# OREGON COMMISSION ON AUTISM SPECTRUM DISORDERS

## REPORT TO THE GOVERNOR

December 2010

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Dear Governor Kulongoski,

In accordance with your 2009 Executive Order 09-07, we are pleased to present you with the Report of the Oregon Commission on Autism Spectrum Disorder.

The Commission was charged to “engage stakeholders, to identify priorities, to promote the efficient use of limited resources, and to create and facilitate the implementation of a long term strategic plan.”

The following document reflects the many hours of work of over 100 individuals, including the thirteen appointed members of the Commission and volunteer subcommittee members, representing individuals with Autism Spectrum Disorder (ASD), family members, service providers, educators, physicians, academics, legislators, state staff, and advocates from around the state. Over 400 Oregonians provided comments and input.

We believe that this report provides an outline for moving Oregon forward to better serve Oregon’s growing population of individuals experiencing Autism Spectrum Disorder. In addition to the report itself, there is work that is going on as a result of the Commission and the subcommittees’ commitment to address the needs of individuals with ASD. It is most evident in the form of the collaboration and information sharing that is developing across agencies and programs.

Throughout the Commission’s recommendations, there are ideas for new activities, suggestions for doing things differently, and ways to do the same things, but do a better, more efficient job. Some of the recommendations in the report are identified as priority items which can be implemented without delay, many of which are already underway. There are many areas which require further development of goals, recommendations and implementation activities.

There is a strong commitment on the part of the many participants in the preparation of the recommendations to make certain this report is a living document that guides implementation activities and evolves as Oregon moves forward on behalf of individuals with ASD and their families.

Sincerely,

Marilyn H. Gense

Marilyn Gense, Chair

# EXECUTIVE SUMMARY

Oregon, like many states across the nation, has experienced a rapid increase in the number of individuals diagnosed with an Autism Spectrum Disorder (“ASD”). Autism Spectrum Disorders are a range of neurological disorders that most markedly involve some degree of difficulty with communication and interpersonal relationships, as well as obsessions and repetitive behaviors. As the term "spectrum" indicates, there can be a wide range of effects. Across Oregon, families, communities, schools, and social service agencies are struggling to address the diverse and complex needs of individuals diagnosed with ASD. Services to individuals with ASD are frequently fragmented and service delivery systems are inconsistent throughout the State. There is no coordinated effort for increasing the capacity to support individuals with ASD.

“Successful ASD treatment and support requires a more thoughtful, coordinated approach to funding, service development and delivery. To move Oregon forward, we must develop a means to provide accurate, current information to families and professionals regarding ASD interventions, services, supports, and expected outcomes. We must ensure that Oregon takes full advantage of the wealth of knowledge available about ASD and best practices for treating and supporting individuals with ASD. We must work to obtain the maximum benefit from the limited federal, state, and local resources available for individuals with ASD and their families.” - *Governor Ted Kulongoski on the creation of the Oregon Commission on Autism Spectrum Disorder*

The Oregon Commission on Autism Spectrum Disorder was created in 2009 through Governor’s Executive Order No. 09-07. The Commission was charged to “engage stakeholders, to identify priorities, to promote the efficient use of limited resources, and to create and facilitate the implementation of a long term strategic plan.”

The following document reflects the work of over 100 individuals, including the thirteen appointed members of the Commission and volunteer subcommittee members, and conversations with individuals with autism spectrum disorders, families, and other stakeholders from around Oregon.

Throughout the Commission's recommendations, there are ideas for new activities, suggestions for doing things differently, and ways to do the same things, but do a better job. It is clear that each agency providing or preparing to provide services and supports for individuals with ASD must take a careful look at efficiencies. In moving forward, precedence should be given to endeavors that directly benefit individuals with ASD and their families through coordination of statewide resources and collaborative efforts to improve the delivery of services.

Some of the recommendations are identified as priority items which can be implemented without delay, many of which are already underway. There are many areas which require further development of goals, recommendations and implementation activities. Many committed individuals have stepped up to take responsibility for implementation. Next Step Actions are identified at the conclusion of the sections below.

**The Commission has identified the following recommendations as its highest priorities for the immediate future.**

**PRIORITY RECOMMENDATION:** Early identification of young children and the immediate provision of appropriate services.

**JUSTIFICATION:** Current research strongly supports early intervention as the cornerstone for skill development of young children with ASD. This recommendation will require additional funding in this time of finite resources. Oregon is dramatically below other western states in the quantity of service it provides young children and their families.

Implementation Strategies:

① Screen all Oregon children for ASD by their second birthday, and use a consistent process for the identification evaluation.

② Support increased funding for Early Intervention / Early Childhood Special Education.

③ Support submission of legislation to create an ASD health insurance mandate to the Legislature during the 2011 session.

**PRIORITY RECOMMENDATION:** Promote the collaboration and integration of services for individuals with ASD and their families by state and local agencies providing the services. Include individuals with autism and/or their families in collaborations.

**JUSTIFICATION:** Both best practice and the current economic times require Oregon to be more efficient and collaborative in our activities.

Implementation Strategies:

① Support legislation requiring key state agencies to develop an interagency agreement on a specific action plan related to transition of youth from secondary education to adult services or continuing education.

② Identify other specific opportunities where interagency collaboration will improve services for individuals with ASD and their families, including training opportunities across agencies.

③ Implement the *Components of a Comprehensive ASD Program* framework as described in diagram ED1, presented in the Education section of the report, to provide a more efficient, consistent delivery of evidence based interventions and practices across all education programs and staff.

**PRIORITY RECOMMENDATION:** Promote the training of personnel throughout agencies, geographic areas, and areas of expertise to ensure that personnel are adequately trained and available throughout the state.

**JUSTIFICATION:** There is currently insufficient and inconsistent training resulting in inadequate personnel to provide services to individuals with ASD and their families.

Implementation Strategies:

① A consistent process will be developed to conduct a systems-wide needs assessment to determine what is available, what content is needed, and what is the best way to deliver the training (e.g. face to face, coaching, online).

② As a first step of implementation, identify one single location for all agencies to post all trainings that are available.

# EXECUTIVE SUMMARY CONTINUED

**PRIORITY RECOMMENDATION:** Extend the operation of the Oregon Commission for Autism Spectrum Disorder through 2015.

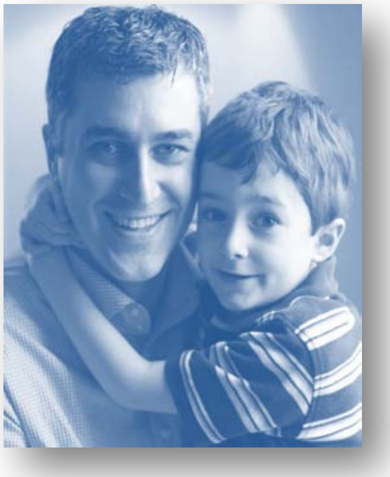
**JUSTIFICATION:** The Commission is necessary to maintain focus, help prioritize goals on Autism Spectrum Disorder, develop implementation plans for the Commission's recommendations, obtain and assist other agencies to obtain grant funding, and oversee the initial implementation of the recommendations. Without the ongoing attention and energy of the Commission, many of the action items identified in the Report are unlikely to occur. This is a requirement for the continued implementation of the 10-year plan.

Implementation Strategies:

① Support submission of legislation during the 2011 Oregon legislative session for the continuation of the Commission; and/or

② Request that the Governor's Executive Order be extended through a new Executive Order.

*Note:* Any expert panel or work group created to address specific recommendations of the 2009-2011 Oregon Commission on Autism Spectrum Disorder will collaborate with the Commission or subsequent entity on an ongoing basis.



# INTRODUCTION

## FRAMING THE WORK

This report was created by the Oregon Commission on Autism Spectrum Disorder for the purpose of communicating its recommendations to the Governor, legislature, agencies, individuals with autism spectrum disorders, their families, and interested others.

The Commission's work was framed by the conversations with professionals from education, health care, community services, families and individuals with ASD. The Commission believes that improved collaborations will result in better services and supports and a more efficient use of resources.

The need for change is clear. The population of individuals identified with autism spectrum disorders has increased dramatically. Many of the services and supports currently available do not reflect today's growing body of research and understandings about autism spectrum disorders. Moreover, the different ways health care, education, and community services are organized often makes it difficult for these systems to implement new research findings, modify existing programs, and collaborate with each other. The resulting issues and gaps can be best addressed by an ongoing commitment to clarify where those gaps exist and to illuminate the shared path to resolving them.

The Commission believes that for change to be successful, individuals with autism spectrum disorders and their families must play a critical role in all aspects of public awareness, training, service design, implementation, and evaluation at both the system and the individual service level.

# FRAMING THE WORK CONTINUED

The information in this report is organized to facilitate both an overall understanding of the recommendations of the Commission and a focused view on particular areas of interest. Although much of the work of the Commission was accomplished through its eight subcommittees, the recommendations are presented in the body of the report in thematic groupings which transcend the subcommittee structure. The report is designed to present the end result of thousands of hours of consideration, debate, understanding and compromise. The details of each subcommittee recommendations and meeting minutes are available on the Commission website at www.orcommissionasd.org.

This report lays out a 10-year plan. The timelines are not specifically identified, with the expectation that there will be a somewhat uneven roll-out of recommendations to take advantage of opportunities as they arise. Some activities have already begun. From the very beginning, Commission members were committed to creating an actionable report. Through the work of the Commission there is momentum and recognition that the momentum must be sustained, even in a challenging economy. Rapid implementation of recommendations will allow us to make better use of the resources we have. Given the current national and state economic situations we don’t anticipate significant new funding. Therefore some recommendations have identified funding sources, and some do not. Early action steps are highlighted throughout the report and in the Executive Summary.

We offer this report as our best effort to achieve a consensus-driven vision for Oregon, knowing that it will have flaws and omissions. It is intended to be a living document, informed by experience, and changing as both circumstances and knowledge evolve. We hope that this report helps guide Oregon to better address the unique services and support needs of individuals with ASD and their families.

# HISTORY OF THE COMMISSION

In the past decade, there have been a number of both legislative and agency initiatives in Oregon designed to address issues related to services for the growing population of individuals who have been identified as being on the autism spectrum and their families. During that time, there have been significant changes in what is known about autism spectrum disorders and responses to the unique challenges of ASD. Controversy continues to exist around identification statistics, causes of the disorder, and appropriate treatments or interventions.

# HISTORY OF THE COMMISSION CONTINUED

In 2008, the Autism Spectrum Disorder Workgroup was created as an ad hoc committee by the Chairs of the House Education and Health Care Committees in response to the frustrations of families and agencies attempting to address the needs of the rapidly growing population of children and adults identified with ASD in Oregon. The Workgroup was chaired by then Representative Chris Edwards and included other legislators, state agency staff, and several family members. The group reviewed the current status of services, developed draft recommendations, held eight community forums and received input from hundreds of individuals. The recommendations of the workgroup are contained in the document, "The Oregon Autism Project – Preliminary Findings and Recommendations."

In March of 2009, Governor Kulongoski issued an Executive Order which created the Oregon Commission on Autism Spectrum Disorder (OCASD or the Commission). The 13-member, Governor-appointed, Commission was charged to build on the efforts of the previous legislative workgroup and to create a 10-year plan for Oregon that helps target limited resources and uses best practices to improve services to all individuals and families experiencing autism spectrum disorders. A report with recommendations and identified action items was presented to the Governor in December 2010. Executive Order No. 09-07 is scheduled to expire on July 1, 2011.

# MISSION STATEMENT

It is the mission of the Oregon Commission on Autism Spectrum Disorder to:

> Develop appropriate, collaborative and timely supports and services across the lifespan. This mission is accomplished by the creation and implementation of a long term strategic plan that increases coordination, promotes best available practice, makes efficient use of resources and both directly engages with, and better responds to, the needs of people with ASD and their families.

# GUIDING PRINCIPLES

## RESPECT

- Do no harm.
- Recognize that autism is a natural part of the human experience, and that all people on the autism spectrum can be contributing members of their communities given the right supports.

## INCLUDE

- Listen to individuals with ASD and their families.
- Recognize that all individuals and their families, including those with diverse cultural backgrounds, have a right to receive information in accessible formats, communicate their needs and preferences, and participate in decisions concerning supports and services in education, health care, the community, and employment.

## SUPPORT

- Maintain high expectations for individuals and their families and provide the education, supports, services, and opportunities necessary to achieve a high quality of life.
- Recognize that appropriate supports to ensure inclusive, meaningful, and safe participation in education, health care, the community, and employment include adapting physical and social environments, providing communication support including assistive technology, and assuring that comprehensive and coordinated services are available to individuals and their families throughout the state.

## COORDINATE

- Respect that the complex and dynamic needs of individuals and families require a seamless coordination of services and resources across the lifespan.
- Increase the capacity of the community to meet the needs of individuals and their families by enabling:
  - Appropriate and timely responses to meet the needs and goals of individuals and families;
  - Quality pre-service and in-service professional development on best practices for educating and supporting individuals and their families, and;
  - A long-term, system-wide perspective on the efficient and effective coordination of services and resources among individuals, families, and medical, educational, and human services providers.

# PROCESS

In order to quickly assess the needs of Oregonians, and to involve a wide array of Oregonians in the process, the Commission created eight subcommittees. The subcommittees were organized around the following topical areas: screening, identification, and assessment; health care; role of health insurance; education; certification / licensure of educational staff; interagency transition; services to children and families; and services to adults. Subcommittee members were selected to provide diversity of perspective and specific content knowledge. Special effort was made to achieve geographic diversity and to include family members and individuals on the autism spectrum. Each subcommittee was provided an initial charter with a specific set of topic-related goals which were edited by the Subcommittee.

Close to 100 volunteers from around the state participated in monthly meetings, numerous conference calls, email and website discussions. They sifted through research reports and evaluated best practice information from around the country. Given that there was some necessary overlap, the subcommittees also coordinated their work through collaboration of chairs and some strategically designed overlap of personnel.

The subcommittees made their recommendations to the full Commission. This report was generated from the synthesis of both the subcommittee recommendations and the Commission's integration activities.

The Commission adopted operational guidelines early in the process that included a commitment to use a consensus process for decision-making. The Commission met fourteen times in full day sessions that included overviews of services, content experts, and lengthy discussions of subcommittee reports.

Opportunity for public comment was available at the monthly Commission meetings. Initial Subcommittee recommendations were posted on the Commission website in June of 2010 and a draft report was released in October 2010. Public forums were held in six locations around the state. Input on the report recommendations was also solicited through the website, online surveys and the Commission listserv.  Numerous education, health care, and social service stakeholder meetings were held to review recommendations prior to finalizing them.

# RECOMMENDATIONS

## AWARENESS & INFORMATION (AI)

### SUMMARY OF ISSUES:

Individuals with ASD are best served when their needs are understood. However, ASD is often incompletely understood, even by professionals who must be relied upon to identify and work appropriately with individuals with ASD. Individuals with ASD and their families struggle to find accurate information and appropriate services. Professionals from a variety of disciplines, from health care to law enforcement to child care providers, do not have the information they need in order to provide effective services.

There is much expertise regarding ASD in Oregon, but there is no entity or system available to ensure that individuals, families and professionals have easy access to updated information necessary for decision making and obtaining or providing appropriate services.

**Goal AI 1: There is an ongoing entity charged to continue the work of improving public awareness, and consolidating information from a wide range of sources.**

**Recommendations:**

**AI 1.1** Continue the Oregon Commission on Autism Spectrum Disorder or another entity with the authority and ability to fulfill the goal.

**AI 1.2** Information on resources, research, trends, policies, services, and current evidence based interventions will be tracked and shared.

**AI 1.3** The entity will oversee the creation of a public awareness campaign on ASD.

**AI 1.4** Individuals with ASD and families will be involved in the design and content of public awareness programs and materials development.

**Goal AI 2: The public is informed about ASD and the importance of early identification through a statewide community education and positive public awareness campaign incorporating diverse media strategies.**

**Recommendations:**

**AI 2.1** Appropriate public awareness materials will be used statewide.

Implementation Activities:

AI 2.1.1 Review available educational materials (e.g. HANS materials, Learn the Signs, First Signs). Determine the need for the development of additional materials for specific audiences, for example, a simple poster to include resource information for families and providers.

AI 2.1.2 Formulate a list of organizations to receive public awareness materials to distribute.

AI 2.1.3 Create a statewide public awareness campaign specific to identification of ASD in older children and adults. Develop and disseminate public awareness materials through health plans, professional groups, student health centers, and at colleges and universities.

**Goal AI 3: There is an updated, easy to use, centralized statewide clearinghouse and web-based directory of available information, trainings, and services.**

**Recommendations:**

**AI 3.1** Information will be shared among the wide range of entities that provide information and services across the state related to ASD.

Implementation Activities:

AI 3.1.1 Private and nonprofit entities, service providers, and state agencies will be invited to participate in a statewide ASD consortium to share information and increase ASD resources throughout the state.

AI 3.1.2 All information for public distribution will be easily accessible and made available in multiple formats.

**AI 3.2** Individuals with ASD and their families will participate in the design, selection, and distribution of information.

**Goal AI 4: Community members including law enforcement, local business persons, co-workers, educators, and classmates have increased awareness, knowledge, and acceptance of individuals with ASD.**

**Recommendations:**

**AI 4.1** Implement programs to improve awareness and promote understanding of disability and diversity in law enforcement, business, and education.

Implementation Activities:

AI 4.1.1 Look for model awareness curriculum available from around the nation.

AI 4.1.2 Implement programs for awareness and acceptance of disability and diversity in the public school setting.

**AI 4.2** Agencies will develop and implement programs to address the bullying of individuals with ASD.

### NEXT STEP ACTIONS:

1. **Request Governor's Executive Order is extended through a new Executive Order *or* Support legislation for the continuation of the Commission submitted during the 2011 Session.**
2. **Review and edit awareness materials.**

# EMPOWERMENT (EM)

## SUMMARY OF ISSUES:

Services and supports, both formal and informal, are most effective when individuals who receive them have a voice in their design, implementation, and evaluation. Peer mentoring and family-to-family support help create networks of community support which are especially important in a period when fiscal resources are increasingly limited.

Individuals experiencing ASD and family members are likely to have both shared and differing perspectives, so it is essential to give opportunities for both to participate in decision making groups that influence service delivery systems.

Individuals with ASD and their families face many barriers to being active participants in design, implementation and evaluation of services. Lack of available, accessible, and understandable information may result in either a dependence on already overextended professionals or inability to successfully navigate and utilize complex service systems.

Failure to use a strengths-based, self-determined and respectful approach that is sensitive to the individual and/or family may result in poor long term outcomes for the individual and their family.

**Goal EM 1: A strengths-based, self-determined, and respectful approach that is sensitive to the individual and family dignity is adopted.**

**Goal EM 2: Families and individuals are able to successfully negotiate service systems and utilize necessary supports as a result of improved awareness, outreach, training, and appropriate accessibility strategies, including navigation supports.**

*Note:* In this context, navigation supports means assistance in locating and accessing appropriate supports and services. A “navigator” is a person who provides system navigation assistance to individuals and families.

**Recommendations:**

**EM 2.1** Information, navigation support, and trainings will be readily available and automatically offered upon identification of ASD, or any time requested.

> Implementation Activities:
>
> EM 2.1.1 Upon identification of autism spectrum disorder, individuals and their families will be offered the opportunity to connect with an independent resource navigator of the family's choice or a peer support for an adult, if requested. Independent resource navigator means an individual or entity that assists a family or individual to locate and access appropriate supports and services.

**EM 2.2** Materials, process, and consultations will be appropriate for the spectrum nature of ASD, be culturally and linguistically appropriate, and be easily available in accessible formats.

**Goal EM 3: Peer supports and family-to-family connection strategies are supported.**

**Recommendations:**

**EM 3.1** Organizations which have existing infrastructure to offer peer mentoring and family-to-family connections will be identified and utilized more effectively though information sharing and coordination.

**EM 3.2** Financial support will be available to current and new self-advocacy organizations to provide peer supports to individuals with ASD.

**Goal EM 4: Individuals with ASD and their family members are informed participants in decision making, designing, implementing, and evaluating services.**

**Recommendations:**

**EM 4.1** Advisory groups assisting policy makers determining public policy specifically related to ASD will be comprised of at least 51% individuals with ASD and family member representatives.

**EM 4.2** Family members and individuals with ASD participating in advisory and policy making groups will receive the training, technical assistance and support needed to maximize their participation.

# ACCOUNTABILITY & QUALITY (AQ)

## SUMMARY OF ISSUES:

High quality, appropriate services to individuals with ASD do exist in many places, but these services are not consistently available across the state. Individuals with ASD and families who live in rural areas or who are members of a linguistic, cultural, or racial minority may often experience even greater difficulty in accessing appropriate services.

Oregon is not taking full advantage of the wealth of knowledge, best practice, and skill currently available in the state and elsewhere. The numbers and needs of individuals with ASD have outgrown the current capacity of our public systems to provide appropriate services and supports.

Current, accurate information and data about the numbers and needs of individuals with ASDs is not sufficiently available for public systems to be accountable and to provide appropriate services.

### Goal AQ 1: There is an ongoing entity charged to provide leadership by guiding system priorities and monitoring outcomes for programs serving individuals with ASD.

**Recommendations:**

**AQ 1.1** Continue the Oregon Commission on Autism Spectrum Disorder or another entity with the authority to fulfill the goal.

**AQ 1.2** Key performance measures and other quality improvement strategies will be used to monitor implementation of recommended actions.

### Goal AQ 2: Access to quality ASD services is consistent across the state.

**Recommendations:**

**AQ 2.1** Review current system delivery infrastructures for opportunities to enhance efficiencies in services to individuals with ASD.

**AQ 2.2** Seek funding opportunities from state, federal, and private initiatives to sustain and enhance ASD service delivery systems.

Implementation Activities:

AQ 2.2.1 Conduct needs assessment to identify system gaps that might be addressed through specific funding opportunities.

**Goal AQ 3: Individuals experiencing ASD and their families have access to coordinated, collaborative, accountable systems that provide information, supports, and services.**

*Note:* This goal is also reflected in recommendations throughout other areas of the report.

**Goal AQ 4: The Oregon Commission on ASD (or ongoing entity) interacts with each public agency (Department of Human Services, Oregon Health Authority, Oregon Department of Education, Department of Justice, health care) to ensure the quality of services and information being provided to professionals, families, individuals and the public**.

*Note:* Any expert panel or work group created to address specific recommendations of the 2009-2011 Oregon Commission on Autism Spectrum Disorder will collaborate with the Commission or subsequent entity on an ongoing basis.

**Recommendations:**

**AQ 4.1** There will be embedded ASD expertise in targeted state agencies to oversee the implementation of the recommendations, develop service guidelines, provide trainings and technical assistance and serve as a liaison with other stakeholders.

**AQ 4.2** Agencies will use key performance measures and other quality improvement strategies to monitor implementation of recommended actions.

**AQ 4.3** Agencies will assure that the recommendations of the Commission are part of their Quality Management Activities and required outcome reporting responsibilities.

**AQ 4.4** Oregon Department of Education will create an ASD Leadership Network in collaboration with higher education ASD training programs to provide statewide leadership for the implementation of the Comprehensive ASD Program and best practice interventions.

**AQ 4.5** Health care professional organizations will incorporate best practices associated with individuals with ASD in initial and continuing professional education offerings. In this context, best practice is intended to mean the use of best available evidence combined with expert guidance in designing individual-based care plans for individuals with ASD.

**Goal AQ 5: There is a valid, data-based foundation for strategically establishing and evaluating system and program improvements for individuals with ASD.**

**Recommendations:**

**AQ 5.1** Accurate data will be collected by agencies that provide supports and services to individuals on the ASD Spectrum.

Implementation Activities:

AQ 5.1.1 Existing agency data and analysis is inventoried, and gaps identified.

AQ 5.1.2 Specific cross-agency data needs are identified.

AQ 5.1.3 Agencies agree to key outcome and data measures to be tracked.

**AQ 5.2** New data collection and analysis will be conducted where there are gaps between the needed information and existing information.

**AQ 5.3** Essential data and analysis needed to investigate, support or evaluate the desired system changes will be clearly defined.

**AQ 5.4** Data will be shared among service entities and the public in a manner which protects confidentiality while supporting funding, evaluation, service planning, and the monitoring of prevalence.

**Goal AQ 6: Oregon systems have improved capacity to respond to the significantly growing population of individuals with ASD and their families who may require support and services**.

**Recommendations:**

**AQ 6.1** There will be a collaborative statewide effort to increase awareness, knowledge and skill of professionals and service providers in the public and private sector who support children, youth, and adults across the spectrum of ASD and their families.

**AQ 6.2** Ongoing training on ASD and technical assistance will be available to increase understanding of ASD and appropriate use of effective interaction strategies. Training and technical assistance should be available to any entity engaged with individuals with ASD and their families.

Implementation Activities:

AQ 6.2.1 Shared trainings across entities will be promoted.

**Goal AQ 7: Individuals with ASD and their families are actively engaged in the design of programs for training and technical assistance, and assessment and evaluation of the services they receive.**

# COORDINATION & COLLABORATION (CC)

## SUMMARY OF ISSUES:

Individuals with ASD and their families may receive services from multiple agencies and programs but these services are frequently not coordinated. The rapid increase in numbers of individuals being identified with ASD, the complexity and diversity of their needs, limited resources, and the pressure on existing education and social services systems and health care require a more thoughtful, coordinated approach to funding, service development, and delivery.

**Goal CC 1: Outcomes for individuals and families are improved through interagency collaboration and coordination.**

**Recommendations:**

**CC 1.1** Written collaborative agreements will exist between relevant agencies, and these agreements will include action outcomes and a process for determining success.

Implementation Activities:

CC 1.1.1 Require the Oregon Health Authority, Oregon Department of Human Services, and Oregon Department of Education to have written agreements which outline mutual and collaborative efforts specifically to address the recommendations of the Commission, and generally to provide services to individuals with ASD.

**CC 1.2** Explicit interagency agreements will be implemented regarding Transition. Joint activities will be developed and maintained between the Department of Human Services (Seniors and People with Disabilities, Vocational Rehabilitation, Child Welfare), Oregon Department of Education, and Oregon Health Authority (Addictions and Mental Health and Oregon Health Plan) that will improve the outcomes for youth transitioning from secondary education to further educational opportunities, employment and successful community living.

# COORDINATION & COLLABORATION (CC) CONTINUED

Implementation Activities:

CC 1.2.1 The Interagency Agreement will reflect common agreement on mission, values, goals and outcomes for transitioning individuals with ASD. It will define the roles and responsibilities of the participating State agencies, including performance expectations of each agency and performance outcomes.

CC 1.2.2 The interagency agreement will be renewed each biennium.

CC 1.2.3 Agencies subject to the Interagency Agreement will participate in state level and local interagency transition advisory committees and other agreed upon collaborative initiatives. These bodies will be utilized to monitor, recommend, and advise on interagency collaborations, transition best practices, and student outcomes.

CC 1.2.4 The State Interagency Transition Advisory Committee (SITAC) will be created and comprised of cooperating state agencies, key stakeholders, individuals with ASD, and families. SITAC will advise on standards for collaboration, performance expectations, student outcomes, transition best practices, and the identification of publications and tools for professionals and students with ASD and their families. Each collaborating agency will assume specific responsibility related to the operation of the SITAC.

CC 1.2.5 Local Interagency Transition Advisory Committees will be formed and will be responsible for developing an annual plan that specifies their activities and goals. The local plan may also include the use of non-publicly funded resources. The local committee may review, recommend and advise on practical standards for collaboration with local providers of services for transition age youth with ASD, optional transition best practices, additional publications and tools for professionals and students with ASD and their families beyond what is recommended or required statewide.

CC 1.2.6 Outcomes of transitioning youth will be tracked to provide data on impact of interagency collaborations.

CC 1.2.7 A matrix of agency roles and responsibilities in transition will be used at the local level to facilitate collaborations.

# COORDINATION & COLLABORATION (CC) CONTINUED

**Recommendations:**

**CC 1.3** Written interagency agreements will be implemented for children requiring significant levels of support from several agencies.

**CC 1.4** Agencies at the state and local level will share expertise, promote common trainings, and collaborate on joint activities.

**Goal CC 2: The goals and outcomes of interagency agreements are transparent to the public.**

**Recommendations:**

**CC 2.1** The Oregon Health Authority, Oregon Department of Human Services, and Oregon Department of Education will be required to make public reports on the data, implementation and service outcomes of interagency agreements.

**Goal CC 3: The Oregon Commission on Autism Spectrum Disorder assists agencies and groups to prioritize, develop, obtain, and assist to obtain grant funding.**

## NEXT STEP ACTIONS:

1. **Support legislation requiring appropriate state agencies to biennially develop an interagency agreement related to transition services from school to adult services or continuing education for youth with disabilities.**

2. **Support the creation of a State Interagency Transition Advisory Committee.**

3. **Complete the matrix of agency roles and responsibilities in school to adult services and postsecondary education transition and begin implementation at the local level.**

# 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.

# SCREENING, IDENTIFICATION & ASSESSMENT (SIA)

CONTINUED

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).

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.

**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).

**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.

**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.

**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).

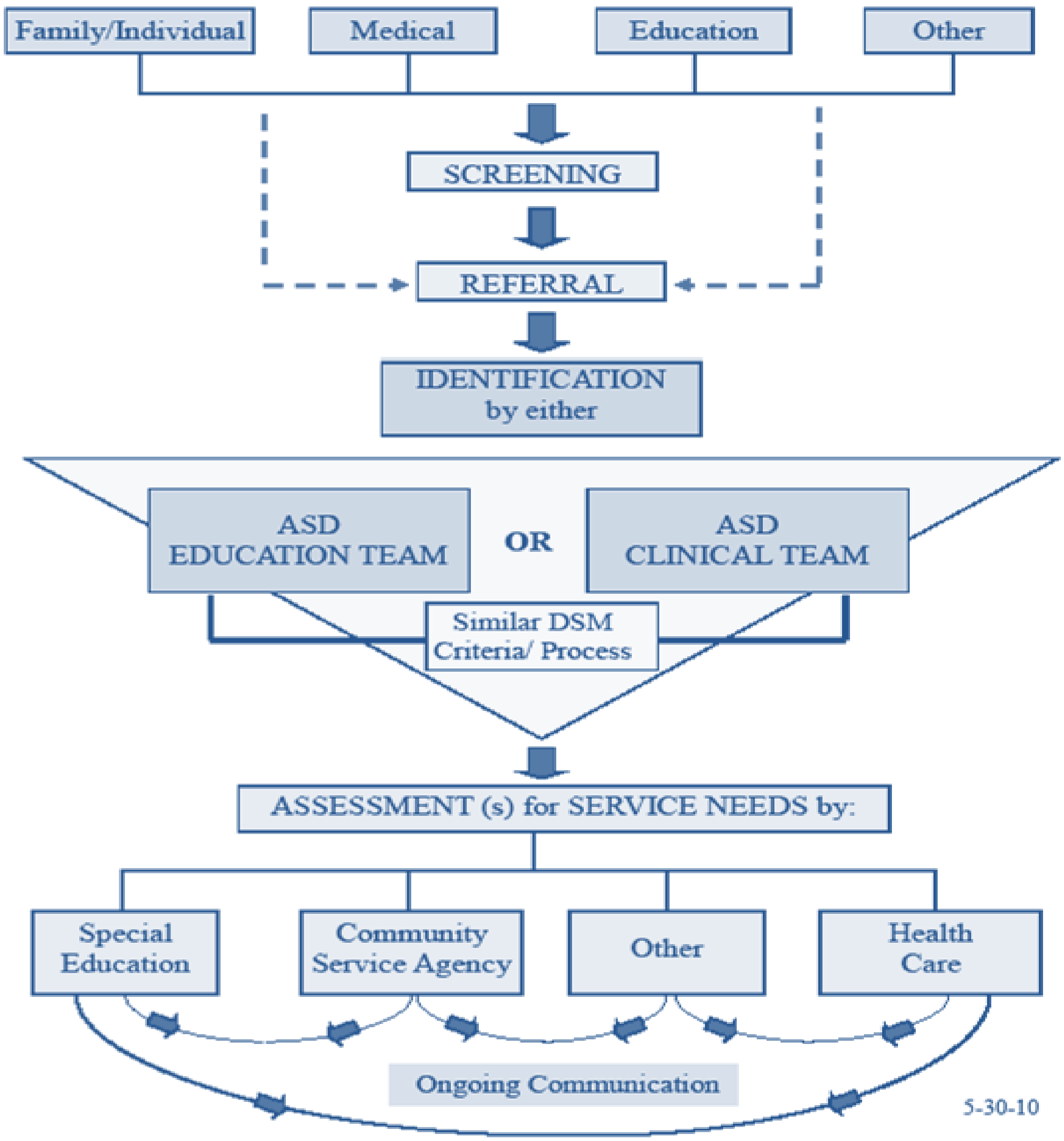
H. Knowledge sufficient to identify red flags indicating need for further referral.

**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.**

# SCREENING, IDENTIFICATION AND ASSESSMENT: CHILDREN (SIAC) CONTINUED

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



# 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.

<u>Implementation Activities</u>:

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.

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.

# SCREENING, IDENTIFICATION & ASSESSMENT (SIA) CONTINUED

## 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.**

# HEALTH (HE)

## SUMMARY OF ISSUES:

Individuals with ASD often face challenges in accessing health care services which are otherwise generally available. Most health care professionals (HCPs) have only a few individuals with ASD in their practices, and little or no formal training in appropriate care or needed accommodations. Individuals and families also experience difficulty in navigating care systems and being effective advocates, managers and directors of care.

**Goal HE 1: Health care professionals (HCPs) are aware of the diagnostic characteristics of ASD and know where to refer for identification services.**

**Recommendations:**

**HE 1.1** See Screening, Identification, and Assessment.

**Goal HE 2: Individuals with ASD are served by health care professionals who have the skills, knowledge and supports to provide high quality health care appropriate to individuals with ASD.**

**Recommendations:**

**HE 2.1** High quality health care, including dental care, to individuals with ASD will include:

A. Understanding of basic treatment approaches and challenges.

B. Use of strategies to address the special sensory, behavioral and communication needs.

C. Identification of associated or co-morbid medical and mental health conditions, with initial treatment and timely referral as needed.

D. Involvement of, and support to, all members of the family, when appropriate.

**Recommendations:**

E. Support for medication management as necessary.

F. Knowledge about all treatments including complementary and alternative options.

G. The same preventive services as are provided to persons without developmental disabilities.

H. Appropriate coding and billing for services provided.

**HE 2.2** Health care professionals will have access to the information and training necessary to provide high quality health care to individuals with ASD.

Implementation Activities:

HE 2.2.1 Develop and maintain a website to support training initiatives and provide resources to HCPs including quarterly updates on statewide medical home activities.

HE 2.2.2 Develop and implement training programs customized for several key groups such as primary care providers for children, adolescents, and adults, medical and surgical specialists, mental health professionals, dentists and dental staff, those serving migrant communities, and first responders.

HE 2.2.3 Provide training in multiple formats including webinars, regional conferences and learning collaboratives. Archive all presentations on a publicly accessible website.

HE 2.2.4 Identify, train and support local health care champions, who would conduct local trainings, consult with local clinicians, schools and other community providers.

HE 2.2.5 Implement Developmental Pediatric and Child Psychiatric remote clinician-to-clinician consultation services to support the local health care pediatric champions and other HCPs.

HE 2.2.6 Identify and support HCPs who are interested and available to assume the health care of adults with ASD, including transition of youth to adult health care.

HE 2.2.7 Clinician training programs (e.g. medical school and residency) review and update the initial training provided regarding both screening/surveillance and serving individuals with ASD on a periodic basis.

Implementation Activities:

HE 2.2.8 Pre-service training programs, e.g. medical school and residency, provide training on the comprehensive care of individuals with ASD including screening and surveillance, diagnostic, management, ongoing care and care coordination.

**Goal HE 3: Individuals with ASD have access to appropriate health care, coordinated among health care providers, individuals, families as appropriate, and community professionals. Materials, tools and programs are available and accessible to individuals and families from diverse groups.**

**Recommendations:**

**HE 3.1** Service providers will determine if individuals have health insurance. If not, they will provide information on the Oregon Health Plan, SCHIP and Healthy Kids.

**HE 3.2** Individuals with ASD will have access to a regular provider who can accommodate needs, proactively manage care, refer to other resources when needed, involve the family when appropriate, and work with schools and community providers.

**HE 3.3** Medical home activities for individuals with ASD and other developmental disabilities will be defined, measured and reimbursed.

**HE 3.4** Community-based care coordination supports, such as DD services coordinators and public health nurses in the CaCoon program will be available to the HCP office based on the needs of the individual, family and office.

**HE 3.5** Specialty consultations will be available across the lifespan to HCPs regarding the care of individuals with ASD.

**HE 3.6** The process of transition from pediatric health care to adult health care will be facilitated to ensure continuity of appropriate care.

**Goal HE 4: The general health and wellness of individuals with ASD is improved by the promotion of healthy behaviors, self-advocacy, self-determination and self-management.**

# HEALTH (HE) CONTINUED

**Recommendations:**

**HE 4.1** Individuals with ASD and their families will have the necessary information and supports, including access to facilities and health and wellness programs, to be able to implement healthy lifestyle choices about diet, exercise, and recreation.

Implementation Activities:

HE 4.1.1 Create accessible health promotion materials to be available in multiple formats, addressing autism-related barriers to healthy lifestyles.

HE 4.1.2 Identify and support self-advocacy groups and help them to create peer-mentoring programs and wellness programs.

HE 4.1.3 Identify and support recreational facilities and other organizations which will make special events available that specifically accommodate the needs of individuals with ASD.

HE 4.1.4 Identify resources to support individuals with ASD to successfully participate in community activities.

**HE 4.2** Individuals with ASD and their families will have the tools and support to effectively inform HCPs about any relevant sensory, behavioral, and communication issues that affect their healthcare.

Implementation Activities:

HE 4.2.1 Create questionnaires that will allow individuals to describe for healthcare providers ways that being on the spectrum affects the individual's healthcare interactions, with potential strategies to facilitate care.

**HE 4.3** Individuals with ASD and their families will be included in medical decision making, and understand the consequences of their decisions.

Implementation Activities:

HE 4.3.1 Compile educational materials and create training programs with individuals and their families about how to communicate with healthcare providers, navigate the healthcare system, and access available resources and supports.

**Recommendations:**

**HE 4.4** Individuals with ASD and their families will have access to necessary information and supports to promote self-management of their health conditions.

Implementation Activities:

HE 4.4.1 Support existing resource centers that can translate patient education materials and instructions into forms that are accessible to individuals' learning needs.

## NEXT STEP ACTIONS:

1. **Work with the START (Screening Test and Referral Training) project of the OPS to develop and include materials on the identification of older children and adults with ASD in their next planned training program on mental health disorders. The START project provides trainings for health care providers in local communities throughout the state. The CCYSHN (Center for Children and Youth with Special Heath Needs) has agreed to support a local pediatrician in one or two sites who will participate on a local inter-agency committee to improve transition from school to post secondary education and services.**
    a. **Develop and post training materials and resources related to the diagnosis and management of individuals with ASD on the website of the CCYSHN Priorities for initial training include pre-service training with students and residents at OHSU, and primary health care providers.**
    b. **Notify primary care providers of the availability of web-based resources and training materials through the newsletters of professional societies.**
    c. **On-going notification of upcoming training events, resources and materials will be included in the quarterly online Medical Home newsletter of the CCYSHN with links to other health professional online newsletters.**

# HEALTH INSURANCE (HI)

## SUMMARY OF ISSUES:

Currently, public and private health insurance in Oregon does not consistently cover behavioral treatments and/or interventions and other health care services related to ASD. Many believe that health insurance should provide critical early access and ongoing treatments/interventions for individuals with ASD that are currently not covered.

A review of the history shows that the role of health insurance in providing specific behavioral interventions, (frequently identified as applied behavioral analysis), has been controversial in Oregon. There has been debate over whether the treatments and/or interventions found most successful for young children with ASD are best described as educational or medical. There has been disagreement whether the treatments/interventions meet the appropriate standard of evidence for medical insurance. In 2007, a subcommittee of the Health Resources Commission was created to review the evidence for various treatments/interventions. The report, for a number of reasons, did not resolve the controversies. Lastly, medical systems are not well designed for coordinating and integrating care with other service providers.

Nationally there has been a significant movement to expand the role of health insurance in providing autism-specific treatments and interventions.

**Goal HI 1: Public and private insurance in Oregon provide medically necessary and appropriate comprehensive integrated health care treatments/interventions for individuals with ASD. Individuals with ASD have access to medical assessment and treatments/interventions associated with ASD across their lifespan.**

**Recommendations:**

**HI 1.1** An ASD health insurance mandate will be submitted for the 2011 Oregon Legislative session, to encompass all health insurance subject to state regulation and state or federal mental health parity laws, including Medicaid and state employees.

**HI 1.2** To the extent possible within the jurisdiction of the state of Oregon, the mandate will cover those insured in Oregon but resident in another state, and those who are residents of Oregon but whose insurance comes from another state.

**Goal HI 2: There is an entity responsible for ongoing oversight and monitoring of best practices and emerging evidence, to provide updated guidance to health care professionals. A standard method for determining best evidence is defined and applied on a consistent basis.**

**Recommendations:**

**HI 2.1** An expert panel will be established or assigned by the Governor, with Senate confirmation. The panel should include representatives from key medical and academic disciplines associated with ASD-related treatment and research, including at least: providers of developmental and behavioral services, a physician, a psychologist, a speech language pathologist, an occupational therapist, and expert on alternative and complementary medicine, an expert on the evaluation of evidence, a payer (public or private), an individual with ASD and a parent or immediate family member of an individual with ASD.

**HI 2.2** The expert panel will agree upon a standard scientific method for determining best available evidence, and apply it on a consistent basis to determine what treatments / interventions should be covered under insurance, when medically necessary and appropriate for the individual, taking into account new information and treatment / intervention options as they become available. *Note*: Additional responsibilities for the expert panel are listed under other recommendations in this section.

**Goal HI 3: Health insurance coverage includes medically necessary and appropriate comprehensive services and treatments / interventions.**

**Recommendations:**

**HI 3.1** All state-regulated health insurance will be required to cover services such as screening, diagnostic evaluation and treatment of co-morbidities.

**HI 3.2** All state-regulated health insurance will be required to cover necessary accommodations and services so that individuals with ASD can receive usual medical care, such as sedation for routine care.

**HI 3.3** All state-regulated health insurance will be required to cover the following treatments / interventions when appropriate for symptoms associated with ASD, with the specific modalities to be determined by the expert panel:

A. Habilitative and rehabilitative care, including methods based on:
   a. Applied Behavior Analysis
   b. Developmental approaches

B. Medical care, including prescribed medications and any health-related services.

C. Psychiatric and psychological care.

D. Speech language pathology, occupational therapy, and physical therapy.

E. Augmentative communication devices and other assistive communication technology.

**HI 3.4** Parent or family member involvement and training will be a part of the provision of treatments / interventions.

**Goal HI 4: Providers have an obligation to the individual receiving treatment / intervention, and also the payer, to provide timely and ongoing documentation of progress, which includes goals and objectives. Data on progress should be provided as applicable for the specific treatment/intervention.**

**Recommendations:**

**HI 4.1** Both payers and clients have the right to periodic review of the evidence of progress, in which the results obtained are clearly tied to the treatment/intervention provided.

**HI 4.2** The expert panel will provide limits on appropriate frequency of payer review for each type of treatment/intervention as needed. The frequency of payer review may appropriately vary depending on the treatment/intervention provided, and should be within usual limits for other medical and behavioral services.

**HI 4.3** If timely documentation of progress is supplied to a payer, the payer will not suspend treatment/intervention for the purpose of evaluating progress.

**Goal HI 5: There is a consistent definition and a consistent process for determining medical necessity regarding health care services associated with ASD which are appropriate for each individual.**

**Recommendations:**

**HI 5.1** The expert panel will determine specific terminology related to medical necessity which will be appropriate for individuals with ASD.

**Goal HI 6: Treatments / interventions associated with ASD are prescribed and provided by professionals with appropriate qualifications.**

**Recommendations:**

**HI 6.1** Under health insurance coverage, treatments/interventions specified under an insurance mandate will be prescribed and overseen by a licensed MD or psychologist with appropriate knowledge of ASD. The expert panel will identify appropriate credentials.

**HI 6.2** All providers of prescribed treatments/interventions to individuals with ASD under health insurance will be licensed, certified, or approved by the state or by a professional credentialing organization recognized by the state. Providers of service will have knowledge of ASD and training specific to the treatment/intervention being offered.

**HI 6.3** Standards will be established for the training and supervision of paraprofessionals, and families will receive training regarding what to expect from paraprofessionals. Close supervision and ongoing training of paraprofessionals will be provided by a provider who meets the qualifications recognized by the state.

**HI 6.4** Training programs for paraprofessionals through the community college system will be explored.

**Goal HI 7: Services provided through medical systems are coordinated and collaborative in approach with care provided in educational and community contexts.**

**Recommendations:**

**HI 7.1** Care coordination is of critical importance. Strategies will be created to ensure that care coordination is available. Coordination of care means a service that:

A. Facilitates the linkage of patients with appropriate services and resources in a coordinated effort to ensure that needs are met and services are not duplicated by organizations involved in providing care;

B. Assists individuals and families to more effectively navigate and use the healthcare systems;

C. Maximizes the value of services delivered to patients by facilitating beneficial, efficient, safe, and high-quality patient experiences and improved healthcare outcomes.

**Goal HI 8: Oregon continues to learn from the experiences of other states in implementing an insurance mandate or similar efforts.**

**Recommendations:**

**HI 8.1** The costs and barriers associated with implementation of an ASD health insurance mandate experienced by other states will be monitored.

### NEXT STEP ACTIONS:

1. **Support submission of legislation to create an ASD health insurance mandate to the Legislature during the 2011 session.**

2. **Continue to monitor experiences of other states in implementing an insurance mandate or similar efforts.**

# EDUCATION (ED)

## SUMMARY OF ISSUES:

The existing education systems in Oregon are often inadequate to meet the increasingly complex needs of individuals identified with ASD. There is frequently insufficient utilization of current best practice information to design and implement programs across the range of learners. The current model of Regional ASD Services no longer meets the needs of school districts that have a rapidly growing population of children and youth with ASD. Services and access to personnel training and support may be different in various areas of the state depending on the capacity, role and expectation of Regional ASD Services, the ESD, EI/ECSE and local school districts. Rural areas of the state experience an even greater challenge in finding and retaining staff trained to work with children and youth with ASD. Access to trainings, specialized services and technical assistance varies.

There is a lack of stable funding to increase statewide capacity to meet the need for skilled ASD specialists, behavior specialists, and teachers.

Many individuals with ASD do not make a successful transition to permanent employment or continuing education. Successful transition from secondary school to employment or continuing education requires strategies that recognize the unique strengths and needs of individuals with ASD. Many post secondary educational and social service programs are uncertain how to support an individual with ASD.

Training, research, and programmatic resources available in higher education are often not well supported or linked to service delivery in public education, social services, and health care.

The education systems must be better equipped to address the range of learning needs. A coordinated, integrated approach (such as Scaling Up) to program planning and instruction which involves parents, students (as appropriate), building administrators, ASD licensed specialists, general and special education staff, local program coaches, instructional assistants, and related staff must be put in place.

Currently resources are available (and accepted in the field) identifying the critical components of comprehensive educational programs for learners with ASD but have not been consistently implemented in Oregon. In addition, best practice information and implementation in the field of ASD is changing rapidly. In the last year, a number of organizations have published evidence of best practice regarding interventions. Oregon needs a consistent system for the design and implementation of this comprehensive system and best practice interventions.

### INTRODUCTION TO THE RECOMMENDATIONS:

The following diagrams, ED 1, ED 2, ED 3, and ED 4 show how a strengthened comprehensive model for learners with ASD should be implemented. The following recommendations propose a significant shift in the current design and implementation of educational services related to ASD. It is the intent of the redesign to assist students to be active participants in the general school setting and in the community at large.

The redesign focuses on the implementation of the evidence currently available concerning effective instruction for learners across the spectrum of autism. The evidence addresses the components needed to design and implement a comprehensive program of instruction. The details of the comprehensive program will be described in the manual entitled “Oregon Education Guidelines for ASD”. The manual will provide EI/ECSE, District, and ESD programs a self assessment and linked support documents to implement the comprehensive program. Licensed ASD specialists will be available to provide training and coaching for all personnel involved in the implementation of the program. Particular emphasis will be placed on addressing the “expanded core curriculum”. In this context the “expanded core curriculum” refers to the curriculum that addresses unique characteristics and learning needs of individuals with ASD. At each stage of implementation of the comprehensive program, all staff and related personnel will be provided training. In addition, at each stage of implementation of a comprehensive program, family members will be encouraged to assist in the delivery and follow up of instruction.

As a number of learners with ASD may be receiving instruction in alternative settings, such as home schooling, additional work still needs to done to make sure all learners have access to the curriculum and resources.

The recommendations increase the capacity of the education system to more effectively and efficiently address the needs of the individuals with ASD. The role of existing ASD specialists will be critical in the implementation of the comprehensive program although their role will modified to better support local programs. It is intended that these reforms are implemented in the most cost neutral manner possible over a period of several years.

# EDUCATION (ED) CONTINUED

## DIAGRAM ED 1: IMPLEMENTATION OF COMPREHENSIVE ASD PROGRAM FRAMEWORK

Provide statewide comprehensive framework for staff, families, and community to support appropriate, consistent instruction for all learners with ASD. As the training and coaching moves toward the point of the arrow, the more specific the implementation to the individual program, school, and learner.

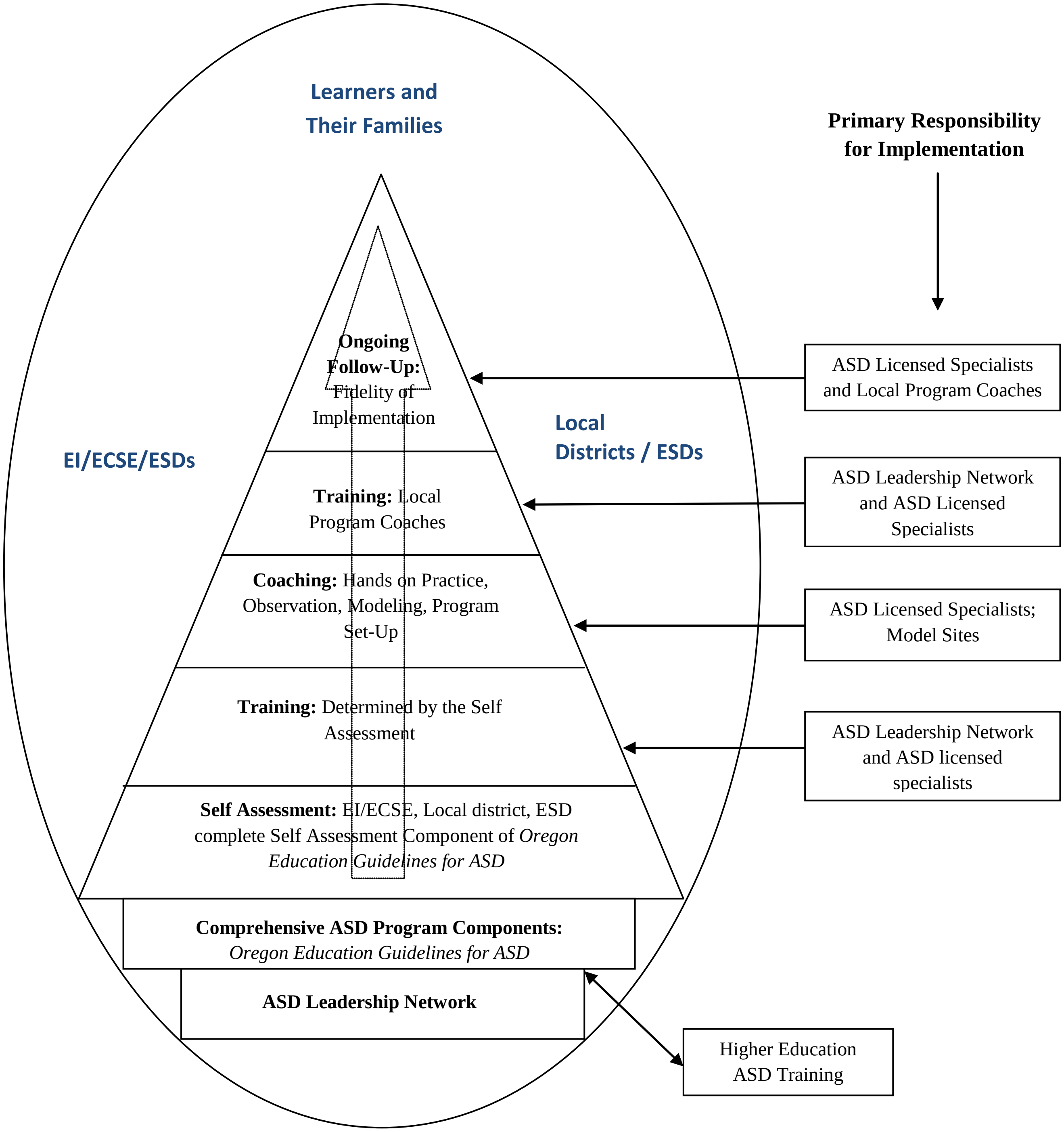
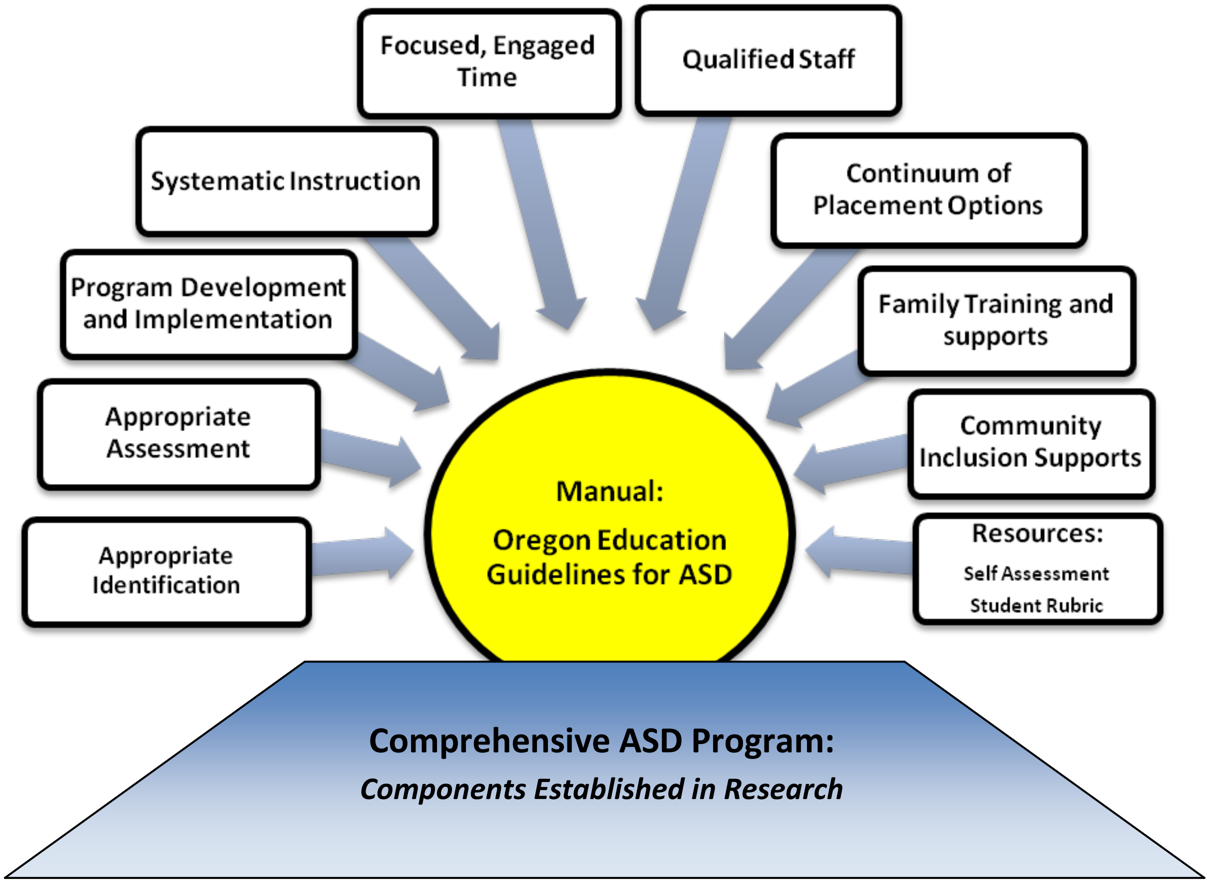


**DIAGRAM ED 2**: OREGON EDUCATION GUIDELINES FOR AUTISM SPECTRUM DISORDERS



# EDUCATION (ED) CONTINUED

## DIAGRAM ED 3: ASD LICENSE AND/OR COMPETENCY REQUIREMENTS

| Position ➲ | **ASD *Licensed* Specialist (ASD-CTL)** | **ASD *Identification* Specialist** | **ASD *Transition* Specialist** |
|---|---|---|---|
| **Requirements** | 1. Obtain ASD-CTL from Teacher Standards & Practice Commission (TSPC).<br>2. Add to current license: Special Education; or EI/ECSE<br>3. ASD-CTL TSPC license can be obtained through competency–based higher education coursework or competency-based, documented Portfolio.<br>4. Meet experience requirements needed to obtain ASD-CTL.<br>*Refer to Education: Teacher Training* | 1. Hold Current License:<br>a. School Psychology;<br>b. Speech and Language;<br>c. ASD-CTL, or<br>d. Special Education<br>2. Meet competency requirements per OARs (Oregon Administrative Rules).<br>3. Meet experience requirements per OARs.<br>*Refer to Education: Teacher Training* | 1. Hold current License:<br>a. ASD-CTL<br>b. Special Education<br>c. General Education<br>2. Meet competency requirements per OARs.<br>3. Meet experience requirements per OARs.<br>*Refer to Education: Teacher Training* |
| **Role** | Support to EI/ECSE, Local district, and ESD programs in the implementation of *Oregon Education Guidelines for ASD* by providing:<br>• Training<br>• Coaching<br>• Program Set-Up<br>• Follow-Up<br>*Refer to Implementation of Comprehensive Program Framework* | Work with EI/ECSE and Local districts to conduct required components of the Identification of an ASD.<br>*Refer to Screening, Identification, and Assessment* | Work with Local School Districts and ESD Programs in the implementation of best practice activities to transitioning youth as identified in the *Oregon Education Guidelines for ASD.*<br>*Refer to Education: Interagency Transition* |
| **Other** | 1. One may be licensed as an ASD-CTL and also serve in role as ASD Identification Specialist or ASD Transition if the competencies for either position are demonstrated.<br>2. Holding an ASD-CTL license does not automatically qualify an individual to serve as an ASD Identification Specialist or ASD Transition Specialist. Separate sets of competencies are required for each. | The Identification team as a whole must possess specific knowledge elements (competencies) for applying the DSM criteria for identification of individuals with ASD. If one individual demonstrates all the competency and experience requirements, they would serve role as ASD Identification Specialist. | This position works in collaboration with local education staff and ASD licensed specialists. |

# EDUCATION (ED) CONTINUED

## DIAGRAM ED 4: EXPANDED CORE CURRICULUM

| **Core Curriculum:**<br>The general curriculum and standards for all learners |
|---|
| • English Language Arts<br>• Mathematics<br>• Health<br>• Physical Education<br>• Science<br>• Second Language<br>• Social Sciences<br>• The Arts |
| **Expanded Core Curriculum:**<br>The curriculum that addresses the unique characteristics and learning needs of learners with ASD |
| • Communication Development<br>• Social Development<br>• Cognitive Development<br>• Sensory Processing<br>• Adaptive Skills; Life Function<br>• Organization Skills<br>• Transitional Skills, including day to day transitions and career and life goals<br>• Self-Advocacy |

# EDUCATION: EARLY INTERVENTION / EARLY CHILDHOOD SPECIAL EDUCATION THROUGH SCHOOL AGE (ED-EISA)

**Goal ED-EISA 1: A statewide *Comprehensive ASD Program* (see Diagram ED 1) is designed and implemented.**

**Recommendations:**

**ED-EISA 1.1** The *Comprehensive ASD Program* will be based on the compilation of most current educational research available on autism spectrum disorders.

Implementation Activities:

ED-EISA 1.1.1 The statewide framework specifies delivery of service and instruction for learners with ASD for the purposes of 1) disseminating consistent evidence-based best practices, 2) providing consistent training and coaching, 3) offering coordinated, collaborative services, 4) proving sufficient instruction to meet the needs of the individual learner, 5) ensuring that mandated timeframes for service are met, and 6) assessing for successful outcomes.

**ED-EISA 1.2** The details for the *Comprehensive ASD Program* will be contained in the implementation manual *Oregon Education Guidelines for ASD*.

Implementation Activities:

ED-EISA 1.2.1 Components of the *Comprehensive ASD Program* will be described in the manual, including:

A. Appropriate identification and assessment.

B. Expanded Core Curriculum for learners with ASD.

C. Evidence based practices (focus on interventions that have an evidence base, while tracking and encouraging further investigation of interventions that have shown promise) related to Instruction; Systematic implementation; and Data.

D. Focused/engaged time – time in which the learner is engaged in systematically planned, developmentally appropriate educational activities aimed toward identified objectives. Where the activities take place and the content of the activities is determined on an individual basis. The learner must receive sufficient attention on a daily basis so that individual objectives can be effectively implemented. Instruction should include direct one-to-one and small group teaching.

E. Qualified staff.

F. Continuum of placement – how the environment and the educational strategies allow for implementation of the individualized goals for the child.

G. Family involvement and supports.

H. Community inclusion supports.

**Goal ED-EISA 2: There is an "ASD Leadership Network", consisting of 5 high level experts, with the responsibility to review, coordinate, and develop policy, disseminate, train and coach on information related to the *Comprehensive ASD Program*.**

**Recommendations:**

**ED-EISA 2.1** Establish the kinds of expertise and qualifications needed for the ASD Leadership Network. Expertise in ASD and additional expertise must be reflected in the Leadership Network in the following areas:

A. Program management.

B. Identification and differential diagnosis.

C. Assessment of ASD educational needs and Expanded Core Curriculum.

D. Early Intensive Behavioral Intervention.

E. Evidence-based interventions.

F. Professional development including training and coaching practices.

G. Transition planning.

H. Working with families.

**ED-EISA 2.2** Create an advisory group to the ASD Leadership Network which will include individuals with ASD, family members and local educational programs.

**ED-EISA 2.3** Determine where ASD Leadership Network staff will be located, and what agency/program will provide oversight for Network.

# EDUCATION: EARLY INTERVENTION / EARLY CHILDHOOD SPECIAL EDUCATION THROUGH SCHOOL AGE (ED-EISA)

CONTINUED

**ED-EISA 2.4** A member of the ASD Leadership Network has expertise in supporting families in the areas of training, coaching problem solving, and facilitating family to family connections.

<u>Implementation Activities</u>:

ED-EISA 2.4.1 ASD Leadership Network will include families when conducting needs assessments, designing the format for training to meet the needs of families statewide, and for implementing and evaluating the effectiveness of training.

ED-EISA 2.4.2 Provide local training, coaching and problem solving to families, in partnership with local staff.

**ED-EISA 2.5** A member of the ASD Leadership Network has expertise in transition to adult life, community outreach and training community partners.

**ED-EISA 2.6** Under the direction of the ASD Leadership Network, provide a web-based clearinghouse of expanded core curriculum materials, evidence-based books, training materials, assessments, and related resources available for short term loan to parents, educators, agencies and community members throughout the state of Oregon.

<u>Implementation Activities</u>:

ED-EISA 2.6.1 Review the resources currently available at the existing statewide library and update as needed.

ED-EISA 2.6.2 Disseminate resource lists statewide through education and community agencies.

**Goal ED-EISA 3: The manual *Oregon Education Guidelines for ASD*, which details the critical components programs need to have available to serve the range of learners with ASD, assists local districts, EI/ECSE programs, and ESDs throughout the state, to implement the components of the *Comprehensive ASD Program* (Diagram ED 2).**

**Recommendations:**

**ED-EISA 3.1** The *Oregon Education Guidelines for ASD* will be developed based on best practice information and will address the following:

A. Appropriate identification.

B. Appropriate assessment, including Expanded Core Curriculum for learners with ASD

C. Program development and implementation, including system wide considerations, student considerations, and positive behavior intervention supports.

D. Systematic instruction, including instruction of the expanded core curriculum using best practice intervention strategies, strategies for inclusion in the general curriculum and school activities, and transition considerations.

E. Focused, engaged time.

F. Qualifications for staff.

G. Family training and supports.

H. Community inclusion supports.

I. Continuum of placement options.

J. Local district, EI/ECSE, ESD Written Improvement Plan format.

K. Best practice resources.

# EDUCATION: EARLY INTERVENTION / EARLY CHILDHOOD SPECIAL EDUCATION THROUGH SCHOOL AGE (ED-EISA)

CONTINUED

Implementation Activities:

ED-EISA 3.1.1 Design the format, content and training for implementation of the *Components of a Comprehensive ASD Program* in the manual: *Oregon Education Guidelines for ASD*:

A. Share draft guidelines with stakeholders. Solicit feedback and make modifications as needed. (Feedback from ASD working groups, special education directors, ASO, self advocates).

B. ASD Leadership Network will train ASD licensed specialists on the components of a Comprehensive ASD Program using the manual *Oregon Education Guidelines for ASD*.

C. ASD Leadership Network will identify EI/ECSE, local district, and ESD program staff to train on use of *Oregon Education Guidelines for ASD*, including the Self Assessment and Written Plan.

D. ASD Leadership Network and ASD licensed specialists will train identified local districts, EI/ECSE, ESD program, parents and others on the components of the *Oregon Education Guidelines for ASD*.

E. Design plan for ongoing review of effectiveness, and updates of *Oregon Education Guidelines for ASD*.

**Recommendations:**

**ED-EISA 3.2** *Oregon Education Guidelines for ASD* will include a self assessment component and written implementation plan format, to be used by each district, EI/ECSE program, and ESD program to determine their level of implementation of the components of the *Comprehensive ASD Program*

**ED EISA 3.3** Design a self assessment for community partners regarding the Transition process to assess their level of need for support from the ASD Leadership Network.

**ED-EISA 3.4** The self assessment and written implementation plan of the *Oregon Education Guidelines for ASD* will serve as a needs assessment for determining the training, coaching, program set up, and follow up provided by the ASD Leadership Network and the ASD licensed specialists to districts, EI/ECSE, and ESDs.

**Goal ED-EISA 4: Licensed educators, specialists, paraprofessionals, ASD licensed specialists, local program coaches, preschool providers and other community providers (based on their education role in serving individuals with ASD) have a sufficient level of skills to ensure implementation of the *Oregon Education Guidelines for ASD.***

**Recommendations:**

**ED-EISA 4.1** There will be qualified ASD licensed specialists available statewide to provide expertise support to local districts and EI/ECSE programs to work in collaboration with the ASD Leadership Network to implement the *Oregon ASD Education Guidelines for ASD.*

**ED-EISA 4.2** Competency-based ASD licensed specialists will be available statewide to provide consistent training, coaching, program set up, and follow up as part of the implementation of the *Oregon Education Guidelines for ASD.*

**ED-EISA 4.3** Ongoing professional development opportunities, coordinated with the components of *Comprehensive ASD Program* described in the *Oregon Education Guidelines for ASD* will be available statewide.

**ED-EISA 4.4** ASD licensed specialists will provide support to districts, EI/ECSE program, and families, in evidence-based interventions: a) systematic didactic training in evidence-based interventions, b) set up materials and setting, c) on-site coaching of evidence-based interventions and d) follow up support to address fidelity of implementation of the *Oregon Education Guidelines for ASD.*

**ED-EISA 4.5** EI/ECSE, local districts, and ESD programs will identify local professionals to serve in the role of local coaches. ASD licensed specialists will train the local coaches to assist with fidelity of implementation of instructional strategies, follow-up and problem solving concerning individual student issues.

**ED-EISA 4.6** The competencies needed for each ASD specialist will be matched to the role in which they serve. In addition to demonstrating competencies, the ASD licensed specialist will be licensed through TSPC: (See Diagram ED 3: ASD License and/or Competency Requirements). The three specified specialist positions are: ASD Identification Specialist; ASD Licensed Specialist; and ASD Transition Specialist.

**ED-EISA 4.7** The role ASD licensed specialist will be to conduct assessments (expanded core curriculum), and to train and coach staff on the implementation strategies needed for the intensive learner and the learner in the general education setting. In this context, the intensive learner strategies mean behavioral teaching procedures based upon the principles of applied behavior analysis. The program provides intensive intervention in highly structured settings.

**ED-EISA 4.8** All staff, building administrators, general education teachers, special education teachers, and paraprofessionals will participate in basic training regarding the needs of learners with ASD.

**ED-EISA 4.9** Staff working directly with learners with ASD in the classroom (general and special education) will be involved in systematic training and onsite coaching specific to the evidence-based interventions used by individual learners.

**ED-EISA 4.10** There will be a sufficient pool of local coaches in schools and buildings (EI/ECSE programs, local district programs, ESD programs) to sustain fidelity of implementation of ASD evidence-based interventions.

**ED-EISA 4.11** A systematic format for training and coaching, including the use of technology, will be used across the state to provide consistency for professional development on evidence-based interventions.

**ED-EISA 4.12** Sufficient funding will be available to implement and sustain all the components of the *Comprehensive ASD Program* framework.

> Implementation Activities:
>
> ED-EISA 4.12.1 Advocate in the 2011 legislative session for adequate funding for both EI/ECSE services and for the ASD licensed specialists needed to support the implementation of the *Comprehensive ASD Program.*

**ED-EISA 4.13** Each staff member providing instruction to learners with ASD will demonstrate basic skills and participate in related professional development activities.

**Goal ED-EISA 5: Appropriate identification and a thorough assessment to determine the need for specially designed instruction is available in a timely manner for all individuals birth-21 referred for an evaluation for an ASD.**

**Recommendations:**

**ED-EISA 5.1** Training is provided to appropriate ASD licensed specialists and experienced education personnel (e.g. school psychologist, speech language pathologist) needed to implement Oregon's identification process for ASD.

**ED-EISA 5.2** ASD Leadership Network, ASD licensed specialists, and identification specialists with the combined expertise in ASD and in recognizing co-occurring and other similar conditions will provide training, coaching and problem solving support to school staff responsible for addressing the identification and assessment of learners suspected of having ASD.

**ED-EISA 5.3** ASD licensed Specialists and the local team, as required by IDEA, will collaborate in conducting the comprehensive assessment to address the Expanded Core Curriculum for learners with ASD, determining the educational impact of the characteristics the learner with ASD displays, and determining the need for specially designed instruction.

**Goal ED-EISA 6: Learners with ASD receive appropriate coordinated instructional and other strategies using best practice interventions and support.**

**Recommendations:**

**ED–EISA 6.1** Young children identified with ASD will receive coordinated intensive intervention and support.

Implementation Activities:

ED-EISA 6.1.1 Seek funding of actual cost of early, appropriate, intensive intervention to meet the needs of learners with ASD from birth-5.

**ED-EISA 6.2** Levels of service (based on assessment data) are sufficient to demonstrate progress toward defined goals, using systematically planned, developmentally appropriate activities. The location of the activities and the content of the activities are determined on an individual basis. The learner must receive instruction from an adult on a daily basis, including direct one-to one and small group teaching, and maximizing planned teaching opportunities.

# EDUCATION: EARLY INTERVENTION / EARLY CHILDHOOD SPECIAL EDUCATION THROUGH SCHOOL AGE (ED-EISA)

CONTINUED

**ED-EISA 6.3** Program planning addresses the Expanded Core Curriculum for ASD for each individual learner: communication development, social / emotional development, cognitive development, sensory processing, adaptive skills/life function, challenging behaviors, organization skills, transitional skills (which address both day-to-day general transitions and changes as well as the long-term development of career and life skills) and self-advocacy.

**ED-EISA 6.4** Flexible placement options are available to meet each student's needs, providing the greatest opportunity for appropriate interactions with typical peers along with access to instruction on the core curriculum (all learners) and the Expanded Core Curriculum (for learners with ASD).

**ED-EISA 6.5** Addressing the needs determined by the comprehensive assessment, instruction is designed to implement evidence-based intervention strategies known to be effective for learners with ASD and match individual strengths and weaknesses.

**ED-EISA 6.6** For each individual learner, a carefully planned sequence of instruction, incorporating evidence-based instructional and intervention strategies, is provided. Progress data will be collected and analyzed, and instruction modified as needed.

**ED-EISA 6.7** Educational placements support the implementation of individualized goals for the learner. Placements promote continuity, cohesion and consistency across all environments to meet individual needs and enhance the learner's independence.

**ED-EISA 6.8** Placement options are sufficient to address the implementation of the *Oregon Education Guidelines for ASD.*

**ED-EISA 6.9** Each learner with ASD shall have appropriate opportunities for successful and meaningful interactions with similar aged peers. The activity and frequency of the activity should consider the preferences of the learner with ASD and the family, as appropriate.

**Goal ED-EISA 7: Children and youth with ASD have the appropriate support, if necessary, to access the general education programs and other school based activities and experiences.**

**Recommendations:**

**ED-EISA 7.1** All educational and support staff will understand the impact of the characteristics of ASD on student learning.

**Goal ED-EISA 8: Effective family involvement provides an opportunity for participation in training, decision making and implementation of educational and other school programs.**

**Recommendations:**

**ED-EISA 8.1** Parent trainings will be available in local communities on a regularly scheduled basis.

**ED-EISA 8.2** A clearinghouse for materials and Frequently Asked Questions (FAQ) will be available to all families.

# EDUCATION: INTERAGENCY TRANSITION (EDT)

**Goal EDT 1: Individuals with ASD make a successful transition from secondary school to permanent employment, higher education, or other post secondary goals.**

**Recommendations:**

**EDT 1.1** ODE data on secondary education outcomes is tracked and available.

**Goal EDT 2: Students with ASD and their families are informed early and frequently about transition processes, best practices and opportunities.**

**Recommendations:**

**EDT 2.1** Students with ASD and their families will be provided with a “Transition Roadmap” or standardized information packet at the key points: 5th grade, 8th grade, and appropriate periods throughout high school.

**EDT 2.2** Students will maintain a *Transition Portfolio* beginning in the 5th grade when s/he first learns about diploma options and throughout the student’s remaining education. Each subsequent year, the student would add to the *Transition Portfolio.* See EDT 6.3 for further description of the *Transition Portfolio*.

> Implementation Activities:
>
> EDT 2.2.1Complete the development of the Transition Portfolio, pilot use, evaluate and modify.

**Goal EDT 3: The Oregon Department of Education will participate in an Interagency Transition Agreement that includes explicit language defining transition, the transition process, and transition services in order to ensure common understanding and consistency in implementation of transition services.**
**(See also Coordination and Collaboration).**

**Recommendations:**

**EDT 3.1** An explicit and readable guide will be used in Oregon schools to describe best practice activities schools *must* provide to transitioning youth and activities which they *may* engage in with transitioning youth.

Implementation Activities:

3.1.1 Develop a matrix to delineate best practice activities for transitioning youth.

**EDT 3.2** The Oregon Department of Education will collaborate with other agencies in the development and distribution of materials on transition for youth with ASD.

**Goal EDT 4: The Oregon Department of Education (ODE) and school districts participate in statewide and local Interagency Transition Committees designed to promote collaborative transition goals, monitor collaborations, address conflicts, support collaborative initiatives, and track transition outcomes.**

**Recommendations:**

**EDT 4.1** ODE and schools will utilize Interagency Transition Committees to monitor, recommend, and advise on interagency collaborations, transition best practices, and student outcomes.

**Goal EDT 5: Transition specialists and ASD licensed specialists work collaboratively to improve the transition outcomes for youth with ASD.**

**Goal EDT 6: Implementation of best practices in the education setting results in more seamless and successful transition outcomes for youth with ASD.**

**Recommendations:**

**EDT 6.1** Oregon Department of Education and local school districts will provide incentives, including credits, and opportunities for students with ASD to participate in transition activities, including:

A. Students may receive academic credit for transition activities (e.g., work experience, internships, 1:1 transition counseling.

B. Students have access to expanded core curriculum in which academic or elective credit is available for courses that teach skills needed for successful transition and self-advocacy.

C. Students have the option, when appropriate, of developing plans that integrate the Individualized Education Plan (IEP) and the goals of the adult services Individualized Support Plan (ISP).

**EDT 6.2** The transition IEP format will specifically include the areas of transition identified in IDEA for the purpose of expanding the focus of transition activities consistent with IDEA.

**EDT 6.3** The Summary of Performance format is expanded to reflect best practices and is made part of the *Transition Portfolio*. *The Transition Portfolio* shall include the documentation that facilitates entry into adult services or continuing education including the most recent testing information, vocational evaluation, present level of performance, strengths, needs and appropriate support strategies.

<u>Implementation Activities</u>:

6.3.1 Students will be taught to how to use the *Transition Portfolio* in self-advocacy in seeking employment or further educational opportunities.

**EDT 6.4** Every student with ASD will have IEP goals and objectives for an expanded core curriculum that reflect the Preferences, Interests, Needs and Services (PINS) in the unique academic and functional skills required to transition effectively into adult life. For example: Social competence/social cognition; self-determination/self-advocacy; and self-awareness.

**Goal EDT 7: Adult service agencies and educational agencies share trainings and best practice in achieving successful transition outcomes for individuals with ASD.**

# EDUCATION: TEACHER TRAINING (EDTT)

**Goal EDTT 1: An adequate pool of skilled ASD licensed specialists, behavior specialists and teachers of children with ASD exists to meet the demand.**

**Recommendations:**

**EDTT 1.1** To serve as an ASD licensed specialist, an individual must obtain ASD Specialist Continuing Teacher License (ASD-CTL) from TSPC. For most of the professionals currently serving in the role as an ASD specialist, there will be minor additions in the competencies they currently demonstrate (See EDTT 2.5 for recommendations relating to phase in).

**EDTT 1.2** Qualified ASD licensed specialists will serve in the identified role of Training, Coaching, Program Set-up, and Follow-up: (Refer to the *Implementation of the Comprehensive ASD Program* and *ASD License and Competency Requirements*).

Implementation Activities:

EDTT 1.2.1 Competencies will be established to align with the role of the ASD licensed specialist (training, coaching, program set-up, follow-up) to address learners with an ASD in both the intensive classroom setting and in the general classroom setting.

EDTT 1.2.2 Timelines will be established to transition current ASD specialists to meet the licensure requirements to maintain an adequate pool of qualified staff.

**Goal EDTT 2: Multiple pathways exist to obtain, document, and demonstrate required knowledge and experience to obtain licensure for CTL–ASD.**

**Recommendations:**

**EDTT 2.1** An ASD licensed specialist continuing teacher license (ASD-CTL) may be added to one of the following Oregon licenses currently offered by TSPC: Special Education (to include Handicapped Learner, Severely Handicapped Learner, Special Educator); and Early Intervention/Special Education.

# EDUCATION: TEACHER TRAINING (EDTT)

## CONTINUED

**Recommendations:**

**EDTT 2.2** An ASD-CTL license may be obtained by completing one of the following paths:

A. University training programs in Oregon that offer consistent coursework statewide to address competencies and ASD-CTL standards, through TSPC.

B. A collaborative university panel will be established to approve the documentation and demonstration of competencies through either coursework or specified portfolio evidence. University panel members must demonstrate ASD qualified expertise for membership.

Implementation Activities:

EDTT 2.2.1 Determine the make-up and qualifications of the university panel.

EDTT 2.2.2 Agree on coursework provided by higher education ASD training programs.

**EDTT 2.3** A consistent tool will be created by the collaborative university panel to evaluate competencies.

**EDTT 2.4** The collaborative university panel will work with the ASD Leadership Network to provide continuous review and update of the competencies based on ongoing research in ASD.

**EDTT 2.5** The ASD-CTL will initially be available January 2012 and fully required through a strategic phase in plan over the course of 5-7 years.

Implementation Activities:

EDTT 2.5.1 Timelines will be established to ensure that adequately trained personnel are available at each stage of the phase in plan.

**EDTT 2.6** ASD specialists employed in Oregon at the date the ASD-CTL through first becomes available through Teacher Standards and Practices Commission will have three years to document and demonstrate competencies and obtain the ASD-CTL.

Implementation Activities:

EDTT 2.6.1 In year one of the initial availability of the ASD-CTL existing ASD specialists will complete a self-assessment of the competencies of the ASD licensed specialist and submit a written plan of how they will document and demonstrate competence by the end of the three years.

**EDTT 2.7** Once the ASD-CTL is available an individual cannot retain the title of ASD licensed specialist without meeting the identified competencies.

**EDTT 2.8** A transition plan and timelines will be developed to successfully phase in the all components of the *Comprehensive ASD Program* framework.

**EDTT 2.9** Some ASD licensed specialists will be qualified to function as "Identification Specialists". These specialists will meet criteria (competencies) required for use of the DSM for identification of individuals with ASD:

A. Typical child development;

B. Atypical child development;

C. Psychopathology appropriate to the age of the person being evaluated. Understand DSM for other conditions to sufficiently differentiate ASD from others such as intellectual disabilities, anxiety, OCD, RAD, ADHD, and bipolar. Understand behavior not explainable by typical cognition/emotion;

D. Formal (structured) and informal (observation/interview) assessment processes;

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. Ideally, knowledge sufficient to identify red flags indicating the need for further referral.

**EDTT 2.10** Other licensed professionals will be qualified to function as an “Identification Specialist” by demonstrating identified competencies and experience for use of the DSM for identification of individuals with ASD (See EDTT1.3 and SIA). Licensed professionals include:

A. School Psychologist;
B. Speech Language Pathologist.

**EDTT 2.11** A licensed professional will be qualified to function as an “ASD Transition Specialist” by demonstrating identified competencies and experience need to implement best practices in the education setting for transitioning for youth with ASD. Licensed professionals include:

A. Special Education Teacher;
B. ASD Licensed Specialist.

**Goal EDTT 3: There is a set of basic qualifications, training, and related professional development activities for each staff member providing instruction and/or support with learners with an ASD.**

**Recommendations:**

**EDTT 3.1** Professionals working with learners with ASD will obtain skills needed to be qualified staff as identified by the *Comprehensive ASD Program* and in the *Oregon Education Guidelines for ASD*, through ongoing professional development activities.

A. Special education teachers;
B. Speech and language pathologists;
C. Paraprofessionals;
D. General education teachers;
E. Board certified behavior analysts;
F. School administrators.

**EDTT 3.2** Professionals are informed and trained on transition processes, best practices and opportunities, specifically as they apply to youth with ASD.

**EDTT 3.3** Pre-service training of future special education teachers, general education teachers, and transition specialists contains content specific to individuals with ASD.

# EDUCATION: HIGHER EDUCATION (EDHE)

**Goal EDHE 1: Adults with ASD will have access to the supports necessary for successful post-secondary educational experiences and outcomes.**

**Recommendations:**

**EDHE 1.1** Disability services offices in colleges will be knowledgeable about ASD and their responsibilities under the Americans with Disabilities Act and will be able to provide the appropriate necessary supports for individuals.

Implementation Activities:

EDHE 1.1.1 Discussions about improving supports to individuals with ASD will be planned with ORAHEAD, the organization of university disability centers.

**EDHE 1.2** Training and support will be available to campus services such as the career centers, security, and student living.

**EDHE 1.3** Students with ASD will be knowledgeable about how to advocate for appropriate supports and where to seek legal assistance if necessary.

**Goal EDHE 2: Students, high school counselors, personal agents, case managers, families, and others, will be aware of the opportunities provided in post-secondary education and the supports needed to make it a viable option for students with ASD.**

**Goal EDHE 3: The college experience will be available to students with ASD who experience academic challenges.**

**Recommendations:**

**EDHE 3.1** Support the THINK COLLEGE planning grant activities proposed by the University of Oregon.

**Goal EDHE 4: Autism specific college programs are available.**

# EDUCATION (ED) CONTINUED

## NEXT STEP ACTIONS:

1. **Complete the initial manual addressing the comprehensive program for ASD: *Oregon Education Guidelines for ASD*. The manual includes components of the comprehensive program, the self assessment for all programs, the individual student rubric, and resources linked to each of the components.**

2. **Pilot the self assessment and corresponding resources contained in the *Oregon Education Guidelines for ASD* in interested EI/ECSE, districts, and ESD programs.**

3. **Seek support from ODE to develop a statewide initiative for the self assessment and implementation of the *Oregon Education Guidelines for ASD* similar to other state initiatives and requirements (e.g. PBIS, RTI, ELL).**

4. **Work with ODE to establish the five person ASD Leadership Network to assist in the ongoing implementation of the *Oregon Education Guidelines for ASD*.**

5. **Review other states with insurance mandates in place to explore the use of qualified education personnel as service providers.**

6. **Complete the design of the *Transition Portfolio* and begin to pilot usage.**

7. **Establish competencies for the ASD Continuing Teacher License, ASD Identification Specialist, and the ASD Transition Specialist. Begin to design training opportunities to address the competencies.**

8. **Work with ODE to redesign the medical statement (as long as it is required to gain more useful information and to encourage collaboration between education and health care.**

9. **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.**

10. **Redo the Summary of Performance document and pilot it.**

11. **Resolve licensure issues for speech language pathologists and school psychologists in the ASD licensure process.**

# COMMUNITY SUPPORTS & SERVICES (CSS)

### SUMMARY OF ISSUES:

The rapid increase in the number of individuals with ASD has put additional demands on publicly funded services and other community services for people with disabilities. There is concern within the state agencies providing social services about how they will be able to respond to the growing population of individuals with ASD and their families who may require support and services. Advocacy and support groups, nonprofit organizations, and other private community groups have been unable to meet the statewide need of the thousands of individuals with ASD and their families.

The identification of ASD does not automatically entitle an individual to any publicly funded services in Oregon. Individuals with ASD must meet additional eligibility criteria to receive services through social service programs such as those offered through Seniors and People with Disabilities, Office of Developmental Disability Services, Addictions and Mental Health or the Oregon Health Plan. Many individuals with ASD require supports and services to be successful but do not meet any eligibility threshold that will entitle them to the needed services. There are few services for children with ASD and their families.

Individuals may struggle to succeed in education, including higher education, employment, making social connections, and independent living, because the entities involved have been unable to adequately respond to the issues presented by ASD.

Supports and services will be more appropriate and effective when individuals with ASD are involved in the creation, implementation, and evaluation at both the system and the individual service level. Individuals with ASD and their families have valuable insight that will enhance public awareness and training activities.

# COMMUNITY SUPPORTS & SERVICES (CSS)

## CONTINUED

**Goal CSS 1: Services are available through the private and public sector to meet the unique needs of individuals with ASD and their families, across the lifespan and across the spectrum.**

**Goal CSS 2: Program administrators and providers have accurate information about ASD and an understanding of the impact of ASD on the individual and their family, resulting in more effective services that better meet the full array of support needs of individuals with ASD and their families.**

**Recommendations:**

**CSS 2.1** The Department of Human Services website will be enhanced to include current resources and directories for program administrators and service providers supporting individuals with ASD and their families.

**CSS 2.2** Each agency will conduct a needs assessment of training and support needs of direct service providers, develop related training programs, and provide training in a variety of formats, including the use of online training.

**CSS 2.3** The Oregon Department of Human Services and the Oregon Health Authority will identify staff with autism expertise to train and provide technical assistance in program areas such as Child Welfare, Developmental Disabilities, and Mental Health.

**Goal CSS 3: Providers of direct services have enhanced skills and competencies to meet the needs of individuals with ASD and their families. Training, research, and programmatic resources are available.**

**Recommendations:**

**CSS 3.1** Recruitment, training and retention will be enhanced to ensure access across the state.

**Goal CSS 4: Community members including law enforcement, transportation system personnel, local business persons, co-workers, educators, and classmates have increased awareness, knowledge, and understanding which results enhancement of natural supports for individuals with ASD in all environments.**

**Recommendations:**

**CSS 4.1** Law enforcement, first responders, corrections, and the judicial system will receive information and training to improve interactions and outcomes for individuals with ASD.

**CSS 4.2** Families and individuals will receive information about strategies to improve interactions with law enforcement, first responders, corrections, and the judicial system.

> Implementation Activities:
>
> CSS 4.2.1 Develop or identify existing informational cards specific to autism that can be used by individuals and families.

**CSS 4.3** Families and individuals will be aware of voluntary police registries with sufficient detail to assure informed choices about participation***.***

> Implementation Activities:
>
> CSS 4.3.1 Research the criteria and regulations for participation in registries in areas where they exist.
>
> CSS 4.3.2 Prepare a document that highlights the pros and cons of registry and make the document available to individuals and families.

**CSS 4.4** Law enforcement, corrections and the judicial systems will improve their ability to identify and appropriately respond to individuals with ASD.

> Implementation Activities:
>
> CSS 4.4.1 Promote the inclusion of information on ASD in the training provided police officers at the Oregon Police Academy.

CONTINUED

**Recommendations:**

**CSS 4.5** Convene a workgroup to explore the issues related to children and adults involved in the juvenile justice system, the adult justice system, and the corrections systems

Implementation Activities:

CSS 4.5.1 Identify members of the ASD justice system work group and schedule first meeting in January 2011.

CSS 4.5.2 Identify appropriate information and training materials and strategies to incorporate into orientations with law enforcement, corrections, and judicial system professionals.

**CSS 4.6** High school and college level peer tutors, youth leaders, and self advocates will participate in existing ASD related training with school personnel to maximize their involvement and inspire future career paths.

Implementation Activities:

CSS 4.6.1 Collaborate with colleges, local school districts, educational service districts, and others to identify and promote the involvement of high school and college level peer tutors, youth leaders, and self-advocates in existing ASD related trainings and skill building opportunities.

**Goal CSS 5: An interactive, easy to use online service navigation and planning tool is available for individuals, families, resource navigators, and service coordinators to assist in identifying appropriate and available services and supports. Independent resource navigator means an individual or entity that assists a family or individual to locate and access appropriate supports and services.**

**Recommendations:**

**CSS 5.1** A process will be established to enhance the DHS website based on identified needs, with current resources and directories for individuals, families, and community members.

**Goal CSS 6: Individuals with ASD and their families will be engaged in the design and delivery of training, review of materials, and the design, implementation, and evaluation of supports and services at the system and individual level.**

**Goal CSS 7: Supportive physical environments and a variety of appropriate housing options are available to individuals with ASD and families.**

**Recommendations:**

**CSS 7.1** Individuals with ASD, their families, and other ASD advocates will engage with low income housing systems and advocates to increase awareness of the need for appropriate housing.

Implementation Activities:

CSS 7.1.1 Identify state and local planning opportunities and encourage participation from the autism community.

CSS 7.1.2 Identify key issues and talking points related to housing issues for individuals with ASD.

**CSS 7.2** Individuals with ASD and their families will have access to information on strategies for community living and safety.

**CSS 7.3** Discussions on housing and the physical environment will be included in person-centered planning activities.

**CSS 7.4** Technical assistance in environmental assessment and modification will be available to individuals with ASD and their families.

Implementation Activities:

CSS 7.4.1 Individuals with ASD will provide guidance on necessary housing options and modifications of specific relevance to individuals with ASD.

**Goal CSSC 1: Children and youth (birth-18) with ASD and their families can access a full continuum of proactive support services through public and private sectors.**

**Recommendations:**

**CSSC 1.1** Eligibility criteria for publicly funded services will consider functional support needs of children with ASD.

**CSSC 1.2** Support services for families will be family-driven, family-centered, strengths-based, reflective of the uniqueness of ASD, and delivered with sensitivity and respect for family dignity.

> Implementation Activities:
>
> CSSC 1.2.1 Participate in Department of Human Services workgroups to increase creative use and integration of public and private funding.

**CSSC 1.3** Person-centered planning and self-advocacy are essential components of services to children and youth and families.

> Implementation Activities:
>
> CSSC 1.3.1 Promote awareness of the value of person-centered planning and self-advocacy to individuals, families, and professionals through publications, websites, and listservs.
>
> CSSC1.3.2 Share opportunities to engage in person-centered planning and self-advocacy through publications, websites, and listservs.
>
> CSSC1.3.3 Increase the number of person-centered planning facilitators by expanded opportunities for training.

**Recommendations:**

**CSSC 1.4** Services for families may include a wide range of both publicly and privately funded supports and interventions.

Implementation Activities:

CSSC 1.4.1 Information regarding resources will be offered to families.

CSSC 1.4.2 Respite services and trained providers will be coordinated and available through publicly and privately funded resources.

CSSC 1.4.3 Engage with Oregon's Lifespan Respite program to improve awareness, effectiveness and accountability in developing services for individuals with ASD and their families.

**CSSC 1.5** Publicly funded services will be efficient, cost effective, and will maximize the use of Medicaid waivers and collaborative funding mechanisms.

Implementation Activities:

**CSSC 1.5.1** Expand the eligibility for the Children's Intensive In-Home Services (CIIS) behavior waiver program to include more children with intense behaviors who may currently be receiving services through Crisis Services or supported by the State General Fund only.

**CSSC 1.6** There will be a clearly defined, transparent continuum of supports available to children and youth with ASD and their families.

Implementation Activities:

CSSC 1.6.1 Children with intensive behaviors that do not meet the CIIS eligibility criteria should be considered for prioritization to receive a minimum level of family support.

CSSC 1.6.2 Families of individuals with ASD will participate on the Seniors and People with Disabilities Advisory Committee on Services to Children.

CSSC 1.6.3 Promote the use of a consistent name for the local DD services office to increase visibility and accessibility to families seeking services.

**Goal CSSC 2: An interagency model of service delivery for children with ASD ensures integrated educational, medical/ mental health, in-home, and community supports and services.**

**Recommendations:**

**CSSC 2.1** Agencies will create individualized child-centered written agreements that specify integrated supports and services.

> Implementation Activities:
>
> CSSC 2.1.1 Create interagency agreements specific to individual children in Children's Intensive In-Home Supports program and other children receiving high levels of supports and services from multiple agencies.

**CSSC 2.2** Children and youth experiencing co-occurring conditions will be accurately identified and will receive appropriate supports and services.

**CSSC 2.3** The level of awareness about ASD and co-occurring conditions will be increased among professionals in the Department of Human Services, the Oregon Youth Authority and the Oregon Health Authority, their local offices and contractors.

**Goal CSSC 3: Information, navigation support, and trainings are readily available to families upon diagnosis, at times of transition, and when requested.**

**Recommendations:**

**CSSC 3.1** Every family will have access to service delivery system navigation map/documents and an opportunity to connect with a resource navigator.

> Implementation Activities:
>
> CSSC 3.1.1 Utilize grant awarded to design and produce navigation map/documents in collaboration with Title IV. Begin design activities with variations for age groupings and develop marketing plan.
>
> CSSC 3.1.2 Convene a workgroup to identify navigator skills and expectations and identify list of possible local navigators in the public and private sector.

**Recommendations:**

**CSSC 3.2** Families will have access to in-home technical assistance (including environmental modification consultation) and positive behavior supports trainings.

> Implementation Activities:
>
> CSSC 3.2.1 Promote opportunities to train families on appropriate environmental modifications.
>
> CSSC 3.2.2 Promote the inclusion of families in positive behavior supports trainings occurring at the local level.

**CSSC 3.3** All families will be aware of community safety resources and will have an emergency response plan.

**Goal CSSC 4: Professionals and service providers working with children and youth with ASD and their families are skilled and knowledgeable.**

**Recommendations:**

**CSSC 4.1** Local publicly funded social and community service program offices will have staff with specific knowledge of characteristics and issues unique to ASD and the resources available.

> Implementation Activities:
>
> CSSC 4.1.1 Identify existing resources, including on-line trainings, and disseminate the information to staff.

**CSSC 4.2** Behavior support providers will have the skill, knowledge and ability to appropriately implement and teach a variety of positive support strategies for use in the family home and other community settings.

**Goal CSSC 5: Crisis services are readily available to individuals and families when other options have been insufficient. These services are delivered in a manner that is respectful of the family and the individual.**

**Goal CSSC 6: Children with ASD have access to a variety of accessible and appropriate recreational and social opportunities.**

## NEXT STEP ACTIONS:

1. **Develop a series of service delivery navigation maps for families through the recently obtained Maternal and Child Health grant.**
2. **Develop outreach plan to assure navigation maps reach families at key contact points and critical times.**
3. **Continue the subcommittee work to expand the implementation activities of the goals and recommendations.**

# COMMUNITY SUPPORTS & SERVICES FOR ADULTS (CSSA)

**Goal CSSA 1: Adult eligibility processes recognize the unique features of adults with autism spectrum disorders and their experiences and concerns.**

**Recommendations:**

**CSSA 1.1** Functional criteria used for eligibility by service agencies will (a) be relevant to autism, (b) relevant to the individual's age (c) account for the role of technology and support in function, and (d) ensure individual and family dignity is respected.

Implementation Activities:

CSSA 1.1.1 Involve adults with ASD in the development and provision of training to service agencies.

CSSA 1.1.2 Provide training on the unique characteristics associated with adults with ASD.

CSSA 1.1.3 Explore use of International Classification of Function (ICF-10) to replace current functional assessments.

**CSSA 1.2** ASD identification information will be portable between agencies and provide needed information to support assessments for eligibility for services from the Vocational Rehabilitation and Developmental Disabilities programs, higher education, and other agencies.

**Goal CSSA 2: Case managers, personal agents, Vocational Rehabilitation counselors and service providers receive information and training to increase their capacity to effectively support individuals across the spectrum during the transition process from school to adulthood.**

**Recommendations:**

**CSSA 2.1** Information on policy initiatives such as "Employment First" is widely distributed to agencies and others providing services and supports to individuals with ASD.

**CSSA 2.2** Information and training regarding ASD and school to adulthood transition is shared among agencies and service providers.

**CSSA 2.3** Individuals with ASD who do not intellectual disabilities will be eligible for services, recreational opportunities and alternatives to regular employment based on the results of appropriate functional assessments.

**Goal CSSA 3: Individuals and families can successfully navigate and utilize the adult services system as a result of improved awareness, outreach, training, and availability of appropriate accessibility strategies.**

**Recommendations:**

**CSSA 3.1** Professionals, including case managers, Vocational Rehabilitation counselors, social workers, health care providers, and mental health workers will demonstrate adequate knowledge, skills and capacity to serve adults with ASD.

Implementation Activities:

CSSA 3.1.1 Effective training and instructional materials will be provided to professionals to assist them to understand and operationalize (a) self-determination, (b) the high variability of ASD, and (c) support needs that may be unique to ASD.

CSSA 3.1.2 Collaborate with individuals and families to understand where eligibility and service processes may be breaking down and how to correct them.

**CSSA 3.2** Eligibility and intake specialists will receive training to (a) better understand the high variability of ASD and (b) improve interpersonal interactions with individuals and their families.

**CSSA 3.3** Materials, processes, and consultations will be culturally and linguistically appropriate and easily available in accessible mediums.

**CSSA 3.4** Service providers will use a strengths-based, self-determined, and respectful approach to service planning and provision.

Implementation Activities:

CSSA 3.4.1 Service providers will collaborate with self-advocates and family advocates to understand where language, processes, or materials may be degrading, and make corrections.

CSSA 3.4.2 Service providers will work with self-advocates and family advocates to improve self-determination and sensitivity training for family members, intake and other service specialists.

**Recommendations:**

**CSSA 3.5** Individuals with ASD and families will have access to the tools and information to successfully navigate and utilize community services and supports.

Implementation Activities:

CSSA 3.5.1 Convene a workgroup, including individuals and families, to begin to identify strategies and create materials to assist individuals and families to better navigate and utilize services and supports.

**Goal CSSA 4: Providers of direct services to individuals with ASD and their families are skilled, and retention is increased.**

**Recommendations:**

**CSSA 4.1** Effective training will be provided to direct service providers to assist them to understand and operationalize (a) self-determination, (b) the high variability of ASD, and (c) support that may be unique to ASD.

Implementation Activities:

CSSA 4.1.1 Include individuals with ASD as subject-matter experts who can provide training.

**CSSA 4.2** Salaries for direct service providers are appropriate to support consistency and retention of skilled professionals.

**CSSA 4.3** Minimum standards for competency, skill levels, and ongoing training will be established for individuals serving as behavior consultants.

**Goal CSSA 5: Publicly funded services meet the full array of support needs of individuals with ASD, and consistently across the state.**

**Recommendations:**

**CSSA 5.1** Establish new service structures that offer ongoing support for which a remediation outcome or skill acquisition is not necessarily required.

Implementation Activities:

CSSA 5.1.1 Collaborate with the Oregon Health Authority, Department of Human Services, and Department of Education in identifying and clarifying desired service outcomes and funding expectations.

CSSA 5.1.2 Agencies will seek grant funding to support activities to design and implement new service structures.

**Recommendations:**

**CSSA 5.2** Quality trainings on the philosophies and processes of person-centeredness and self-determination will be available and accessible to individuals, families and providers.

Implementation Activities:

CSSA 5.2.1 Work with Oregon Technical Assistance Corporation (OTAC) and Autism Society of Oregon (ASO) and other such individuals and organizations, to design and promote opportunities for trainings and information on the person-centered planning and self-determination for individuals, families, and service providers.

**Goal CSSA 6: Alternative supports are available for individuals and families who do not qualify for publicly funded services.**

**Recommendations:**

**CSSA 6.1** Peer mentoring services will be established as an option for support for individuals not eligible for publicly funded services.

Implementation Activities:

CSSA 6.1.1 Support mentoring programs in organizations that may have existing infrastructure (e.g. Independent Living Centers) or create new ones.

CSSA 6.1.2 Link individuals to private funding, foundations, or charitable organizations that may provide services or equipment not available through public funding.

Implementation Activities:

CSSA 6.1.3 Work with leaders of self-advocacy groups and ASD-specific organizations to identify an effective peer mentoring model and funding opportunities.

**Goal CSSA 7: The need for, and sometimes specialized nature, of recreation and social interaction for people with ASD is recognized and supported.**

**Recommendations:**

**CSSA 7.1** Recreation and opportunities for social interaction will be included in cross-agency planning and person-centered planning.

Implementation Activities:

CSSA 7.1.1 Increase awareness of the importance of including recreation and social opportunities in Individualized Support Plan goals for individuals with ASD.

**CSSA 7.2** Make existing community opportunities for recreation more “autism friendly.”

Implementation Activities:

CSSA 7.2.1 Work with existing entities providing adult recreational and social opportunities to develop a strategy for increasing access to individuals with ASD.

**Goal CSSA 8: Individuals with ASD have opportunities for successful employment and a full range of employment opportunities such as regular, supported, volunteer, and entrepreneur activities.**

**Recommendations:**

**CSSA 8.1** Individualized employment supports will be available, appropriate and flexible to meet the needs of individuals with ASD.

**CSSA 8.2** Job coaches, job developers, and direct support staff will demonstrate adequate knowledge and implementation of skills to work with individuals with ASD.

Implementation Activities:

CSSA 8.2.1 Provide technical assistance capacity to support both employers and employees.

CSSA 8.2.2 Long term employment supports need to be flexible enough to meet the needs of individuals with an ASD.

CSSA 8.2.3 Analysis and follow-up on job success will ongoing.

CSSA 8.2.4 Individuals will have tools for effective communication with their employers about their needs, including supports and a plan for problem solving.

**Recommendations:**

**CSSA 8.3** Entities, the individual, and families involved in the support of the individual will work collaboratively to achieve a healthy and sustainable balance between work and other activities of daily living for each individual.

**CSSA 8.4** Individuals with ASD will be considered in all Oregon employment disability initiatives conducted by state agencies and in their outreach to businesses.

Implementation Activities:

CSSA 8.4.1 Ensure that the “Employment First Initiative” includes specific technical assistance and strategies to promote the employment of individuals with ASD, including outreach to community businesses.

**CSSA 8.5** Vocational Rehabilitation offices will have counselors with specialized knowledge on ASD***.***

**CSSA 8.6** Individuals with ASD, and their families as appropriate, will understand their ADA employment rights.

**Goal CSSA 9: Families providing support to adult family members with ASD have access to needed support services including respite.**

**Recommendations:**

**CSSA 9.1** Service agencies separate the funding for caregiver supports from the funding supports provided to the individual still living in the family home.

**Goal CSSA 10: Transportation systems implement accommodation needs of individuals with ASD.**

**Recommendations:**

**CSSA 10.1** The Oregon Department of Transportation will support efforts to increase availability and responsiveness of transportation systems in Oregon to the accessibility requirements of individuals with ASD.

**CSSA 10.2** Public transit systems will utilize training and information provided by individuals with ASD to make transportation accessible.

**CSSA 10.3** Appropriate transit training will be provided to individuals with ASD.

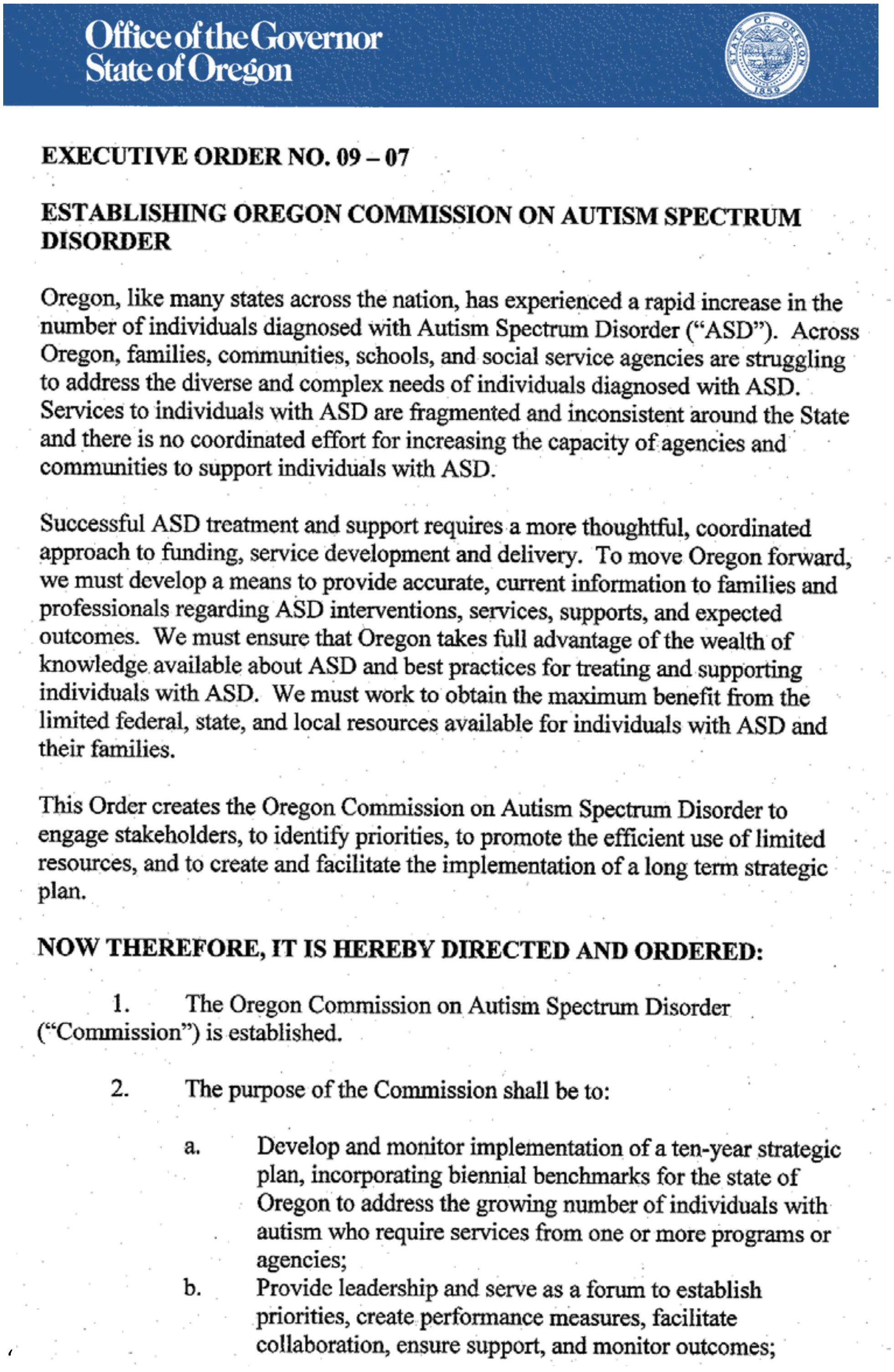
**CSSA 10.4** Develop alternative transportation options for areas of the state which do not have public transportation.

## NEXT STEP ACTIONS:

1. **The Commission will develop a process for engaging adults with ASD, families, and others to expand implementation activities for addressing recommendations identified in this section.**

2. **Convene a work group focused on the issues of youth and adults involved in the judicial and corrections systems and schedule the first meeting.**

## EXECUTIVE ORDER



Office of the Governor
State of Oregon

### EXECUTIVE ORDER NO. 09 – 07

### ESTABLISHING OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

Oregon, like many states across the nation, has experienced a rapid increase in the number of individuals diagnosed with Autism Spectrum Disorder ("ASD"). Across Oregon, families, communities, schools, and social service agencies are struggling to address the diverse and complex needs of individuals diagnosed with ASD. Services to individuals with ASD are fragmented and inconsistent around the State and there is no coordinated effort for increasing the capacity of agencies and communities to support individuals with ASD.

Successful ASD treatment and support requires a more thoughtful, coordinated approach to funding, service development and delivery. To move Oregon forward, we must develop a means to provide accurate, current information to families and professionals regarding ASD interventions, services, supports, and expected outcomes. We must ensure that Oregon takes full advantage of the wealth of knowledge available about ASD and best practices for treating and supporting individuals with ASD. We must work to obtain the maximum benefit from the limited federal, state, and local resources available for individuals with ASD and their families.

This Order creates the Oregon Commission on Autism Spectrum Disorder to engage stakeholders, to identify priorities, to promote the efficient use of limited resources, and to create and facilitate the implementation of a long term strategic plan.

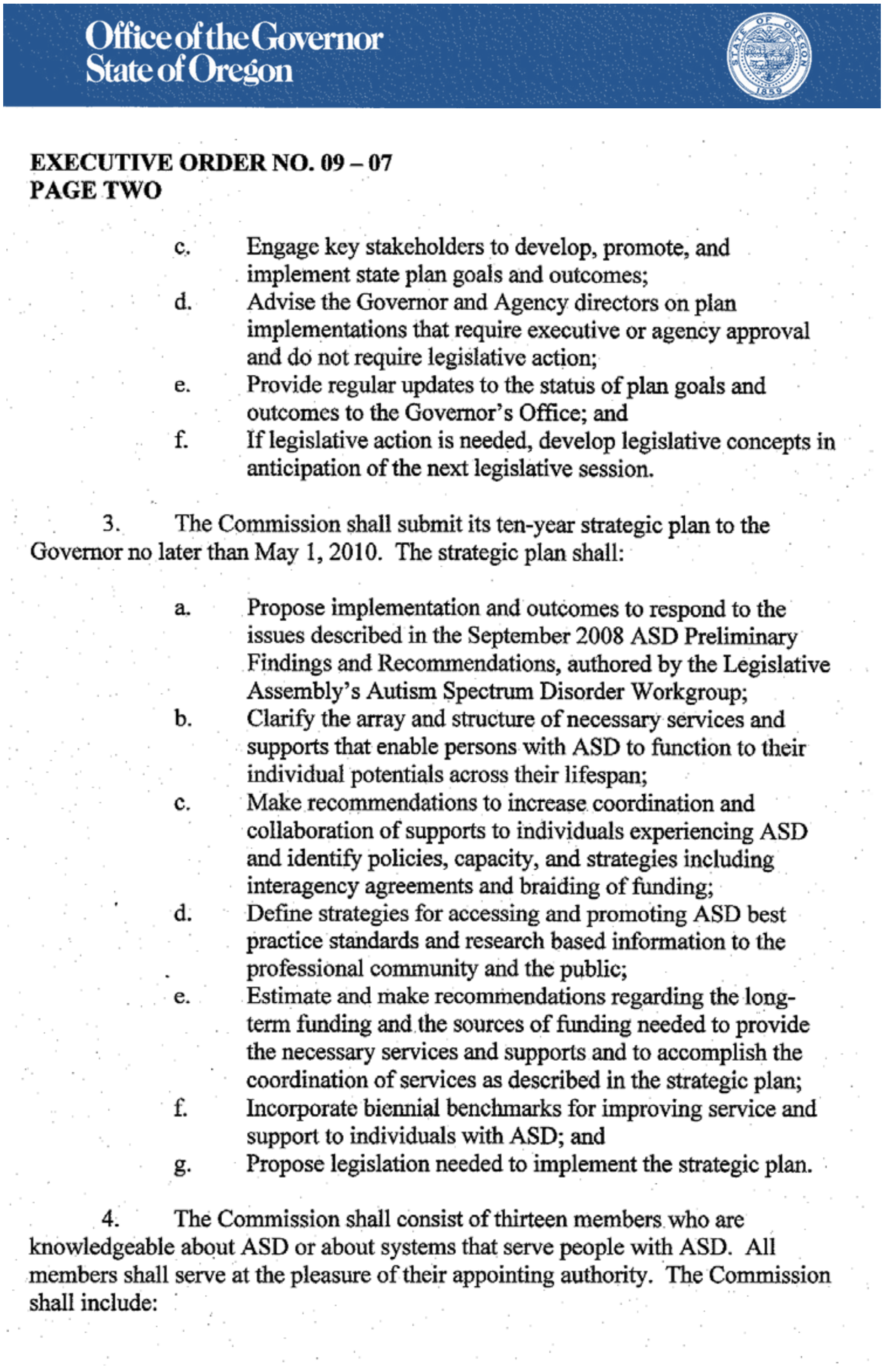
**NOW THEREFORE, IT IS HEREBY DIRECTED AND ORDERED:**

1. The Oregon Commission on Autism Spectrum Disorder ("Commission") is established.

2. The purpose of the Commission shall be to:

   a. Develop and monitor implementation of a ten-year strategic plan, incorporating biennial benchmarks for the state of Oregon to address the growing number of individuals with autism who require services from one or more programs or agencies;
   b. Provide leadership and serve as a forum to establish priorities, create performance measures, facilitate collaboration, ensure support, and monitor outcomes;

# EXECUTIVE ORDER CONTINUED



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**PAGE TWO**

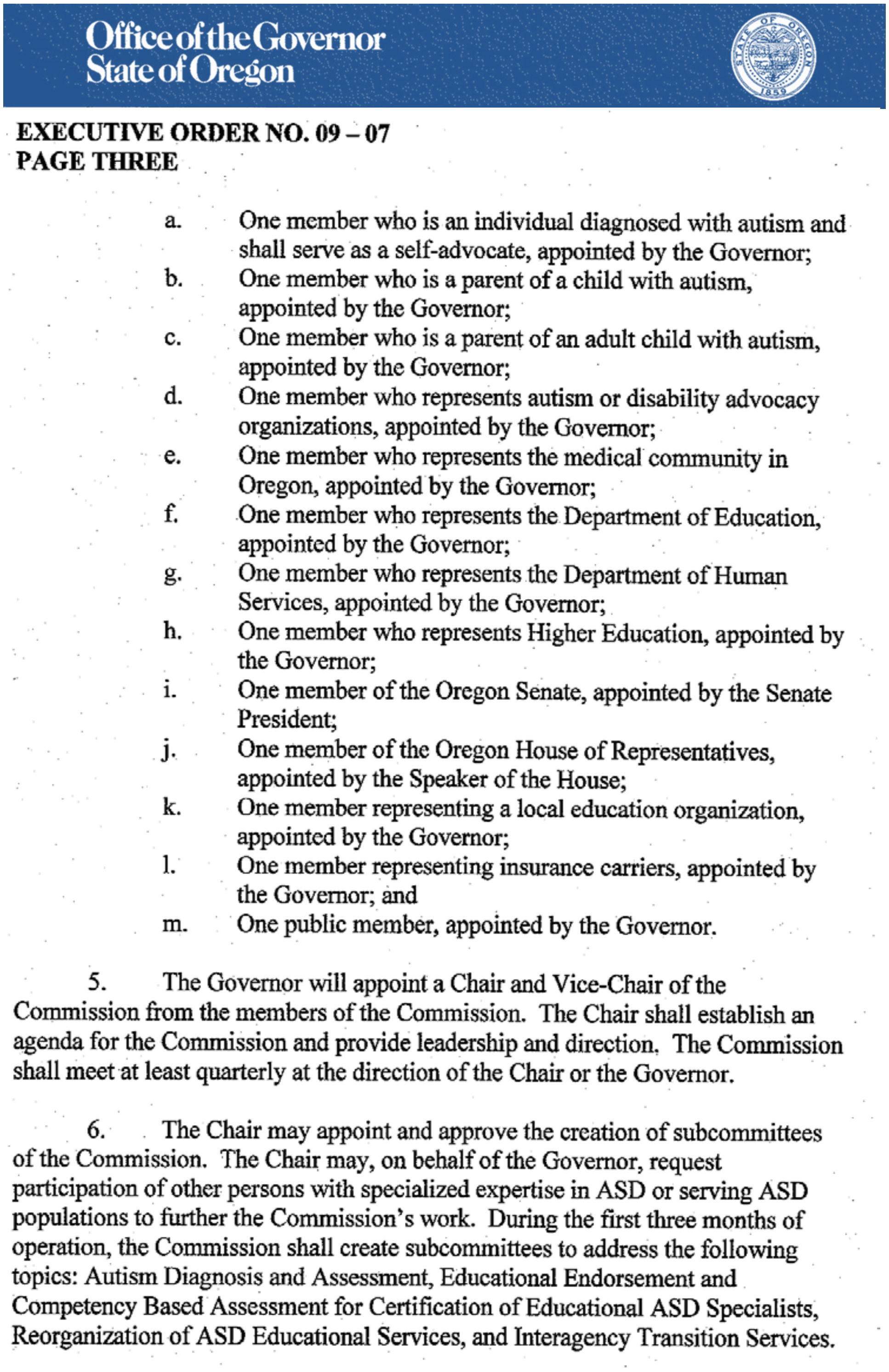
c. Engage key stakeholders to develop, promote, and implement state plan goals and outcomes;
d. Advise the Governor and Agency directors on plan implementations that require executive or agency approval and do not require legislative action;
e. Provide regular updates to the status of plan goals and outcomes to the Governor's Office; and
f. If legislative action is needed, develop legislative concepts in anticipation of the next legislative session.

3. The Commission shall submit its ten-year strategic plan to the Governor no later than May 1, 2010. The strategic plan shall:

a. Propose implementation and outcomes to respond to the issues described in the September 2008 ASD Preliminary Findings and Recommendations, authored by the Legislative Assembly's Autism Spectrum Disorder Workgroup;
b. Clarify the array and structure of necessary services and supports that enable persons with ASD to function to their individual potentials across their lifespan;
c. Make recommendations to increase coordination and collaboration of supports to individuals experiencing ASD and identify policies, capacity, and strategies including interagency agreements and braiding of funding;
d. Define strategies for accessing and promoting ASD best practice standards and research based information to the professional community and the public;
e. Estimate and make recommendations regarding the long-term funding and the sources of funding needed to provide the necessary services and supports and to accomplish the coordination of services as described in the strategic plan;
f. Incorporate biennial benchmarks for improving service and support to individuals with ASD; and
g. Propose legislation needed to implement the strategic plan.

4. The Commission shall consist of thirteen members who are knowledgeable about ASD or about systems that serve people with ASD. All members shall serve at the pleasure of their appointing authority. The Commission shall include:

# EXECUTIVE ORDER CONTINUED



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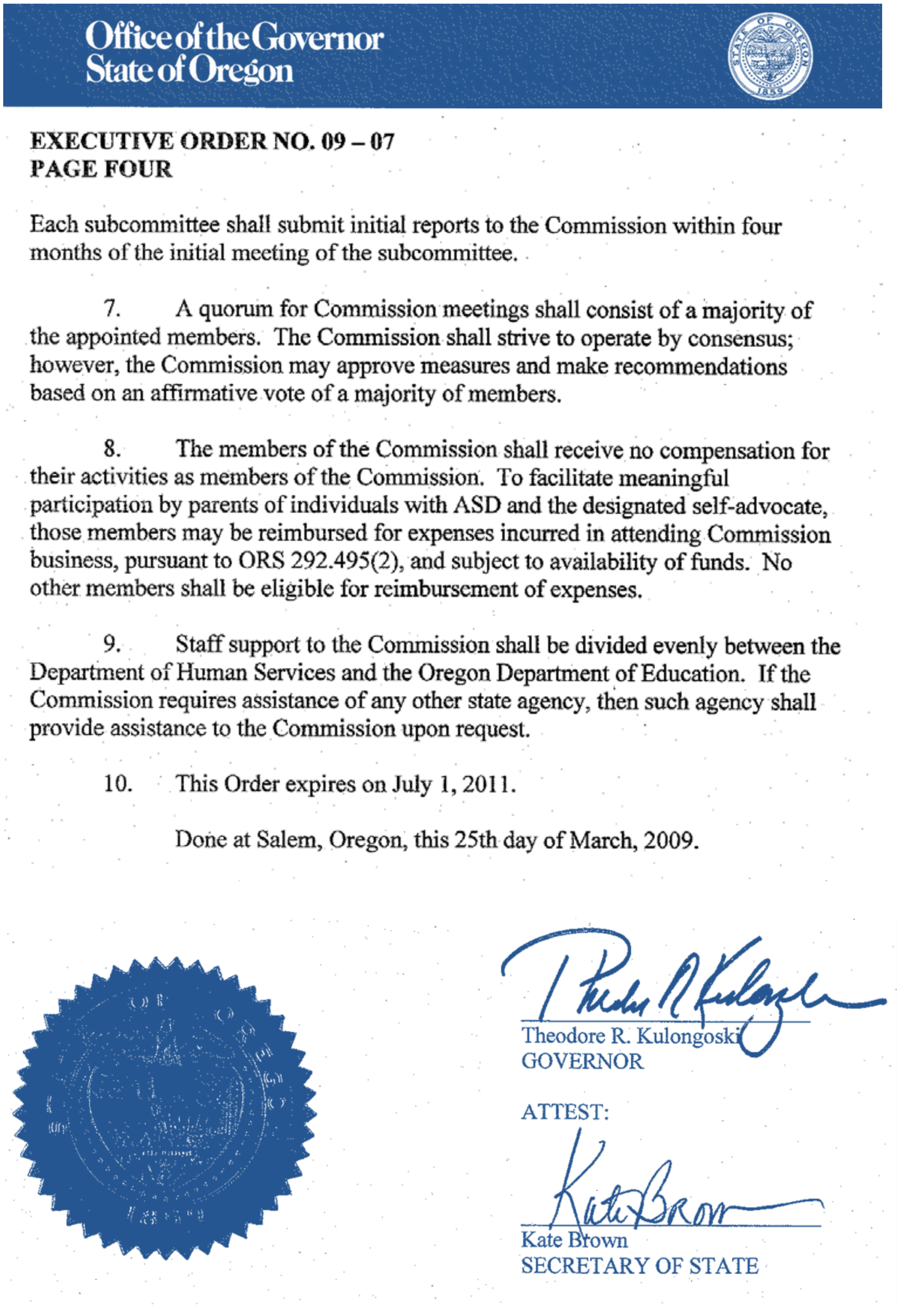
a. One member who is an individual diagnosed with autism and shall serve as a self-advocate, appointed by the Governor;
b. One member who is a parent of a child with autism, appointed by the Governor;
c. One member who is a parent of an adult child with autism, appointed by the Governor;
d. One member who represents autism or disability advocacy organizations, appointed by the Governor;
e. One member who represents the medical community in Oregon, appointed by the Governor;
f. One member who represents the Department of Education, appointed by the Governor;
g. One member who represents the Department of Human Services, appointed by the Governor;
h. One member who represents Higher Education, appointed by the Governor;
i. One member of the Oregon Senate, appointed by the Senate President;
j. One member of the Oregon House of Representatives, appointed by the Speaker of the House;
k. One member representing a local education organization, appointed by the Governor;
l. One member representing insurance carriers, appointed by the Governor; and
m. One public member, appointed by the Governor.

5. The Governor will appoint a Chair and Vice-Chair of the Commission from the members of the Commission. The Chair shall establish an agenda for the Commission and provide leadership and direction. The Commission shall meet at least quarterly at the direction of the Chair or the Governor.

6. The Chair may appoint and approve the creation of subcommittees of the Commission. The Chair may, on behalf of the Governor, request participation of other persons with specialized expertise in ASD or serving ASD populations to further the Commission's work. During the first three months of operation, the Commission shall create subcommittees to address the following topics: Autism Diagnosis and Assessment, Educational Endorsement and Competency Based Assessment for Certification of Educational ASD Specialists, Reorganization of ASD Educational Services, and Interagency Transition Services.



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Each subcommittee shall submit initial reports to the Commission within four months of the initial meeting of the subcommittee.

7. A quorum for Commission meetings shall consist of a majority of the appointed members. The Commission shall strive to operate by consensus; however, the Commission may approve measures and make recommendations based on an affirmative vote of a majority of members.

8. The members of the Commission shall receive no compensation for their activities as members of the Commission. To facilitate meaningful participation by parents of individuals with ASD and the designated self-advocate, those members may be reimbursed for expenses incurred in attending Commission business, pursuant to ORS 292.495(2), and subject to availability of funds. No other members shall be eligible for reimbursement of expenses.

9. Staff support to the Commission shall be divided evenly between the Department of Human Services and the Oregon Department of Education. If the Commission requires assistance of any other state agency, then such agency shall provide assistance to the Commission upon request.

10. This Order expires on July 1, 2011.

Done at Salem, Oregon, this 25th day of March, 2009.

Theodore R. Kulongoski
GOVERNOR

ATTEST:

Kate Brown

Kate Brown
SECRETARY OF STATE

# COMMISSIONERS

**Marilyn Gense, Chair**
Position: At-Large

**Jean Rystrom, Vice Chair**
Position: Insurance

**Chris Edwards**
Position: State Legislator

**Judy Stiegler**
Position: State Legislator

**Dora Raymaker**
Position: Consumer

**Gleason Eakin**
Position: Advocacy Organization

**James Toews**
Position: Department of Human Services

**Joyce Bernheim**
Position: Parent of a child

**Julie York**
Position: Department of Education

**Kirby Erickson**
Position: Parent of an adult

**Michelle (Mickey) Pardew**
Position: Higher Education

**Robert Nickel**
Position: Medical Community

**Susan Gartland**
Position: Local Education

**Previous Commission Members:**
Clyde Saiki, Oregon Department of Human Services
Eric Richards, Oregon Department of Education
Kristi Sandvik, Local Education

# SUBCOMMITTEE MEMBERS

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Kathryn Weit, Liaison
Dora Raymaker
Jill Sorenson
Kate Tarter
Kathy Drew
Len Ray
Mary Anne Seaton
Mary-Minn Sirag
Robert Costello

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Emilie Sampson
Genevieve Athens
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Kay Lutz-Ritzheimer
Marilyn Hartzell
Pat Budo
Rita McMillan
Sandy Stewart
Stephanie Hunter
Tamara Bakewell
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Eric Richards
Susan Gartland
Annette Skowron-Gooch
Judy Newman
Katherine Procter
Michelle Olson
Shelley Joyce
Susan Holmberg
Teri Geist

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Allyson Pex
Cynthia Herr
Cynthia Velasquez-Bogert
Erin Barton
Gregg Gassman
Helen Young
Laura LaMarsh
Lynne Griffin
Marilyn Nersesian
Mary Apple
Ruth Falco

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Gleason Eakin
Christine Niciolaidis
David Conant-Norville
Deborah Ferguson
Debra Koutnik
James Mackay
Kathleen Henley
Michele Raddish
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Kirby Erickson
Clayton Rees
David Abramowitz
Jackie Burr
Jonathan Chase
Kathy Eckert-Mason
Larry Deal
Liz Fox
Peter Fitzgerald
Phyllis Coyne
Randy Phelps
Sue Hayes
Victor Cummings

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Susan Gartland
Amy Donaldson
Carol Markovics
David Pass
David Willis
Jack Pauley
Molly Jacobsen
Paul Terdal
Rachel Oh
Rich Blum
Robin McCoy
Marilyn Gense, Facilitator
Bill Lynch, Facilitator

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Mickey Pardew
Robert Nickel
Darryn Sikora
Donna Libby
Donna Rabin
Elesia Ashkenazy
Gretchen Ford
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# ACKNOWLEDGMENTS

Thank you to the Oregon Council on Developmental Disabilities, the Oregon Department of Education and Oregon Department of Human Services for making the work of the Commission possible.

# SUBCOMMITTEE CHARTERS

## GENERAL CHARTER FOR OCASD SUBCOMMITTEES

Charge, goals and guidelines established for the Subcommittees by the Commission. The commission intends the charters to serve as guides for the individual subcommittees and to provide accountability amongst themselves and to the public.

**Charge:** Provide the subject area expertise to implement the Subcommittee Charters and support the Commission mission to develop appropriate, collaborative, and timely supports and services across the lifespan of individuals on the Spectrum.

### Goals

- Identify “Quality Core Program/Service Indicators” across the age span and the Autism Spectrum using best available research in the specific area of focus.
- Identify and develop recommendations for addressing the challenges and opportunities in the specific area of focus.
- Address the issues presented by geographic, racial, ethnic, cultural, linguistic, and economic diversity.
- Identify strategies for increasing collaborations and eliminating barriers to effective and efficient services and supports in the specific area of focus.
- Identify key stakeholders and technical assistance resources
- Review recommended documents
- Build on information and resources already available.
- Develop an implementation plan that includes specific objectives, timelines, strategies for implementation, and funding options including public / private partnerships.
- Create data collection and analysis strategies that enhance clarity, provide a baseline for measurement of change and quality improvement.

## COMMUNITY SERVICES FOR ADULTS SUBCOMMITTEE

**Charge:** Develop a plan for community services and supports for adults with ASD that provide what is needed, when it is needed, and in a manner that is respectful to the desires of the individual.

### Goals

1. Identify current publicly funded supports and services for Adults with ASD in the areas of residential supports, housing, employment, social / recreation, transportation, education, and health (see also: Health Subcommittee).
2. Identify best practice models in the public and private sector.
3. Identify the gaps, barriers, and access issues in services and supports to adults in Oregon across the spectrum and make prioritized recommendations for addressing the gaps.
4. Develop strategies to improve the public and private sector awareness of the specific needs of individuals experiencing ASD across the spectrum in employment, healthcare, housing, transportation, recreation, education, public safety and first responders.
5. Identify opportunities to enhance effectiveness through collaboration and integration of services and supports to adults with ASD across the public and private sector.
6. Clarify issues and make recommendations related to eligibility.
7. Address the issue of individuals not eligible for publicly funded services.
8. Identify supports needed by families who continue in the care giving role for adult family members with ASD.
9. Develop an implementation plan to improve the capacity for self-determination and self-advocacy for adults.
10. Address the issues of availability, competency, training, and quality of providers

## COMMUNITY SERVICES FOR CHILDREN & FAMILIES SUBCOMMITTEE

**Charge:** Develop a plan for providing services and supports for children with ASD and their families that address the needs of the child and supports the role of the family.

### Goals

1. Identify current supports and services for children with ASD and their families.
2. Identify best practice models in the public and private sector.
3. Identify the gaps and barriers in services and supports to children and their families in Oregon across the spectrum and make prioritized recommendations for addressing the gaps.
4. Develop strategies to improve the public and private sector awareness of the specific needs of children experiencing ASD and their families in employment, healthcare, housing, transportation, recreation, education, public safety and first responders.
5. Identify opportunities to enhance effectiveness through collaboration and integration of services and supports within the public sector and across the public and private sector.
6. Clarify issues and make recommendations related to eligibility.
7. Address the issues of children and families not eligible for publicly funded services.
8. Address the issues of availability, competency, training, and quality of providers.

## EDUCATIONAL ASD SERVICES REDESIGN SUBCOMMITTEE

**Charge:** Develop a plan for comprehensive educational services to children and youth with ASD from age of identification to age 21, to provide appropriate service in all settings for the range of the spectrum.

### Goals

1. Design a plan to identify and provide appropriate service intensity and core service components for children eligible for ASD services in EI/ECSE programs
2. Design a plan to provide appropriate service intensity and core service components for children eligible for ASD services in school age programs
3. Identify opportunities to collaborate with the Transition Subcommittee to design a plan for Transition age students with ASD.
4. Design a plan for the ongoing consistent review and dissemination of interventions based on best available evidence, addressing needs across the spectrum.
5. Design a plan to build and maintain consistent statewide training for all levels of service (e.g. ASD specialist, classroom teacher, parent, instructional assistant, related service providers)
6. Develop recommended standards for collaboration with other providers of services to children with ASD, both inside and outside of education.
7. Develop a plan for collaborating with families and students with ASD in the education process.

## EDUCATIONAL ENDORSEMENT COMPETENCY BASED ASSESSMENT SUBCOMMITTEE

**Charge:** Develop educational endorsement and competency based assessment for certification of Educational ASD Specialists.

### Goals

1. Identify “Quality Core Certification Competencies” for endorsement, licensure and or certification for an ASD specialist using best available research.
2. Review current ASD Specialist and CEC competencies.
3. Review licensure and endorsement requirements from other states.
4. Identify and match pre service and in service requirements to core competencies.
5. Develop implementation plan that has stakeholder support including timelines for phased implementation for full certification / endorsement.
6. Identify criteria for maintaining endorsement/ certification linked to best available research.
7. Collaborate with Reorganization of ASD Educational Services.

## HEALTHCARE SERVICES SUBCOMMITTEE

**Charge:** Ensure that all individuals with ASD receive high quality, comprehensive and coordinated, family and patient centered health care.

### Goals

1. Improve the knowledge and skills of health care professionals and the supports available to them for providing health care to individuals with ASD.
2. Improve the funding of medically indicated services for individuals with ASD.
3. Improve the general health of individuals with ASD by promoting a healthy lifestyle, self-advocacy, self-determination, and self-management.
4. Ensure that health care services for individuals with ASD are coordinated and integrated among health care providers, families and community professionals.

## INTERAGENCY TRANSITION SUBCOMMITTEE

**Charge:** Develop and put into action an interagency plan that establishes the movement of transitioning youth with ASD into adult life of choice by developing individualized supports and services that maximize opportunities for participation in lifelong learning, employment experiences and community participation.

### Goals

1. Identify best practices in transition programming for youth with ASD.
2. Identify the opportunities and strategies to enhance effectiveness through collaboration between K-12 education and adult services, employment and continuing education.
3. Create an interagency plan that identifies the barriers and aligns solutions for a successful coordinated transition of youth with ASD from the K-12 educational settings to adult services, employment and education.
4. Develop practical standards for collaboration with providers of services for transition age youth with ASD.
5. Increase the awareness of transition processes and opportunities for youth with ASD by professionals, families, and youth.
6. Identify strategies to measure progress over time.

## ROLE OF HEALTH INSURANCE SUBCOMMITTEE

**Charge:** Define the role of the private and public health insurance system in the care and treatment of individuals on the Autism Spectrum across the age span.

**Goals**

1. Analyze the role and implementation of public and private health insurance in other states as it relates to children on the Autism Spectrum.
2. Identify which services appropriately fit within the responsibility of health insurance.
    - Specify the best available evidence supporting that this service is effective
    - Identify the criteria for medical necessity for each service.
3. Make recommendations related to the providers of services, including the issues of capacity development. Recommendations should address each type of service (e.g. screening, diagnosis, specific treatment, medication, nutritional supplements)
    - What credentials are necessary to prescribe / authorize services?
    - What credentials are necessary to monitor implementation and evaluate progress?
    - What credentials are necessary to provide services?
4. Specify measures for determining success of service(s)
5. Map a structure and process for coordination and integration between health care, education, publically funded services and privately provided services.
    - Determine appropriate limits on services under health insurance. States with mandates have created limits based on: Age; Age at diagnosis; $ amount per year or lifetime; Hours of service per week

## SCREENING, IDENTIFICATION AND ASSESSMENT SUBCOMMITTEE

**Charge:** Develop a plan to ensure that all Oregon's children will be screened for ASD by age of 24 months. All Oregonians throughout the lifespan will, as appropriate, receive an efficient and timely multidisciplinary evaluation, meeting quality core indicators, and prompt referral to services. Develop a plan to ensure that initial and ongoing assessments identify an individual's current level of functioning in all relevant domains.

**Goals**

1. Identify quality core indicators for screening and evaluation processes such that the results can be used in multiple state agency and health care contexts as acceptable evidence that an individual has an ASD.
2. Identify strategies to increase public awareness about the importance, availability, and features of screening, evaluation, and assessments for ASD. Identify strategies for (a) increasing capacity throughout Oregon for screening, evaluations, and assessments; (b) ensuring that the quality indicators are being met; (c) ensuring that all children receive a screening for ASD by 24 months, and later when appropriate; and (d) ensuring that adults who have not previously been identified as having an ASD are evaluated when appropriate.
3. Identify methods to ensure that agencies and health care providers make appropriate and timely referrals for services.
4. Identify quality core indicators for assessments for educational and relevant health care service planning.

# SERVING AND SUPPORTING PEOPLE WITH AUTISM SPECTRUM DISORDER AND THEIR FAMILIES

## Summary of Preliminary Findings and Recommendations
## (September 2008)

### *Focus of Report*

This report summarizes issues, findings and recommendations relative to six key areas that impact services and support to individuals experiencing Autism Spectrum Disorder (ASD) and their families in Oregon. The focus of this work addresses those issues from birth through adulthood that have direct impact on safety, well being and success of individuals with ASD.

### *Committee Purpose and Membership*

The Autism Spectrum Disorder Workgroup was created as an ad hoc committee by the Chairs of the House Education and Health Care Committees in response to the issues of the rapidly growing population of children and adults identified with ASD in Oregon. The Workgroup was chaired by Rep. Chris Edwards. The charge of the group included:

- Review the current status of services to children / adults with ASD in Oregon.
- Review recommendations and proposals from state agencies, families and advocates for addressing the needs of children / adults with ASD in Oregon.
- Develop a set of recommendations for addressing the needs of children/ adults with ASD in Oregon.
- Engage the ASD community and families in providing input on recommendations.
- Create a prioritized list of possible legislative initiatives and other short term and long term activities.
- Present legislative proposals to appropriate Interim Committees.

The Workgroup supported the following vision for individuals experiencing ASD and their families:

- Appropriate, effective and research based treatments, supports and services are available through the lifespan.
- Families and individuals with ASD must be involved in all aspects of service design and delivery. “Nothing about us without us.”

- Early identification and effective research based treatments and services for children are provided by skilled professionals.

- Integrated, coordinated wrap-around services are available to support the child and their family in the family home.

- Systems collaborate to avoid duplication and enhance effectiveness of supports and services.

- Children and adults with ASD are included and contributing members of their schools and communities.

- Recommendations made by this Workgroup will seek a healthy balance between quality of services and number of individuals served in order to produce the best societal outcomes given funding limitations.

Workgroup activities included:

- Review of services currently provided by state agencies.

- Review of a summary of task force reports from 13 other states.

- Discussion of proposals from state agencies.

- Development of report on findings and recommendations.

Committee Members:

Rep. Chris Edwards, Chair
Rep. Peter Buckley, Chair of House Committee on Education
Rep. Linda Flores
Rep. Sara Gelser
Rep. Ron Maurer
Sen. Alan Bates
Nancy Latini, Oregon Department of Education
Morgan Allen, Oregon Department of Education
Mary Lee Fay, Oregon Department of Human Services
Janel Salazar, Parent and Oregon Autism Alliance
Kathryn Weit, Parent, Oregon Council on Developmental Disabilities

## *Infrastructure for a Collaborative Approach to Autism Spectrum Disorder*

**Issue:** Oregon currently lacks a coordinated approach to providing information, supports and services to individuals experiencing Autism Spectrum Disorder and their families.

**Key Findings:**

- The rapid increase in the numbers of individuals being identified with ASD, the complexity / diversity of their needs, limited resources and the pressure on the existing education and social service systems requires a more thoughtful, coordinated approach to funding and service development.

    - The needs of individuals with ASD and their families are often very complex. They receive services from a number of programs and agencies.
    - Greater awareness and coordination among agencies and stakeholders will result in more appropriate and cost effective services.
- Oregon is not taking full advantage of the wealth of knowledge, best practice, and skill currently available in the state and elsewhere.
- There are a number of initiatives being developed to serve individuals with ASD in Oregon.
    - A single entity charged with tracking what is needed and what is happening in the state will reduce any unnecessary redundancy and increase the chances of addressing all relevant issues.
- Oregon lacks a means to provide accurate, up-to-date information to parents and caregivers relative to interventions, services, supports and expected outcomes.
- There is no accountability to make sure changes actually occur.
- There is a need for leadership that is consistent and includes all portions of the community.

**Recommendations:** Create an ongoing Oregon <u>Commission on Autism Spectrum Disorder</u> to provide leadership and serve as a forum to establish priorities, set direction, ensure support, and monitor outcomes.

- Develop and monitor implementation of a detailed, goal and outcome oriented <u>state plan</u> for ASD; that develops and aligns performance measures with appropriate agencies.
    - Provide regular updates on the status of plan goals and outcomes to the Governor, Legislative Assembly, and public.
    - Engage key stakeholders in developing, promoting, and implementing state plan goals and outcomes.
- <u>Develop implementation strategies</u> that utilize education, social services, Higher Education, health care, insurance, and community resources.
- Promote <u>interagency agreements</u> and other processes necessary to assure collaboration and coordination of services.
    - Promote universal screening, timely diagnosis and appropriate referral.
    - Create strategies for <u>accessing and promoting best practice / research based information.</u>
    - Promote <u>regional coordination and collaboration</u> of services and supports across agencies.
    - Define <u>data needs and refine current data tracking</u> systems.

- Develop strategies for braiding funding sources to ensure coordination and collaborative supports to individuals experiencing ASD and their families.

- Promote the development of an easily accessible clearinghouse / web based directory of services and information on Autism Spectrum Disorder.

    - Facilitate a communication network among stakeholders to keep apprised of initiatives and activities related to ASD in Oregon.

- Promote increased training opportunities on ASD for individuals with ASD; families, educators, health care and social service professionals, service providers, child care providers, law enforcement, and others.

    - Support certification and licensure activities related to ASD.

Membership:

- The Interagency ASD Committee should include representatives from the Department of Human Services, Oregon Department of Education, Institutes of Higher Education, Health Resources Commission, Title V of Maternal and Child Health, medical community, insurance providers, family members that represent different stages of life, individuals with Autism Spectrum Disorder and other key stakeholders.

## *Early Identification and Referral*

**Issue:** Oregon lacks a coordinated system for early identification and referral for young children. Early identification and referral for services is important for the success of young children with ASD.

**Key Findings:**

- Not every young child in Oregon receives a wellness screening.

- Physicians may not do the recommended screenings at 18 months.

- There have been several significant efforts to provide physicians with ASD screening materials in Oregon.

- Most children are identified as having ASD by school programs.

- There is a difference between a medical diagnosis of ASD and an education eligibility determination for ASD services. This disparity **may** result in inappropriate services or failure to recognize important medical conditions.

- The Oregon Pediatric Society has sponsored a workgroup to look at the issues related to accurate assessment /identification with other stakeholders including education.

**Recommendations:**

- Oregon should have an agreed upon established standard practice and procedure for diagnosis / identification and referral.
- Oregon children should receive a well baby check and be screened for ASD at 18 months as recommended by American Pediatric Association.
- All children suspected of ASD should be referred immediately for a more thorough multidisciplinary diagnostic evaluation that reflects a medical diagnosis and an educational eligibility assessment.
- Children identified with ASD and their families should be referred immediately to the local Early Intervention / Early Childhood Special Education Program.
- As soon as possible, any child identified with ASD will begin an individually designed program that reflects the needs of the child and family and uses research based best practice strategies.

## *Education Services*

**Issue:** Access to quality ASD services is not consistent across the state.

**Key Findings:**

- High quality services to children / youth with ASD do exist in many places throughout the state.
- The numbers and needs of children / youth with ASD have outgrown the current capacity of educational personnel.
    - Current ASD Specialists carry a high caseload, focus a significant amount of their time on assessments and do not have time to provide the needed assistance to classroom teachers.
    - Rural areas of the state experience an even greater challenge in finding and retaining staff trained to work with children and youth with ASD.
- Access to trainings, specialized services and technical assistance varies.
    - There is frequently not sufficient utilization of current best practice information or model programs.
    - Services and access to personnel training and support may be different depending on the capacity, role and expectation of Regional ASD Services, the ESD, and local school districts.
- The current model of Regional ASD Services no longer meets the needs of school districts that have a rapidly growing population of children and youth with ASD.

**Recommendations:**

- Create statewide service standards for research based best practice educational services for children and youth with ASD.
- Create service /support options that reflect the spectrum nature of Autism Spectrum Disorder.
- Recognize and address co-morbid mental health conditions.
- Reorganize the existing ASD Regional Program and funding strategies to better align services with the needs of students with ASD and school districts serving these students.
- Make better strategic use of existing resources.
- Increase accountability for use of research based best practice and student outcomes.
- Specify the definition of "engagement time."
- Increase the funding for ASD services to expand the number of highly trained staff available to work with children / youth and support classroom teachers and paraprofessionals birth to 21 years of age.
- Create a system of family support and training relative to educational opportunities and expectations.
- Increase family access to trainings that will help them support instruction in the home setting.

**Issue:** Current levels of service for young children are significantly lower than the National Research Council Recommendation of 20-25 hours of engagement per week.

**Key Findings:**

- Services and strategies must be appropriate to the individual child with ASD.
    - Not every child will require 20-25 hours per week.
    - Instructional strategies that use such as Applied Behavioral Analysis are often effective with many students.
- Some providers report service averages of 8-12 hours per week for a child with ASD. Many children receive as little as 1-3 hours of service.
- The current birth – 3 program (EI) is not designed or funded to respond to the needs of children / families identified with ASD under the age of three.

**Recommendations:**

- Seek additional funding to increase the engagement time and intensive services for young children experiencing ASD based on individual need.

**<u>Issue</u>:** There are not enough <u>skilled ASD Specialists, behavior specialists and teachers</u> of children with ASD to meet the demand.

**Key Findings:**

- Best practice in the field of ASD is changing rapidly. Some ASD Specialists and teachers lack the most current information and ability to apply appropriate strategies.

- The lack of stable funding to increase statewide capacity to meet the need for skilled ASD specialists, behavior specialists, and teachers.

- Oregon does not have Board Certification for Behavioral Analysts.

**Recommendations:**

- Work with higher education and Teacher's Standards and Practices to <u>create an endorsement and a competency based certification</u> process for ASD specialists.

- Increase the <u>opportunities for professional development</u> for teachers of children and youth with ASD.

- Increase the opportunities for professional development for districts who select not to participate in the current Regional Program system.

- Increase funding to meet increased capacity needed for skilled staff.

- Provide incentives to increase number of skilled professionals to work in more remote, rural areas of state.

**<u>Issue</u>:** Many children and youth with ASD are a part of the regular school programs. All educational staff must understand the potential impacts of ASD on students.

**Key Findings:**

- Many children and youth with ASD are fully capable of participating in the regular school program.

    - Teachers and other education personnel interacting with students with ASD must understand how ASD may affect the student's learning and behavior and how to adjust educational strategies and activities.

- Students with Asperger's frequently do not receive the appropriate support they need in school, particularly in the area of social skills.

**Recommendations:**

- Provide <u>training on ASD for all teachers and school staff</u> within and outside of the current Regional structure.

- <u>Improve the support</u> available for children and youth experiencing Asperger's and high functioning autism.

**Issue:** Many individuals with ASD do not make a successful transition to permanent employment or continuing education.

**Key Findings:**

- Successful transition from secondary school to employment or continuing education requires strategies that recognize the unique needs of individuals with ASD.
  - Many post secondary educational and social service programs are uncertain how to support an individual with ASD.

**Recommendations:**

- HS Transition programs must work with DHS / DD / VR, continuing and higher education programs to develop and implement appropriate transition services for individuals w ASD.
  - Build on the current interagency model of collaboration utilized in HS Transition that is not readily accessible for students with ASD. This will require specially trained staff dedicated to this model.

## *Social Services*

**Issue:** DHS currently lacks the capacity to respond to the significantly growing population of individuals with ASD and their families who may require support and services from DHS.

**Key findings:**

- Services that were designed for individuals with physical or cognitive disabilities often fail to address the unique environmental, behavioral, communication, or sensory considerations that make ASD a distinct condition.

**Recommendations:**

- Add ASD Specialists within the Office of Developmental and Disabilities Program of Seniors and People with Disabilities with the following responsibilities:
  - Represent DHS on a state level workgroup.
  - Create a plan for addressing training and service issues within the Department.
  - Develop policy strategies, monitor / facilitate/ implement trainings to a variety of audiences and direct training and technical assistance contracts to support children and families.
  - Coordinate DHS services with other state agencies, higher education and stakeholders.
  - Provide or facilitate technical assistance to other program areas of DHS.
  - Promote the use of evidence based practices.

    - <u>Provide staff support for the Oregon Commission on Autism Spectrum Disorder.</u>

**<u>Issue</u>:** Staff and administrators in the Department of Human Services lack current accurate information about Autism Spectrum Disorders and understanding the impact of ASD on the individual / family and their ability to be successful. There is an expressed desire for access to information that is useable, current and reliable.

**Key Findings**:

- Survey of DHS agencies indicated a perception that there is an increase in the number of individuals / families experiencing ASD receiving services from DHS.
- Individuals may “fail” in current services because DHS programs may not understand and / or have been unable to adequately respond to the issues presented by ASD.

**Recommendations:**

- DHS ASD Specialists will <u>develop and/or identify publications</u> to educate DHS staff and field about ASD.
- DHS ASD Specialists will <u>develop, promote or facilitate training opportunities</u> and best practice information on ASD for social service staff, direct care staff and others.
- DHS will identify and attempt to address those areas where individuals with ASD are “falling through the cracks.”

**<u>Issue</u>:** There are an insufficient number of qualified behavioral consultants able to respond to the needs of both DHS and education programs serving children and adults with ASD.

**Key Findings:**

- It is difficult to find behavior consultants who have the skills to effectively work with children and adults in the family home.
- Some individuals who identify themselves as behavior consultants lack knowledge of effective, safe, appropriate, and approved interventions with individuals expressing significant challenging behavior.

**Recommendations:**

- ODE, DHS and Higher Education programs should work together to <u>develop strategies to increase the availability of qualified behavioral consultants.</u>
    - Explore incentives and recruitment strategies.
    - Strengthen or develop training and certification programs.
- ODE and DHS should consider a <u>teaming model of support</u> utilizing the strengths of personnel in both agencies.

**Issue:** There is a lack of coordinated intensive intervention /treatment and support for young children experiencing significant levels of ASD.

**Key Findings:**

- Frequently the families of young children with autism are unaware that case management / service coordination services might be available to them. County developmental disability programs may tell families that they have nothing to offer them so families do not pursue enrollment.

- The eligibility standard for the current Medicaid Behavior waiver which provides intensive support is very high and only children who pose a risk to themselves or others are eligible. The waiver is not at capacity.

    - Technical assistance and support delivered to the family in the family home is sometimes highly successful.

    - Not every child / family experiencing ASD will require intensive wraparound services.

- Few children with ASD receive the intensive intervention recommended by the National Research Council.

**Recommendations:**

- ODE and DHS should work together to develop integrated wrap around services for children experiencing significant levels of ASD and their families.

- DHS should explore expanding the existing behavior Medicaid waiver or consider creation of another waiver specific to ASD to provide time limited intensive interventions.

- DHS should provide comprehensive wrap around service coordination for young children with ASD and their families when needed.

**Issue:** There is a lack of adequate support for families / foster care families and providers experiencing challenges with an individual with ASD.

**Key Findings:**

- County DD Programs report an increase in numbers of families with youth with ASD requesting access to services.

    - Family support programs have been unable to assist the growing number of families requesting support.

    - Some families may need to seek out in home placement for their family member in order to get sufficient help.

    - Some families may not have enough resources to work and support their adult or child at home.

    - Children with ASD going into foster care are increasingly complex and there is insufficient training and support for providers.

- DD case manager case loads are too high to be able to provide the support families need.

- Throughout DHS, Family Support services for families caring for children and adults experiencing ASD are limited.

- Empowered families are an important key to long term success for a child with ASD.

- Families may have no one to connect to when they first receive a diagnosis of ASD and have no idea how to navigate the system.

**Recommendations:**

- DHS must <u>increase supportive services that help empower families / foster families</u>. These services may include information / referral, respite, behavior consultation and assistance, appropriate home modifications, and in-home staff support if necessary.

- Increase training for case managers, providers, and families to build appropriate plans to keep individual in the home setting.

- Access to support services must be available before they reach crisis.

**<u>Issue</u>:** Services to individuals with ASD must be available across the lifespan.

**Key Findings:**

- Individuals with ASD have the lowest employment rate of any disability category.

- Individuals with ASD frequently fail in continuing education and higher education settings.

- Families express concerns about their ability to continue to provide in-home support for their adult family member who experiences with significant ASD and challenging behaviors.

- Access to community resources like recreation and public transportation are important for a full and active life for many adults with ASD.

**Recommendations:**

- DHS and ODE must develop and implement <u>integrated transition services</u> for individuals with ASD.

- DHS must work to <u>improve long term employment outcomes</u> for individuals with ASD.

- DHS must <u>increase access to appropriate 24 hour comprehensive services</u> for individuals with ASD.

- DHS must collaborate with other agencies to <u>increase access to technology and appropriate, affordable housing.</u>

- DHS must <u>increase the capacity of providers</u> to serve individuals with ASD.

**<u>Issue</u>:** Rural and linguistic, cultural, or racial minorities.

**Key Findings:**

- Individuals with ASD and families who live in rural areas or who are members of a linguistic, cultural, or racial minority <u>may experience even greater difficulty in accessing appropriate services.</u>

**Recommendations:**

- There must be an <u>increased effort to include strategies to address geographic, linguistic, cultural, and racial service disparities.</u>

**<u>Issue</u>:** Access to appropriate /timely crisis and law enforcement services.

**Key Findings:**

- Law enforcement is often poorly trained on how to deal with an individual with ASD in crisis.
- Because of their inability to communicate well or unusual behaviors, individuals with ASD may not receive necessary support in crisis or protection from law enforcement.

**Recommendation:**

- <u>Provide training about ASD to law enforcement</u>.
- Identify options for appropriate crisis response.

## *Health Care*

**<u>Issue</u>:** Many Physicians are not aware of the diagnostic characteristics of ASD.

**Key Findings:**

- The American Academy of Pediatrics has issued practice guidelines for the early identification and referral of children with ASD.

  See above “Early Identification and Referral”
- Internal Medicine and family practice physicians frequently provide care to individuals with ASD but may not receive the necessary training or information.

**Recommendations:**

- Provide information and technical assistance to all pediatric, internal medicine and primary care settings to <u>implement the nationally recommended ASD screening and surveillance guideline.</u>

- Provide accurate up-to-date information on diagnostic and support resources for individuals with ASD to all physicians.

**Issue:** Many individuals with ASD require additional or specialized interventions to access basic health care.

**Key Findings:**

- Many individuals with ASD may not receive appropriate basic health care because of the possible impacts of sensory differences, language and communication issues, and challenging behaviors.

- Many physicians are not aware of the possible associated medical and co-morbid mental health conditions related to ASD.

**Recommendations:**

- Provide information and technical assistance to all physicians.

- Provide comprehensive health services in a medical home knowledgeable about ASD and its associated medical and co-morbid mental health conditions.

- Physicians must be able to access additional or specialized interventions necessary to support basic health care.

- Physicians must be able to authorize treatments necessary to identify and address associated medical and co-morbid mental health conditions.

**Issue:** Currently public and private insurance in Oregon does not provide comprehensive integrated coverage for physician directed treatment plans for Autism Spectrum Disorders.

**Key Findings:**

- Many states have successfully passed insurance legislation that covers physician directed intensive treatments for ASD.

**Recommendations:**

- Review and analyze insurance initiatives in other states.

- Explore specific health Insurance coverage for physician directed, medically necessary ASD treatments, as part of a comprehensive strategy for braiding funding for services.

**Issue:** Children with developmental disabilities are sometimes unable to access treatment services if the condition is considered to be the result of their disability.

**Key Findings:**

- Despite passage of HB 2918, there are still children being denied access to therapy services.

**Recommendations:**

- Further legislation may be required to protect children with disabilities including ASD from being denied access to important medical treatments.

- Track current insurance practice related to children with disabilities.

## *Higher Education*

**Issue:** Training, research, and programmatic resources available in higher education are often not well supported or linked to service delivery in education, social services, and health care.

**Key Findings:**

- Oregon has nationally recognized programs and individuals working in fields related to ASD.
  - Often the information from Oregon institutions of higher education is more widely recognized outside the state.

**Recommendations:**

- Participate in the Oregon Commission Autism Spectrum Disorder to identify needs in the areas of personnel preparation, research and training.

- Form a collaboration of higher education personnel to work on the issues related to ASD research and information dissemination.

- Assist Oregon agencies to develop a research based best practice approach to treatment interventions and service delivery.
  - Assist in the identification and dissemination of information and research on ASD.
  - Encourage funding and wider dissemination of proven best practices related to ASD.

- Increase ASD specific training for physicians and other health related professions.

- Improve professional development in education, social service, direct care services, technical assistance professionals.
  - Create a statewide collaboration to develop certification and licensure for specialists in the area of ASD.

Sept 2008 Committee Edited v2 092208.15

# Report by Oregon Commission on Autism Spectrum Disorder

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To access this report online, visit the Commission website at:
www.orcommissionasd.org

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Edited by Marilyn Gense, Jean Rystrom and Kathryn Weit
Report design by Cheryl Cisneros, December 2010