

**OREGON COMMISSION
ON
AUTISM SPECTRUM
DISORDER**

**REPORT TO THE
GOVERNOR**

February 2018

TABLE OF CONTENTS

Letter to the Governor	3
Executive Summary	5
INTRODUCTION	
History of the Commission	6
Mission Statement	7
Guiding Principles	7
Subcommittees.....	8
STRATEGIC PLAN	
Framing the Work.....	14
Process	14
Identification Process	15
Education	16
Health Care	18
Supports for Community Living	18
Systems Collaboration.....	20
RECOMMENDATIONS	
New Executive Order.....	22
.....	
APPENDICES	
Executive Order 11-05.....	24
Commission Members & Staff	30



OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

Dear Governor Brown,

In accordance with the Executive Order 11-05, we are pleased to present you with this report on the Oregon Commission on Autism Spectrum Disorder. The purpose of this report is to update your office and the legislature on the work of the Commission over the past few years.

The Commission was originally guided by the efforts of a legislative workgroup established in 2008-09 and directed by Senator Chris Edwards. Their work served as a starting point and developed with the use of seven subcommittees. Each had a specific charter and goals and was populated with membership to ensure expertise and representation from a broad range of stakeholders. In 2009 and 2011 Executive Orders were executed to support the continued work of the Commission.

During the summer and fall of 2016 the Commission facilitated community focus groups across the state in an effort to refocus its work and meet the changing needs of the Autistic community. Commission members and subcommittee volunteers committed many hours to this effort and prepared a 2017-2019 Short-Term Strategic Plan to address these needs. The strategic plan moves toward the use of focus driven workgroups instead of standing subcommittees with the purpose to answer questions that came out of the meetings, prepare goals and an action plan to address the questions, and set a timeline for completion. Starting in January 2018, new focus driven workgroups will work toward the goals outlined in the 2017-19 Short-Term Strategic Plan. These workgroups include: Identification; Education; Health Care; Support for Community Living; and Systems Collaboration.

Included in this report is information on the three main subcommittees of the Commission that have been active over the past few years. The Screening, Identification and Assessment (SIA) and the Education subcommittees are actively completing their work and preparing for the focus driven work outlined in the new strategic plan. The Health Care Subcommittee completed its work during 2015 and moved to support the work of the SIA and Education subcommittees as they supported the use of the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition) criteria in the diagnosis and identification of children with Autism.

As the Commission prepared the strategic plan, they also did a review of the current Executive Order (EO) and the structure of the Commission. Concerns included term limits, the exclusion of limits for agency representatives, maintaining active members representing the legislature, allowing more flexibility in the description of positions, adding additional positions, and providing a sunset clause with an option to lengthen the new EO.

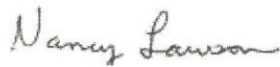
The sunset clause would allow greater oversight and a regular check-in process by the Governor's office to see if additional changes need to be made to the EO, as well as to discuss any possible change in the focus of the Commission.

The Commission currently is supported by an administrative assistant and communications specialist and meets six times per year. Commission information such as meeting dates, agendas, official minutes, membership, and goals are posted on the Commission's website located at <http://www.orcommissionasd.org>.

The Commission appreciates the committed work of its members, subcommittee members, agencies, organizations, and engaged members of the public. Past and future work would not be possible without the support of the Oregon Council on Developmental Disabilities, the Oregon Department of Education and the Department of Human Resources.

As always, the Commission appreciates the opportunity to help Oregon develop collaborative and meaningful supports and services across the lifespan for individuals with Autism and their families.

Sincerely,

A handwritten signature in cursive script that reads "Nancy Lawson".

Nancy Lawson, OCASD Chairman



EXECUTIVE SUMMARY

This report is being provided to give the Governor's office and the legislature an update on the progress of the Oregon Commission on Autism Spectrum Disorder, its activities and the 2017-19 Short-Term Strategic Plan. Included is the history of the Commission, its mission statement, guiding principle and the process used to identify the needs of the Autism community. Recent work by subcommittees is also included.

In the fall of 2016, the Commission hired a facilitator to meet with members of the Autism community across the state of Oregon. Meaningful supports and services across the lifespan for individuals with Autism and their families were identified. In 2017, the Commission began putting together a short-term plan designed to highlight a pathway to address these needs through questions, goals, activities and timelines.

The strategic plan has five workgroups that will be formed in early 2018. These workgroups will focus on: Identification, Education, Health Care, Support for Community Living, and Systems Collaboration. Commissioners and stakeholders with topic specific experience and expertise will manage the work flow of each workgroup.

Moving from a subcommittee to a workgroup structure will give members an opportunity to complete the work on short-term goals and continue with the next goal or the ability to step away once a goal is completed. This structure will give leadership time to evaluate progress made on specific goals and decide if the membership should be changed based on any new focus. The change in structure should allow for more flexibility and offer a healthier dynamic. The Commission will have an annual discussion about how workgroups are performing in order to review the process and change the structure if needed.

Also included in this report are recommendations for a new Executive Order (EO). Issues regarding terms and term limits that impact representatives from ODE, OHA, and DHS, transitional periods, and the need for institutional knowledge need to be addressed. Changes to membership roles as well as the process for appointing legislative representatives are important adjustments in a new EO. The Commission is also asking for greater oversight by the Governor's office with a regular check-in process to discuss possible changes to the focus of the Commission by adding a sunset clause.

INTRODUCTION-HISTORY

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 Disorder and responses to the unique challenges of ASD.

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 were contained in the 2010 Governor's report stating the preliminary findings and recommendations of the Oregon Autism Project.

In March of 2009, Governor Kulongoski issued an Executive Order (EO), which created the Oregon Commission on Autism Spectrum Disorder (referred to as the 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 Strategic Plan (SP) for Oregon that would help target limited resources and the use of 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 Governor Kulongoski in December 2010.

Executive Order No. 09-07 signed by Governor Kulongoski in March 2009 expired on July 1, 2011. The purpose of the new Executive Order (EO) No. 11-05 was to continue the work of the OCASD and implement the 10-year strategic plan to identify biennial goals for the State of Oregon by providing leadership, establish priorities, create key performance measures, facilitate collaboration, ensure support and monitor outcomes. The Commission was also directed to expand and strengthen formal and informal partnerships among systems serving individuals with ASD and identify and incorporate any needed revisions to the 10-year plan to address gaps, barriers, and solutions for individuals with Autism Spectrum Disorder (ASD). The EO also increased the Commission membership to 15, adding representatives from the Oregon Health Authority and the mental health community.

Since June 2011, the OCASD has been working on the strategic plan outlined in the 2010 Governor's report and as directed in the 2011 Executive Order. Subcommittees working

on interagency transition services, education, adult services, health care, and screening identification and assessment were set up with specific goals toward the implementation of the 10-year SP.

In 2016, the Commission discussed the need to provide a way for parents, advocates, and those with ASD to give feedback on roadblocks they still faced in Oregon. In the summer and fall of 2016, focus groups and forums were held to obtain this information and help the Commission refocus its efforts. A new short-term strategic plan was approved and a request for a new Executive Order was requested.

In the following pages, a review of the OCASD mission, guiding principle, and the short-term Strategic Plan will be discussed, as well as recommended modifications in the existing Executive Order.

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 long-term and focus driven short-term strategic plans that increase coordination, promote best available practice, efficiently use resources, and both directly engages with and better responds to the needs of people with Autism Spectrum Disorder (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 with ASD 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, the community, and employment.

SUPPORT

- **ASD** Maintain high expectations for individuals and their families and provide the education, supports, services, and opportunities necessary to achieve a high quality of life.
- **ASD** Recognize that appropriate supports to ensure inclusive, meaningful, and safe participation in education, 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

- **ASD** Respect that the complex and dynamic needs of individuals and families require a seamless coordination of services and resources across the lifespan.
- **ASD** 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.

SUBCOMMITTEES

EDUCATION:

Chairman: Brad Hendershott

Subcommittee Members: Annette Skowron, Mary Apple, Mickey Pardew, Ruth Falco, Sharon Lohse, Susan Holmberg, Lisa Darnold, Marilyn Nerresan, and Linda Brown

Charge: Develop a plan for a comprehensive educational system for children and youth with ASD, from age of identification to age 21, which provides for the implementation of appropriate service in all educational settings.

The Education Subcommittee of the OCASD brings together a diverse group of stakeholders with a shared interest in evaluation and services for individuals eligible for special education under the category of ASD from the data of identification to age 21. This includes representatives from school districts, low incidence regional programs, higher education, the Oregon Department of Education (ODE), and the Oregon Program Autism Training Sites and Support (OrPATs).

Goals:

1. Design a plan to identify core service components and appropriate service intensity for children eligible for ASD services in Early Intervention and Early Childhood Special Education (EI/ECSE) settings.
2. Design a plan to identify core service components and appropriate service intensity for children eligible for ASD services in school age settings.
3. Identify opportunities to collaborate with the Community Services for Adults with ASD Subcommittee in planning for transition age students with ASD.
4. Design a plan for the ongoing, consistent review and dissemination of educational interventions based on the most current evidence based best practices that address individual needs across the spectrum.
5. Assure implementation of the identified practices with fidelity and consistency.
6. Design a plan to build and maintain opportunities for statewide training at all levels of service (e.g. ASD specialist, classroom teacher, parent, instructional assistant, related service providers, related community agencies) incorporating the most current evidence based practices.
7. Collaborate with higher education on the preparation and recommendations of ASD specialists.
8. Identify and recommend competencies for other professionals (Speech Language, Occupational & Physical Therapy, School Psychology, Paraprofessionals) and their implementation of statewide ASD educational services.

Activities:

The Education Subcommittee has taken on a number of specific initiatives. For example, the Autism Program Self-Assessment and Action Plan (APSA-AP) is a tool developed by subcommittee members to assist school districts in assessing the degree to which key elements are in place to ensure high quality services for their students with ASD. The domains include the following: (1) provide appropriate identification and assessment; (2) provide appropriate development of an Individual Family Service Plan (IFSP), Individual Education Plan (IEP) and Transition Plan; (3) provide appropriate qualified staff; (4) provide appropriate systematic program development and implementation; and (5) provide appropriate family and community training and supports. The Education Subcommittee leadership oversaw a pilot project to develop and refine the tool with several districts in Oregon. In 2016, members of the Education Subcommittee participated in a process to review and update the tool to produce a second edition, currently available to all school districts and local education agencies statewide. The goal of these efforts was to strengthen and enhance the quality of instructional services provided to students with Autism, consistent with evidence-based practices (EBPs) identified for students with ASD.

In addition, the Education Subcommittee continued to disseminate information regarding the Autism specialization available via the Teachers Standards and Practices Commission

(TSPC). The specialization ensures that school-based professionals who identify as an “Autism Specialist” possess requisite skills and competencies to evaluate and serve students with ASD, as well as train and support others to do so. The Education Subcommittee has interfaced with TSPC and other groups on questions and issues related to licensure, pre-service training, and ongoing professional development for those currently working within the schools.

The Education Subcommittee has remained engaged with efforts led by the Screening, Assessment, and Identification (SIA) subcommittee to update and modernize Oregon’s eligibility criteria and required evaluation components for ASD evaluations used for special education eligibility determination. Members of the Education Subcommittee have assisted by reviewing training modules developed by the SIA subcommittee. In relation to these efforts, members of the Education Subcommittee have taken on a significant role in developing a new ASD Technical Assistance Paper (TAP) in coordination with ODE. The ASD TAP provides guidance to school-based professionals in the state regarding tools and methods for conducting ASD evaluation and eligibility determinations aligned with principles of evidence-based assessment. The TAP also informs best practices in Individual Education Plan (IEP) development, instruction, and accommodations and modifications.

Next Steps:

The Education Subcommittee requested clarity regarding its purpose and focus, which has been addressed in the 2017-19 Short-Term Strategic Plan. While worthwhile projects were identified, individuals struggled to find the time to work on the project goals, given their personal and work related demands. The Education Subcommittee will move toward a focus driven workgroup structure with goals as outlined in the short-term plan.

SCREENING, IDENTIFICATION & ASSESSMENT:

Chairman: Joyce Bernheim

Subcommittee Members: Mary Apple, Debra Koutnik, Nancy Lawson, Bob Nickel, Justin Potts, Darryn Sikora, Annette Skowron, Rebecca Smallwood, Linda Brown, and Mary Hough

Charge: (1) Develop a plan to ensure that all Oregon’s children will be screened for ASD by the 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; and (2) 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 Autism Spectrum Disorder.
2. Identify strategies to increase public awareness about the importance, availability, and features of screening, evaluation, and assessments for ASD. Identify strategies for (1) increasing capacity throughout Oregon for screening, evaluations, and

- assessments; (2) ensuring that the quality indicators are being met; (3) ensuring that all children receive a screening for ASD by 24 months, and later when appropriate; and (4) ensuring that adults who have not previously been identified as having 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.

Activities:

Over the past two years the Screening, Identification, and Assessment Subcommittee has seen two of its long-standing objectives take major strides to fruition. These include: (1) revision of the Oregon Administrative Rules (OAR) governing the definition and identification of Autism for purposes of special education eligibility, and (2) preparation and piloting of internet-based training modules on the differential identification of Autism.

Oregon Administrative Rules: One of the issues leading to creation of the Commission was the disparity in the definitions of Autism between education and all other services providers in the state. In 2006, there surfaced evidence of extremely high rates of students being identified with Autism who did not have Autism when evaluated by Oregon's best-trained health care diagnostic teams. In 2010, the Commission recommended that all state agencies use the scientific definition of Autism and use a common, minimal set of elements for the evaluation process. However, since the scientific definition was undergoing revision at that time, SIA and the Commission held off on requesting a rule change until the new standards were published in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition ("**DSM-5**"), published by the American Psychiatric Association in 2013.

In the fall of 2013, SIA submitted to ODE a proposed rule incorporating the Commission's recommended minimum Autism evaluation standards, including use of the DSM-5 criteria. In March of 2017 however, ODE announced that it would not make the amendments requested by SIA. It thereafter submitted proposed rules to the State Board of Education incorporating several other changes to its Autism eligibility rules. In June, 2017, several members of the Commission and SIA Subcommittee acting individually, the Autism Society of Oregon, and Disability Rights Oregon submitted testimony in opposition to ODE's proposed rule. This resulted in the Board of Education requesting that ODE consult more educators about its proposed rule. In October, 2017, ODE issued a survey of educators, parents, and physicians and received approximately 200 responses, 78% of whom supported use of the DSM-5 criteria. ODE then announced at the October, 2017 meeting of the Board of Education that it would adopt the DSM-5 criteria for Autism. ODE is currently holding a series of stakeholder workgroup sessions to develop a new rule addressing other features of its eligibility evaluation process. Two members of the Commission are participants in the stakeholder workgroup.

Training Modules on the Differential Identification of Autism: In 2010, the Commission recommended to the Governor that identification of Autism (in health care or education) be performed by teams possessing minimum competencies. From 2011 to 2013 SIA worked on fleshing out those competencies in greater detail. In 2014 SIA surveyed school psychologists to determine if they possessed these competencies. Most of them said they did not, but were interested in learning more about how to differentiate Autism from other disorders that are sometimes mistaken for Autism. Accordingly, with funding from the Commission and in-kind support from DiagnoseFirst (an online company with a large video library of ASD behaviors), a workgroup of the SIA Subcommittee began developing a set of internet-based training modules on how to differentiate Autism from other disorders. The ultimate goal is to develop a 10-hour training for professionals in both health care and education. The modules will allow flexibility for users, depending on their prior knowledge and whether they practice in health care or educational settings.

The SIA Workgroup ultimately hopes to get sufficient funding through grants from outside organizations. To that end, they prepared an approximately two-hour pilot and hired an independent evaluation firm to test the pilot primarily with school psychologists. The pilot was evaluated in the spring of 2017, with 29 participants responding to an anonymous online questionnaire. Responses were overwhelmingly positive as to need, content, format, and impact. As a result of this response and requests by other educators, the workgroup is in the process of making the pilot available to a broader audience, while it proceeds with development of the full training.

Next Steps:

Members of the SIA Subcommittee will continue the work toward obtaining a grant to support the training modules outside of the structure of the OCASD in order to be more successful. A new Identification Workgroup will be formed with members of the current SIA Subcommittee invited to become a member. They will work on the goals and activities as outlined in the 2017-19 Short-Term Strategic Plan.

HEALTH CARE

(Includes Medical, Vision, Dental, Insurance, Mental Health, and Behavioral Health)

Chairman: Dr. Michele Raddish

Subcommittee Members: Bob Nickel, Christina Nicolaidis, Dora Raymaker, Pat Brady, Kathy Henley, Amy Donaldson, Robin McCoy, Kersti Petit-Kekel, David Solondz, Mark Whittaker, and David White

Charge: To promote the optimal health and wellness of individuals with ASD and ensure access to health care that is high quality, comprehensive, coordinated and patient centered.

Goals:

1. Reduce inequities in health care access and quality for individuals with ASD.
2. Improve the knowledge and skills of health care professionals in the care of individuals with ASD.
3. Develop recommendations on a process to determine medically indicated treatments for individuals with ASD.
4. Improve the funding of medically indicated services for individuals with ASD.
5. Ensure that health care services for individuals with ASD are coordinated and integrated among health care providers, families and community professionals.
6. Improve the general health of individuals with ASD by increasing the self-determination, health promotion, and self-management skills of individuals with ASD and their families.

Activities:

1. Determine what autism treatments/behavioral supports are currently approved by health plans and the Intellectual and Developmental Disability (I/DD) systems.
2. Review Coordinated Care Organization (CCO) funding of medically indicated services for individuals with ASD.
3. Aggregate the data received and determine inconsistencies between service providers (goal 1) and funding (goal 4).
4. Identify barriers to coordinating interventions and funding.
5. Determine current sources of information for individuals with ASD (goal 6).
6. Make recommendations to OCASD.

Next Steps:

The Health Subcommittee will move toward a focus driven workgroup structure with goals as outlined in the short-term plan. The current subcommittee will review the short-term plan and identify goal priorities and if they will separate into additional work groups to work through more than one goal at a time.

FRAMING THE WORK

During the April 2016 meeting, the Oregon Commission on Autism Spectrum Disorder (OCASD) “discussed the importance of setting short and long-term Commission goals to achieve recognizable change through small accomplishments as well as more significant systems change”. As a result, it was decided that a short-term strategic plan needed to be crafted with specific goals drawn from community input and aligned with the Governor’s Executive Order.

The input process for this plan involved public forum/focus groups held in Salem, Medford, Bend, Baker City, and Portland with video conference connections available in Klamath Falls and Roseburg. Additional information was gathered through informal conversations with people and groups interested in the topic and through a survey. In total, nearly 150 people throughout the State of Oregon, with direct or indirect affiliation with the Commission, provided input.

The OCASD December 2010 report to the Governor included an extensive array of recommendations and implementation activities that are still relevant. To narrow the scope, determine current status, and provide continuity, the Commission selected to evaluate six areas during the public forum/focus group sessions. These areas included: Identification Process, Systems Collaboration, Awareness & Advocacy, Education, Health Care, and Supports for Independence. With the input provided, the Commission updated these areas as part of its short-term strategic plan process.

Across stakeholders and regional areas there were pervasive concerns regarding diagnosis, training, resources and communication. It should be noted that the volume of data gathered from participants was infused with excellent ideas and information that will benefit the Commission now and in its future work.

This plan is designed to highlight a pathway to address these concerns through questions. Focus workgroups comprised of Commissioners and stakeholders with topic specific experience and expertise will manage the workflow of each project.

PROCESS

The following questions came out of the public forum/focus group discussions held during 2016 in Salem, Medford, Bend, Baker City, and Portland with video conference connections in Klamath Falls and Roseburg. The questions with associated goals, activities and timelines are part of the strategic plan to support families with ASD over the next two years.

IDENTIFICATION PROCESS



Question #1:

How can OCASD help with the alignment of the educational eligibility criteria with the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) medical diagnosis criteria in order to alleviate the confusion and frustration often experienced while seeking support?

Goal:

Work directly with the Oregon Department of Education (ODE) and other community partners to align the educational eligibility criteria to be consistent with the scientific consensus regarding the core features of Autism Spectrum Disorder (ASD).

Action Items:

1. Engage ODE leadership, K-12 leaders, interested legislators, and other community partners to ensure that special education administrative rules incorporate scientifically based criteria, such as the DSM-5 criteria, with appropriate phase-in periods to permit implementation with fidelity.
2. Engage Oregon Developmental Disabilities Services (ODDS), the Oregon Health Authority (OHA), health insurance plan providers, and health care providers to ensure consistent acceptance of ASD identification.
3. Obtain and use educational and medical eligibility/diagnosis data to determine disproportionality amongst different linguistic, cultural, ethnic, geographic areas, and gender. This data will be used to inform the work of this project.
4. Survey community partners on the availability and use of normed assessments throughout the state that are appropriate for different linguistic, ethnic, and cultural communities.

Timeline:

The Identification Workgroup will report back to the OCASD quarterly with a final report by June 2018.

Question #2:

How can the OCASD support timely identification and diagnosis of Autism (focusing on birth to 12) as well as improve access to trainings for professionals who work with those who have been found eligible/diagnosed with Autism?

Goal:

The OCASD will set up an Identification Workgroup to survey parents of school aged children to see how long it took to identify and/or diagnose their child's Autism and their experience with educational evaluation teams and health care professionals.

Identification Process (Continued)

Action Items:

1. Prepare a survey that addresses the timeline for identifying and diagnosing Autism and parent's experience with health care professionals.
2. Decide how to present the survey (phone, in person, survey monkey-internet, hard copy, etc.).
3. Aggregate the data received and provide a summary to the OCASD with recommended options on how to navigate roadblocks that slow down the process.
4. Aggregate the data received and provide a summary to the OCASD with recommended options on trainings needed for health care professionals based on parent input.

Timeline:

The Identification Workgroup will report back to the OCASD quarterly, including current survey findings and progress, with a final report due December 2018.



EDUCATION

Question #1:

How can the OCASD encourage parents, paraprofessional staff, and schools to use evidence based practices including Positive Behavior Supports (PBS) and maximize parental involvement?

Goal #1:

The OCASD will investigate and set up an Education Workgroup to survey Oregon school districts to see how many use evidence based practices, including PBS, and how they maximize parental involvement for those students with Autism Spectrum Disorder (ASD).

Action Items:

1. Review extant data sources to examine the use of evidence-based practices in schools at both state and national levels.
2. Prepare a survey that addresses the areas of evidenced based practices and parental involvement.
3. Decide how to present the survey (phone, in person, survey monkey-internet, hard copy, etc.).

Education (Continued)

4. Aggregate the data received and provide a summary to the OCASD with recommended options on how to encourage PBS use with Autistic children to school districts that do not currently use the program.
5. Aggregate the data received and provide a summary to the OCASD with recommended options on how parents of children experiencing Autism can get more involved in their child's education and some of the road blocks they may come up against.

Timeline:

The Education Workgroup will report back to the OCASD quarterly, with current survey findings and progress, with a final report by March 2019.

Goal #2:

The OCASD will support efforts to develop and disseminate training and technical assistance materials for school-based professionals to promote implementation of evidence-based practices.

Action Item:

1. The OCASD will engage with ODE and regional programs to determine how educational professionals participating in the Commission may partner with regard to revisions in the ASD Technical Assistance Paper.

Timeline:

The Education Workgroup will report back to the OCASD quarterly, with current survey findings and progress, with a final report by March 2019.

Question #2

How can the OCASD encourage school-based professionals to employ evidence-based assessment (EBA) related to evaluation and eligibility determination for special education under the category of ASD?

Goal:

The OCASD will support efforts to develop and disseminate training and technical assistance materials for school-based professionals to promote the use of evidence-based assessment (EBA) related to evaluation and eligibility determination for special education under the category of ASD.

Action Item:

1. The OCASD will engage with ODE and regional programs to determine how educational professionals participating in the Commission may partner with regard to revisions in the ASD Technical Assistance Paper to be in alignment with the revised ASD criteria per the Oregon Administrative Rules.

Timeline:

The Education Workgroup will report back to the OCASD quarterly, with current survey findings and progress, with a final report by September 2018.

Education (Continued)

Question #3:

How can the OCASD help parents ensure access for assistive technology, effective language translation services, transitional services and distance learning?

Goal:

Partnering with ODE, the Education Workgroup will survey parents and other stakeholders on the services provided to families who have children with Autism.

Action Items:

1. Prepare a survey that addresses the areas of assistive technology, effective language translation services, transitional services and distance learning.
2. Decide how to present the survey (phone, in person, survey monkey-internet, hard copy, etc.).
3. Aggregate the data received and provide a summary to the OCASD with recommended options on how parents can obtain the services noted.

Timeline:

The Education Workgroup will report back to the OCASD quarterly, with current survey findings and progress, with a final report due December 2018.

HEALTH CARE

INCLUDES MEDICAL, VISION, DENTAL, INSURANCE, MENTAL HEALTH & BEHAVIORAL HEALTH

Question:

How can the healthcare community support the health care needs of Oregonians with ASD?



Goal:

Survey stakeholders, including Oregonians with Autism and their families along with health care providers and insurance companies, regarding health care needs in order to develop an action plan.

Timeline:

The Health Care Workgroup will report back to the OCASD quarterly, with current survey findings, with a final report due December 2018.

SUPPORTS FOR COMMUNITY LIVING

Question:

How can the OCASD educate community partners on how to best communicate and support those who have Autism over the age of 18 and support housing and independent living for those individuals?

**Goal #1:**

The OCASD, with help from the Oregon Council on Developmental Disabilities (OCDD), will establish a Support Workgroup with the charge to evaluate shared housing options for adults with Autism or developmental disabilities seeking employment who are homeless or near homeless and look at how to provide training to those who may come in contact with adults who have Autism with regard to their housing needs (police, landlords, housing advocates).

Action Items:

1. Identify policy barriers related to housing with the OCDD.
2. Leverage current efforts to provide sustainable housing options, such as work being done by the Housing Alliance and Fairview Trust.
3. Survey housing advocacy groups to see how many currently support parents of adult children with Autism or adults with Autism who have rental complaints due to behavior or developmental disability issues.
4. Prepare a list of housing advocacy resources for dissemination and publishing on the OCASD website.

Timeline:

The Supports Workgroup will report back to the OCASD quarterly, with current findings and progress, with a final report by December 2018.

Goal #2:

Engage first responders (law enforcement, resource officers, and the justice system) by providing funding support for training awareness regarding interacting with people on the Autism Spectrum as well as those who also simultaneously have mental health issues.

Action Items:

1. Determine training and communication systems currently in place nationally.
2. Establish and engage these professionals in Oregon in an ongoing process to understand barriers, and then develop policy and training opportunities.
3. Collaborate with stakeholders to make training accessible to first responders.

Timeline:

The Support Workgroup will report back to the OCASD quarterly, with a final report and recommendations by December 2018.



SYSTEMS COLLABORATION

Question #1:

With the increasing access to Autism treatment via health plans, how can the support plans developed by the various child-serving systems be coordinated to assure consistency of supports in varying settings?

Goal:

The OCASD will set up a Systems Collaboration Workgroup to identify and address barriers to coordinating interventions via health plans and the Intellectual and Developmental Disability (I/DD) systems.

Action Items:

1. Determine what Autism treatments/behavioral supports are currently approved by health plans and I/DD systems.
2. Define nomenclature between systems.
3. Identify barriers such as ethnic, language, etc.
4. Aggregate the data received and determine inconsistencies between service providers.
5. Identify barriers to coordinating interventions.
6. Make recommendations to OCASD.

Timeline:

The Systems Collaboration Workgroup will be convened during the first quarter of 2018 and will report back to the OCASD quarterly. The timeline for reporting out on the workgroup will be determined by June 2018.

Question #2:

How can the OCASD increase access to support materials on Autism for families that do not speak English?

Goal:

The Systems Collaboration Workgroup will explore how to partner with healthcare, ODE, ESDs and school districts to provide diversity in materials on Autism to ensure access to advocacy information on early intervention and the role of school districts through public announcements, posters, brochures, and other key resources for families that do not speak English.

Systems Collaboration (Continued)

Action Items:

1. The Systems Collaboration Workgroup, working with ODE, will survey Oregon school districts, ESDs, and health care providers to find out how they disseminate information on Autism, if it is available in hard copy as well as online, and if it is available in languages other than English.
2. Explore how to partner with ODE, ESDs, health care providers and school districts to provide the same information to those who are not of school age.
3. Review materials and recommend specific materials to be available through the OCASD.

Timeline:

The Systems Collaboration Workgroup will report back to the OCASD quarterly on its progress and submit a final report with recommendations to the Commission by December 2018.

Next Steps:

With stakeholder collaboration, proper staffing and financial resources for leveraging projects in the field, the Commission feels it can move forward with noticeable positive impact for people identified with Autism Spectrum Disorder, their families and communities statewide. The OCASD plans to implement the 2017-19 Short-Term Strategic Plan (SP) and expects a new Executive Order to be in place by early 2018. In the future, the OCASD would also like to fill the open positions on the Commission, move from subcommittees to specific workgroups to support the work of the strategic plan, and put on a statewide conference for ASD families, first responders, and those who work in the health care and education communities.

OCASD Recommendations—New Executive Order

In mid-2017, members of the OCASD met with Victoria Demchak, a member of the Governor's staff who oversees different commission activities. Leadership of the OCASD asked that several changes be made to the current 11-05 Executive Order (EO) so that terms could be increased and leadership from the Senate and the House of Representatives could be approved through the Senate President and Speaker of the House. The following is the list of recommendations submitted in December 2017:

1. Allow members to serve additional terms. It is recommended that members serve two-year terms with a limit of 4 terms, or to serve four-year terms with a limit of two. It was noted that two-year terms might be more beneficial for legislators who are on the Commission.
2. Clarify that members may be allowed to remain on the Commission due to transitional periods or for their institutional knowledge, even when their "term limit" has expired (with the written recommendation of the Commission Chairman and approval of the Governor's office).
3. Keep the wording to allow for staggered terms.
4. Exclude representatives from Oregon Health Authority (OHA), Department of Human Services (DHS) and Oregon Department of Education (ODE) from term limits.
5. Include language regarding \$100 stipend per meeting for members, if not compensated through the scope of a Commissioner's present employment, plus reimbursement for mileage at the federal rate for members who travel greater than 50 miles one way.
6. Allow members who are representing agencies such as OHA, DHS, or ODE to assign an alternate representative from their agency to attend meetings and vote when the main representative cannot attend due to agency needs.
7. Allow for more flexibility in the description of the positions (i.e. there are currently three positions for advocacy, but they are very specific to the type of advocate) and reduce the number of positions, with two positions that simply are noted as an individual advocate (with descriptors such as a self-advocate, parent of a child with Autism, or parent of an adult child with Autism).
8. Add an additional at-large position, which could be filled based on the needs of the Commission in alignment with the strategic plan, and may include someone to represent housing, early learning, first responders, or justice.
9. Add two new positions on the Commission that represent individuals who are a licensed professionals with Autism credentials. This may include a Clinical Psychologist with Autism credentials (such as a BCBA-Board Certified Behavior Analyst) or a licensed Clinical Social Worker with Autism credentials.
10. There are currently no representatives from either the Senate or the House of Representatives on the OCASD. The OCASD recommends that the new EO revert back to having the Speaker of the House and the Senate President appoint members of the legislature to the Commission, without having to be recruited and approved by the Governor. Legislative leadership is needed on the Commission and this appointment process was successful in the past.
11. Add a sunset clause with a renewal option to lengthen the EO. This would allow the Governor's office to have a regular check-in process with the Commission to see if additional changes need to be made to the current EO, as well as to discuss any possible change in the focus of the Commission.

APPENDICES



EXECUTIVE ORDER NO. 11 - 05

CONTINUING OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

Oregon, like many states across the nation, has experienced a rapid increase in the number of individuals being diagnosed with Autism Spectrum Disorder (ASD) and both the public and private systems have had difficulty responding. Services are often fragmented and inconsistent around the state. Oregon is not taking full advantage of the wealth of knowledge, best practices and skill currently available in the state and elsewhere. Oregon lacks a means to provide accurate, up-to-date information to families and professionals regarding interventions, services, supports and expected outcomes. There is currently no consistent approach to increasing the capacity of agencies and communities to support individuals with ASD.

The rapid increase in the numbers of individuals being identified with ASD, the complexity and diversity of their needs, limited resources, and the consequent pressure on families, communities, existing education and social service systems, requires a more thoughtful, coordinated approach to funding, service development and delivery. Executive Order 09-07 established the Oregon Commission on Autism Spectrum Disorder and charged it with creating a 10 Year Strategic Plan on Autism Spectrum Disorder to address the issues confronting Oregon. This Plan was submitted to the Governor in December 2010. Executive Order 09-07 provides that the Oregon Commission on Autism Spectrum Disorder expires on July 1, 2011.

There exists an ongoing need to guide the implementation of the 10 Year Strategic Plan on Autism Spectrum Disorder. Therefore, this Order continues the Oregon Commission on Autism Spectrum Disorder to implement the 10 Year Strategic Plan.

NOW THEREFORE, IT IS HEREBY DIRECTED AND ORDERED:

1. The Oregon Commission on Autism Spectrum Disorder ("Commission") previously established in Executive Order 09-07 shall continue its work as modified by this Executive Order.
2. The purpose of the Commission shall be to:
 - a. Guide implementation of the 10 Year Strategic Plan and identify biennial goals for the state of Oregon by providing leadership,



EXECUTIVE ORDER NO. 11 – 05
PAGE TWO

- establishing priorities, creating key performance measures, facilitating collaboration, ensuring support and monitoring outcomes;
- b. Expand and strengthen formal and informal partnerships among systems serving individuals with ASD, including any ASD related expert panels;
 - c. Identify and incorporate any needed revisions to the 10 Year Strategic Plan to address gaps, barriers, and solutions for individuals with ASD;
 - d. Convene, facilitate, and lead key stakeholders in developing, promoting, and implementing recommendations from the 10 Year Strategic Plan; and
 - e. Provide regular updates on the status of plan implementation and outcomes to the Governor, Legislative Assembly, and the public.
3. The Commission shall consist of 15 members, who are knowledgeable about Autism Spectrum Disorder or about systems that serve people with Autism Spectrum Disorder or both. The Governor shall appoint all members but will receive recommendations from the Senate President and Speaker(s) of the House in regard to Legislative members of the Commission. The members shall include:
- a. One member who is an individual with autism who shall be considered a self-advocate, appointed by the Governor;
 - b. One member who is the parent of a child with autism below the age of 18 at the time of appointment, 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 Oregon Health Authority, recommended by the Director of the Authority and appointed by the Governor;
 - g. One member who represents the Department of Human Services, recommended by the Director of the Department and appointed by the Governor;



EXECUTIVE ORDER NO. 11 – 05
PAGE THREE

- h. One member who represents the mental health community, appointed by the Governor;
- i. One member who represents healthcare systems/insurance, appointed by the Governor;
- j. One member who represents the Department of Education, recommended by the Superintendent of Public Instruction and appointed by the Governor;
- k. One member who represents Higher Education, appointed by the Governor;
- l. One member representing a local education entity, appointed by the Governor;
- m. One member from the Oregon House of Representatives, appointed by the Governor;
- n. One member from the Oregon Senate, appointed by the Governor; and
- o. One public member at large, appointed by the Governor.

4. All appointments to the Commission shall be made on or before July 1, 2011. New appointments will typically be for two years, but reappointments of members from the existing Oregon Commission on Autism Spectrum Disorder in 2011 shall be for 1 year in order to establish staggered terms. Any subsequent reappointments shall be for two year terms. A minimum of 1/3 of the members of the existing Oregon Commission on Autism Spectrum Disorder whose terms expire in July, 2011 will be retained for a period of at least one year to assist in the transition of the new Commission.

5. All members serve at the pleasure of their appointing authority. If a vacancy should occur for any reason it shall be the responsibility of the appointing authority to make an appointment effective immediately that meets the requirements of section 3.

6. The Governor shall select a chair and vice-chair from the Commission's membership.

7. The Commission may create as many subcommittees as it deems necessary to carry out the scope and mission of the Commission. Each subcommittee shall include a Commission member and may be composed of



EXECUTIVE ORDER NO. 11 – 05
PAGE FOUR

members outside of the Commission. Subcommittees should strive for geographic diversity in membership.

8. The Commission shall meet at least quarterly and more often as the Commission determines is necessary and as funding allows. A quorum for meetings shall consist of a majority of the appointed members. The Commission shall strive to operate by consensus.

9. To facilitate meaningful participation by parents of individuals with ASD and self-advocates, those members may be paid a per diem pursuant to ORS 292.495(1) and reimbursed for expenses incurred in attending Commission meetings, pursuant to ORS 292.495(2), and subject to availability of funds. No other members shall be eligible for a per diem or reimbursement of expenses.

10. The Director of the Department of Human Services, the Director of the Oregon Health Authority and the Superintendent of Public Instruction shall provide staff and support necessary to support the activities of the Commission and its subcommittees, subject to availability of funds. All other agencies of state government are ordered to assist the Commission in the performance of its duties and to the extent possible, provide the Commission with representatives as outlined in Commission membership as well as the information and advice considered necessary by members of the Commission to meet their responsibilities.

11. The Oregon Council on Developmental Disabilities may accept, on behalf of the Commission, contributions of moneys and assistance from the United States Government or its agencies, or from any other source, public or private and agree to conditions upon the monies, not inconsistent with the duties of this Commission and as otherwise allowed by state and federal law.

12. The Commission shall use the 10 Year Strategic Plan to develop goals, outcomes, and implementation strategies to ensure effective services to individuals experiencing Autism Spectrum Disorder and their families. The Commission shall continue to monitor implementation and amend the Strategic Plan designed to:

- a. Clarify the array and structure of necessary services and supports that enable persons with Autism Spectrum Disorder to function to their individual potentials across their lifespan;
- b. Ensure effectively coordinated service systems for persons with



EXECUTIVE ORDER NO. 11 – 05
PAGE FIVE

Autism Spectrum Disorder in Oregon through strategies that might include interagency agreements, braiding of funding, and other processes necessary to assure collaboration and coordination;

- c. Define and recommend strategies for accessing and promoting best practices and research-based information to the professional community and the public;
- d. Identify and recommend strategies to increase the capacity of agencies and the community to appropriately support individuals experiencing Autism Spectrum Disorder; and
- e. Estimate and make recommendations regarding the long-term funding and the sources of funding needed to provide the necessary services and supports described in the 10 Year Strategic Plan.

13. The Commission shall submit a report to the Governor and the appropriate Legislative Committee each year, no later than the fall prior to the annual legislative session. The report shall include but need not be limited to:


- a. An update on implementation and outcome priorities identified in the 10 Year Strategic Plan;
- b. Biennial goals for providing services and supports to persons with Autism Spectrum Disorder in Oregon as outlined in section 12;
- c. Proposals for legislation is necessary for implementation of the goals; and
- d. Recommendations to applicable principal departments of the state concerning policies, procedures, and to improve services that benefit people with Autism Spectrum Disorder or to improve coordination among state agencies that provide services that benefit people with Autism Spectrum Disorder.



EXECUTIVE ORDER NO. 11 – 05
PAGE SIX

14. The Commission shall continue its work as set forth in this Executive Order until the Executive Order is revoked.

Done at Salem, Oregon, this 29 day of June, 2011.



John A. Kitzhaber, M.D.
GOVERNOR

ATTEST:



Kate Brown
SECRETARY OF STATE





COMMISSION MEMBERS

Pat Sublette, Chairman (Resigned September 2017)
Nancy Lawson, Chairman (Appointed September 2017)
Representing: Local Education

Mark Whitaker, MD (Resigned October 2017)
Anne Saraceno (Appointed February 2018)
Representing: Medical Insurance

Corey Stump
Representing: Advocacy Organization

Bruce Baker
Representing: Department of Human Services

Sydney Shook (Resigned January 2018)
Heather Olivier (Appointed February 2018)
Representing: Parent of a Child with ASD

Lisa Darnold
Representing: Department of Education

Cheryl Cisneros (Resigned December 2017)
Open Position
Representing: Parent of an Adult with ASD

Bradley Hendershott
Representing: Regional Programs

Michele Raddish, MD
Representing: Medical Community

OPEN POSITIONS

Parent of an Adult with ASD
Oregon Health Authority
Higher Education
Oregon Senate
Oregon House of Representatives

COMMISSION STAFF

Mary Richards-Administrative Support
Rebecca Barnhart –Communications Specialist

REPORT BY OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

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OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

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