other time. **Therefore, OCASD recommends that the determination of whether an individual has ASD should be postponed until instruments designed for in-person administration can be administered in-person and until trained staff can make an adequate in-person observation of the individual.**

Portions of the evaluation that do not require in-person administration of standardized instruments may be completed online via an encrypted/secure telehealth system or educational platform. These include:

a) the diagnostic interview/developmental history,
b) unstructured observations, and
c) some behavior checklists that are used in the evaluation process, such as the Autism Spectrum Rating Scale or Behavior Assessment System for Children, 3rd Edition

OCASD does not support "preliminary" identification of ASD based on partial or incomplete information. The risk of an inaccurate identification, or of missing ASD when it is present, is too great. For special education purposes, it may be appropriate to give a child up to age 9 an eligibility of developmental delay, if the team and the family agree that it is urgent to make the

child eligible for special education services immediately. In that event, however, OCASD strongly recommends completion of the additional elements of the ASD evaluation when it is possible to perform in person evaluations safely.

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[1] Oregon Commission on Autism Spectrum Disorders (2010). Report to the Governor. https://www.orcommissionasd.org/cms/lib/OR50000467/Centricity/Domain/20/OCASD_2010_Report_FINAL1.pdf

[2] The Commission identified the following instruments as meeting these criteria: the ADOS, ASIEP-3 (interaction assessment and sample of vocal behavior module), and the CARS-2.

[3] The developmental assessment should include the following: (a) cognition: thinking and reasoning (b) adaptive functioning (c) functional communication, including speech and language skills (d) sensory processing, and (e) social and emotional skills.

[4] Hyman, Susan L., Levy, Susan E., & Myers, Scott M. AAP Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics (2020). Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics*, 145(1):e20193447. https://DOI.org/10.1542/peds.2019-3447.

https://pediatrics.aappublications.org/content/145/1/e20193447

[5] The Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2) is considered to be one of the most accurate ASD evaluation tools. The publisher of the ADOS-2, Western Psychological Services, discourages the use of the ADOS-2 via telehealth platforms. It also discourages the administration of the ADOS-2 while wearing a face mask or shield, or through a protective barrier such as plexiglass. Email from Kailey Bax, Product Support Specialist, Western Psychological Services, to Darryn Sikora, Providence Children's Development Institute (May 20, 2020) (available on request).

Similarly, the Childhood Autism Rating Scale, 2nd Edition (CARS-2), often used in educational settings, is an OCASD recommended observation tool. In order for the CARS-2 to be valid, the following guidelines must be adhered to:

1) To complete CARS-2 ratings, convergent information from multiple sources, MUST be used. Parents or teachers should NOT complete the forms.
2) Only well-informed professionals should complete the ratings. The professional must have a good understanding of each of the criteria used for each rating AND BE IN A POSITION TO COLLECT INFORMATION FROM MULTIPLE SOURCES, including direct observation, parent and teacher interview, prior assessments of cognitive functioning and adaptive behavior, and information from the CARS-2 Questionnaire for Parents/Caregivers.
3) CARS-2 ratings should be considered as only one part of a multimodal, multidisciplinary decision-making process.
4) Direct observation and a developmental history MUST ALWAYS be included in the assessment process.