

SCREENING, IDENTIFICATION & ASSESSMENT (SIA)

SUMMARY OF ISSUES:

Oregon lacks a coordinated system for early identification of children with ASD. Not every young child in Oregon receives the recommended screening for autism.

A coordinated screening and referral system must include many types of service providers, including health and educational professionals, public health nurses, and child care providers. Many families don't have the information they need to know when evaluation is warranted. Early identification and referral for services is important to the success of young children with ASD.

Currently, there is neither a consistent process nor a common criteria for making the identification or diagnosis of ASD. Individuals who are not properly identified may not receive the services they need. Individuals who are not properly identified may receive services they don't need, thereby wasting precious time for the individual and resources that could be better used for the benefit of other individuals. Inaccurate identification distorts public policymaking, service planning, and allocation of finite resources.

The Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association is the definitive source for specifying the characteristics which must be present for the diagnosis of autism in health care settings within the United States. The DSM does not describe all of the characteristics of an individual with autism, but it does describe the characteristics which must be present to ensure that the condition is autism rather than some other condition. Frequently individuals with autism experience co-occurring conditions and those must also be identified. The DSM is periodically updated. The current version is DSM IV; the DSM V is expected in 2013.

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The following definitions will apply concerning screening, identification and assessment and related topics in this report:

Screening is the use of standardized tools at specific intervals (snapshot) to evaluate all members of a population. Screening may result in further evaluation.

Surveillance is an ongoing process of identifying individuals at risk, based on red flags, in the context of unfolding development throughout the lifespan. It is especially pertinent to individuals who were not identified through early screening.

Interdisciplinary evaluation means the process through which several practitioners in different disciplines participate in determining whether or not an individual has an ASD using DSM criteria.

Identification refers to the determination of whether an individual has the characteristics of ASD. In a medical setting, this would also be called a diagnosis.

Assessment refers to additional steps beyond identification, for the purpose of determining eligibility for services.

SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC)

Goal SIAC 1: Primary care providers (PCPs) screen all children for an ASD by their second birthday.

Recommendations:

SIAC 1.1 Support statewide expansion of the Oregon Pediatric Society's START Program (Screening Tools and Referral Training), which provides on-going training on screening young children for ASD and referral to community services and/or education services including Early Intervention / Early Childhood Special Education. The START project helps health care practices implement the developmental and behavioral screening guidelines of the American Academy of Pediatrics (AAP).

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Implementation Activities:

SIAC 1.1.1 Encourage collaboration between START and the Community Connections Network of the Center for Children and Youth with Special Health Care Needs (CYSHCN) to identify local physician “champions” who will help expand START to rural areas through a train-the-trainer model.

SIAC 1.1.2 Recommend the START program incorporate public awareness and educational materials regarding ASD.

SIAC 1.1.3 Ensure training programs and materials on screening for ASD are based on current research and are updated regularly to reflect best practices.

SIAC 1.1.4 Include the participation of Federally Qualified Health Care medical staff in START training.

Recommendations:

SIAC 1.2 The number of family practitioners, physician assistants and nurse practitioners, psychiatrists, and other mental health professionals who regularly screen young children for developmental and behavioral problems in their practice will be increased.

Implementation Activities:

SIA 1.2.1 Work with the Oregon Pediatric Society, Oregon Chapter of Family Physicians, Oregon Rural Practice Research Network (ORPRN), Oregon Primary Care Association (OPCA), Oregon Council on Child and Adolescent Psychiatry (OCCAP), Federally Qualified Health Centers (FQHCs), and state professional organizations of physician assistants and nurse practitioners to improve screening rates.

SIA 1.2.2 Ensure that public and private payers will reimburse health care professionals for recommended screening activities.

SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC) CONTINUED

Goal SIAC 2: Public and private agencies, organizations and individuals increase surveillance and referral for identification of young children who may have an ASD and/or co-occurring conditions. Families of young children are knowledgeable and empowered to appropriately seek screening and evaluation services for a potential identification of ASD and/or co-occurring conditions.

Recommendations:

SIAC 2.1 Public and private organizations and advocacy groups will work to develop a statewide public awareness program specific to the early recognition of and screening for ASD.

Implementation Activities:

SIAC 2.1.1 Review existing materials by the Help Autism Now Society (HANS) and the Center for Disease Control (CDC), and develop new materials as needed.

SIAC 2.1.2 Include public awareness information in materials provided by Oregon Health Plan, State Children's Health Insurance Program and Healthy Kids, for families whose children do not have a primary care provider.

SIAC 2.1.3 Engage individuals with ASD and their families in the design of public awareness activities and materials related to screening and early recognition.

SIAC 2.1.4 Distribute information on the importance of early identification of ASD, with training and resources available to health care, education and other providers involved in screening, referral and identification.

SIAC 2.2 Screening and early recognition of ASD will be increased by organizations which serve young children and their families, including Oregon Pre-K, Healthy Start, Babies First, Head Start, child care providers, and others.

SIAC 2.3 Improve the early recognition and referral for screening of young children with ASD in migrant families and other cultural groups.

Implementation Activities:

SIAC 2.3.1 Distribute public awareness materials in Spanish and other languages through appropriate organizations such as community centers and Federally Qualified Health Centers (FQHC).

SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC) CONTINUED

Recommendations:

SIAC 2.4 The identification of co-occurring conditions will be improved.

Goal SIAC 3: Collaboration and coordination among individuals, families, and public and private agencies involved in screening and early identification for ASD is improved.

Recommendations:

SIAC 3.1 Partnerships between local primary care providers and education programs will be strengthened and expanded.

Implementation Activities:

SIAC 3.1.1 Develop and use standard forms for improving communication between the education system and health care providers, such as a standard referral form.

SIAC 3.2 Increase the collaboration between local school districts and other community providers to improve Child Find and other referral activities.

SIAC 3.3 Support the implementation of the Child Health Profile or similar interactive database by DHS to improve coordination of care among health care providers and public health nurses (expansion of the ALERT immunization database based on Vermont's model).

Goal SIAC 4: Identification is standardized, coordinated, efficient and timely. The resulting identification will be accepted universally and across systems in Oregon as a part of the eligibility determination for services. See Diagram SIA1.

Recommendations:

SIAC 4.1 DSM criteria will be used for all identifications.

SIAC 4.2 The identification will be made through an interdisciplinary evaluation.

SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC) CONTINUED

SIAC 4.3 The standard evaluation for the identification of an ASD will include at least the following elements:

- A. Diagnostic interview, including family history, with pertinent people such as child/person, parent/caregiver, and education staff.
- B. Standardized observation using research-based, autism-specific instrument(s). Currently, the ADOS, ASIEP-3 (interaction assessment and sample of vocal behavior module), and CARS-2 meet these criteria. This list will be updated periodically by the entity responsible for best practice (see Goal SIAC 5).
- C. Observation of the individual in unstructured activity, to include at least one observation outside of the team evaluation setting, which might include any of the following:
 - a. Familiar setting
 - b. Unfamiliar setting
 - c. Unstructured peer interaction
 - d. Unstructured independent activities
- D. A developmental assessment, using the best available standardized tools, (based on current research and updated regularly to reflect best practice), appropriate to the age and developmental level of the individual, for:
 - a. Cognition: thinking and reasoning
 - b. Adaptive functioning
 - c. Functional communication, including speech and language skills
 - d. Sensory processing
 - e. Social and emotional skills
- E. A formal hearing test for those up to age 5, for the first evaluation, if none has been done in the previous 6-12 months AND one or more of the following is true:
 - a. No newborn screen was done, or the child failed a screen without follow up
 - b. There is a family history of progressive hearing loss; or
 - c. There is a recent history of recurrent ear infections or persistent serous otitis (middle ear fluid). *Note:* A hearing assessment should be appropriate to the age and developmental level of the individual.
- F. Vision screening, if indicated.
- G. A Once identification has been made; reports will be made available to caregivers in accessible language and format, with specified content areas included regarding the findings.
- H. Once identification has been made, there will be a “starter pack” of information for families regarding next steps and available resources.

SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC) CONTINUED

SIAC 4.4 The identification team as a whole must possess at least the following specific knowledge elements for applying the DSM criteria for identification of individuals with an ASD:

- A. Typical child development
- B. Atypical child development
- C. Psychopathology appropriate to the age of the person being evaluated and sufficient to differentiate an ASD from other conditions (such as intellectual disabilities, anxiety disorders, reactive attachment disorder, ADHD, and mood disorders).
- D. Formal (structured) and informal (observation/interview) assessment practices.
- E. Characteristics of ASD appropriate to the age of the person being evaluated.
- F. Assessment tools/methods for ASD and differential identification sufficient for referral for further evaluation.
- G. Family and environmental dynamics/systems (e.g. maternal depression, abuse, culture).
- H. Knowledge sufficient to identify red flags indicating need for further referral.

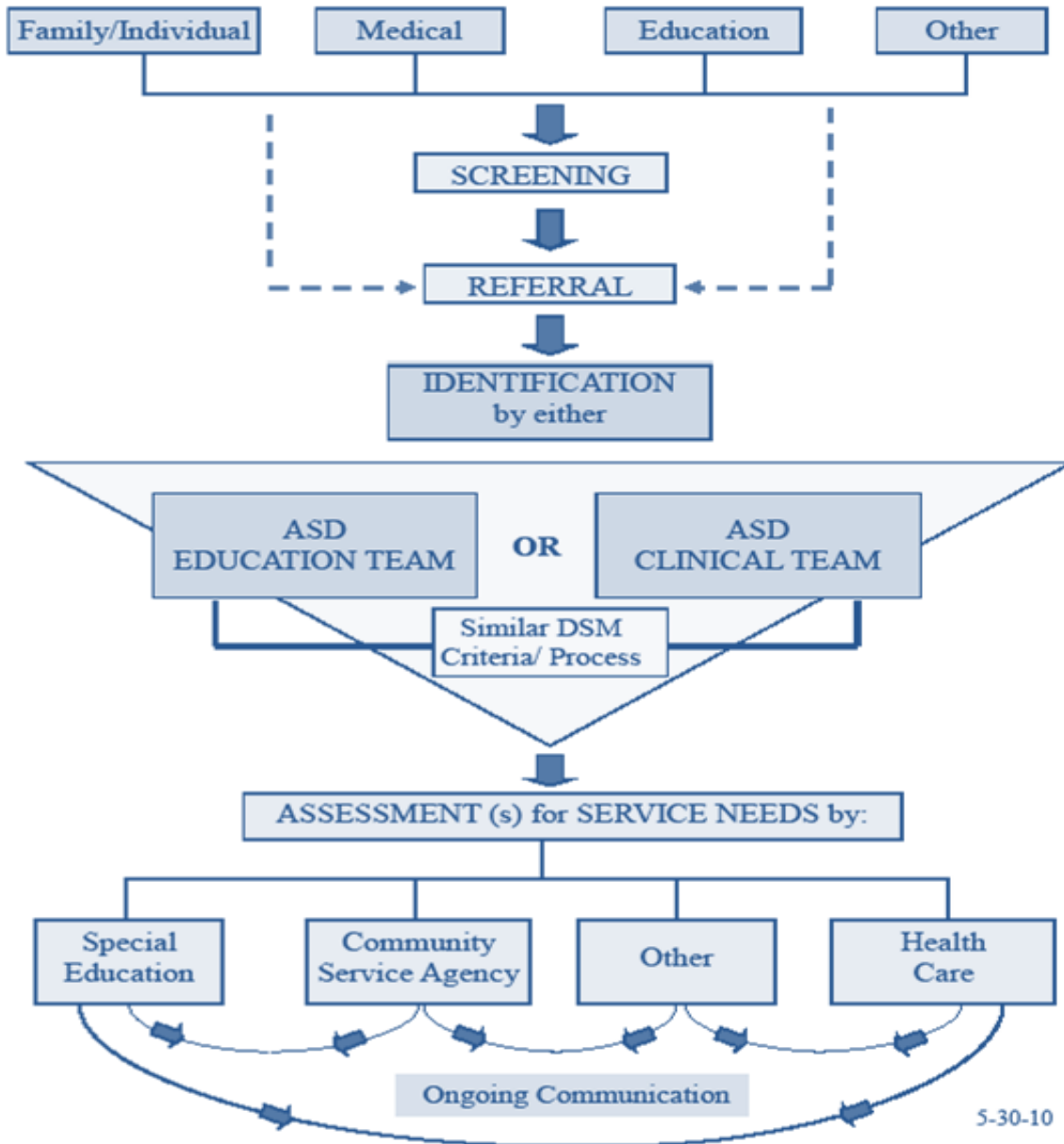
Goal SIAC 5: An entity is identified to assume responsibility for dissemination of evolving best practice regarding ASD screening and identification.

Goal SIAC 6: There is an identified process for determining which children need to be re-evaluated after implementation of these recommendations, and providing appropriate follow up.



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DIAGRAM SIAC 1: SCREENING & REFERRAL, IDENTIFICATION & ASSESSMENT FLOWCHART



5-30-10

IDENTIFICATION AND ASSESSMENT: ADULTS (IAA)

Goal IAA 1: Older children and adults with ASD are appropriately identified and referred for evaluation.

Recommendations:

IAA 1.1 Information and resources on the identification of ASD in older children and adults will be incorporated in training programs for health care providers (primary care providers, medical specialists, and mental health professionals), the justice and corrections system, and education professionals (including student health centers at community colleges and universities).

Implementation Activities:

IAA 1.1.1 Develop best practices for an initial brief evaluation to be used in health care and education (to determine if a full evaluation is warranted). Include training materials and resources, as well as information regarding screening and identification. Engage individuals with ASD and their families in development of practices, materials and trainings.

Goal IAA 2: The identification evaluation is standardized, coordinated, efficient and timely, and will be performed with appropriate sensitivity to the social and emotional differences between adults and children. The resulting identification will be accepted universally and across systems in Oregon as a part of the eligibility determination for services.

Recommendations:

IAA 2.1 The standard evaluation process for individuals over the age of 18 (or emancipated), who are being evaluated outside of the education system, will be the same as provided above for children, with these changes:

- A. The individual being evaluated will give informed consent, even if the evaluation is initiated by someone else.
- B. The individual being evaluated is as involved in the evaluation process and decision-making as much as possible.

IDENTIFICATION AND ASSESSMENT: ADULTS (IAA) CONTINUED

- C. Developmental and medical history is provided by the individual and:
 - a. A family member and/or others who knew the individual in childhood (may be completed by phone), if possible.
 - b. Medical recommendations or other documentations.
 - c. Interview with the individual, if possible.
 - d. Interview with another adult who knows the individual well (partner, roommate, friend, caregiver), if possible.
- D. Standardized cognitive assessment, if not done in the previous 3 years.
- E. Communication assessment
 - a. Standardized, to evaluate for the presence of a language disorder, if not done in the previous three years.
 - b. Informal assessment of strengths and weaknesses associated with ASD.
- F. Standardized assessment of adaptive behavior, completed by the individual and with the consent of the individual being evaluated, other knowledgeable adults, preferably from multiple environments (such as home, school, and work), using an interview format, if possible, in person or by phone; or paper assessment form if interview is not possible.
- G. When additional information is needed for diagnostic clarification, informal observation may be part of the clinical evaluation, either in the clinic setting or outside of clinic, in a location agreeable to the individual (home, school, workplace, community, etc.).

Goal IAA 3: Resources are available to adults and their families both in seeking evaluation and in seeking to understand what to do after identification.

Recommendations:

IAA 3.1 Individuals and families will be provided with a “starter packet” (“You've just been diagnosed, now what?”) for newly diagnosed individuals and families. These will be available through clinicians, agencies, and the Internet. See community services sections for related recommendations.

IAA 3.2 There will be an online clearing house for official information regarding adults seeking diagnosis and services.

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NEXT STEP ACTIONS:

1. **Collaborate with START (Screening Test and Referral Training) of the Oregon Pediatric Society (OPS) to support on-going training of health care professionals in local communities on screening and identification of young children for ASD.**
2. **Collaborate with START of the OPS to support training on the identification of older children and adults with ASD in their next planned training program on identification of mental health disorders.**
3. **Collaborate with the Child Care Resource and Referral Network (CCRR), Early Head Start and Head Start to increase awareness of the early signs of an ASD and to increase the number of providers who use a formal screen for ASD with children in their programs.**
4. **Develop and implement a public awareness program on the importance of early recognition and identification of children with ASD. Families and individuals with ASD will be actively engaged in the development of the materials and program.**
 - a. **Distribute materials through insurance programs for kids including OHP, SCHIP and Healthy Kids**
 - b. **Distribute materials through health care offices, CCRR, Early Head Start/Head Start and others.**
5. **Work with ODE to redesign the medical statement to gain more useful information and to encourage collaboration between education and health care.**
6. **Work with ODE to begin training district, EI/ECSE, and regional staff to understand the components of the DSM for identification. Set up teams to receive training on the components of the proposed evaluations. Develop training modules using an expert team made up of members from both health care and education.**