



OREGON COMMISSION ON AUTISM SPECTRUM DISORDER

Notes March 16, 2017

A meeting of the Oregon Commission on Autism Spectrum Disorder was held on March 16, 2017 at 9:30 am in room H-470 of the Oregon State Capitol Building located at 900 Court Street NE in Salem Oregon. This meeting was originally scheduled from 8:00-10:30 am, but had to be rescheduled due to room availability at the Capitol. A conference call line was provided for those Commissioners who could not attend in person, but wished to participate in the meeting.

CALL TO ORDER/ROLL CALL

Commission Co-Chair, Pat Sublette called the meeting to order at 9:30 am. Those in attendance personally and via conference call included: Commissioners-Pat Sublette, Sydney Snook, Chris Edwards, Cheryl Cisneros, Dr. Michele Raddish and Lisa Darnold. Commissioners Bruce Baker and Mark Whitaker were absent.

Others in attendance included: SIA Committee Chairman-Nancy Lawson; Commission Consultant-Margaret Theisen; ODE Educational Specialist-Linda Brown; Representative Jodi Hack and Mary Richards.

Several Commissioners noted they would need to leave the meeting early due to the change in the original meeting timeframe.

APPROVAL OF THE AGENDA

Due to time constraints, introductions, the approval of the Commission's calendar and the SIA funding request were moved to the end of the agenda.

Dr. Michele Raddish made a motion for the March 16, 2017 agenda be approved as modified. It was seconded by Cheryl Cisneros and passed unanimously 6-0.

APPROVAL OF JANUARY MEETING MINUTES

The minutes were prepared from the January 19, 2017 meeting for members of the Commission to review. Several revisions were requested including: the reference to a three-year plan changed to an *interim plan* on page 1; the reference to a monthly meeting changed to *every odd month* (meeting every two months) on page 5; and the reference of

a change to meeting times so that it notes the meeting time was changed *due to the legislative session* on page 5.

Dr. Michele Raddish made a motion for the January 19, 2017 OCASD minutes be approved as revised. It was seconded by Sydney Snook and passed unanimously 6-0.

FORUM & FOCUS GROUP REPORT

At the last meeting, an update of the focus groups was given to the Commission. Since then the final focus group occurred in Portland on January 27th. This was facilitated by a bilingual, bicultural consultant from an organization called Parents in Action. The format of the focus group was an informal conversation with Latino parents, in order to gather the most spontaneous and important information from the parents' lens and experience. The group in Multnomah and Washington Counties who participated in the focus group had been attending Parents in Action meetings for at least six months. The parents from Linn and Benton Counties had attended Parents in Action meetings for four years, meeting each month to learn about human/civil rights, special education rights and the service system in Oregon. Phone interviews were also completed.

Margaret Theisen reviewed the findings of the forum at the meeting. She also submitted back up information on the January forum and a summary of her work so far.

The forum and focus groups held over the past year have given the Commission an overall view of barriers that parents of autistic children deal with and their needs and overall concerns. The forum/focus group meetings were held in Medford (with video conference connecting with Klamath Fall and Roseburg), Salem, Baker City, Bend, and Portland with Portland focused on Spanish speaking families. Additional input was sought in an on-line survey and overall, approximately 150 people provided input, about the same number who gave input into the Commission's original strategic plan. Information gathered from participants showed that communication, training, and resources were important factors to parents and those that deal with children and adults with Autism Spectrum Disorder (ASD).

REVIEW OF DRAFT OCASD STRATEGIC PLAN

At the last meeting in January, it was suggested that the Governor be provided with a status report and that a revised short term plan be developed as an amendment to the original OCASD Strategic Plan. It was also noted that professional representation on the Commission may need to be expanded and that there may be a need to move away from long-term subcommittees and move toward short-term project work groups or task force initiatives.

A drafted framework for the amendment to the OCASD Strategic Plan was prepared by Margaret Theisen based on her interactions with the Commission as well as those who

attended the forum/focus group meetings or completed the on-line survey. This framework was included in the meeting packet.

Margaret reviewed the six sections of the framework with the Commission. These sections included: 1) Identification (Diagnosis) Process; 2) Systems Collaboration; 3) Awareness and Advocacy; 4) Education; 5) Medical; and 6) Supports and Independence. Members of the Commission thanked Margaret for her huge scope of work with the forum/focus group meetings and for her succinct work on the drafted framework.

Below are comments and/or concerns regarding the drafted plan separated by heading:

Identification (Diagnosis) Process:

- There was a need to align the medical and educational identification of eligibility for those with a DSM-5 diagnosis.
- There is a lot of interest from rural and Spanish speaking populations regarding access for assessments with noted struggles for travel to OHSU for these assessments; therefore mobile assessments of some sort were recommended.
- It was suggested that the word “diagnosis” be removed from this heading, even though a diagnosis of DSM-5 was referred to within the subsection.
- There was an “Access Grant” completed that helped to address some of the needs noted in this section. It is important to promote its extension.
- Video conference availability is very important and allows 100’s more to participate than would otherwise be able to-as seen with the “Feeding Matters” Conference. This video option would be especially good for families with disabilities.

Systems Collaboration:

- There was a lot of feedback noting the need for better training and support for law enforcement to understand those with ASD.
- There is a high need for a consolidated source for information and resources for ASD.
- It was suggested that the Commission partner with the Autism Society of Oregon to post information needed for families.
- Representation on the Commission needs to include those with a background in the mental health, housing, and law enforcement fields.

Awareness and Advocacy:

- Policy work is needed to require positive training for how to work with special populations at the law enforcement level.
- Basic tools and information need to be available in Spanish.
- There were no comments by the Commission on this area as far as needed changes.

Education:

- The Commission may want to adopt a policy paper that is already nationally recognized as described in the framework.
- Online training on ASD needs to be available for school districts statewide.
- A survey may be needed to determine what is occurring and what should be added to help schools.
- Early interventions usually begin prior to age three, when there is a medical diagnosis however, many children do not get identified until they enter the school system.
- Brad Hendershott has been working with multi-regional team of 8 people to update the Technical Assistance Paper (TAP) for Special Education-Autism Spectrum Disorder. The TAP is expected to be drafted by the end of April/May.
- It is important for educators to know what the researched based characteristics are for ASD eligibility.
- There is a need to review options for language translation services, distance learning, online learning, technology use and assisted technology assessments.
- Many parents are opting out of public education and homeschooling their ASD child instead-these may be the strongest voices for what is missing in public education.
- A three tiered system with a core writing team to prep the assessment is now available to schools and families. The newly revised self-assessment form is great and also helps to push out the needs for professional development.
- The National Leadership for online Special Education services is currently moving forward to support ASD students.

Sydney Snook excused herself from the meeting at 10:30 am.

Medical:

- There was a lot of feedback noting the need for better training and support for the medical community to evaluate and understand the needs of those with ASD.
- ADA access is ongoing work, but minimal.
- The Access grant had some information on medical needs.
- Medical providers need to collaborate with social workers, case managers, and those who support those with ASD, especially those who work with the child day to day at home and at school.
- Access to dental and vision services is an issue for those with ASD. Many providers do not know how to handle behavior issues for many with ASD.
- A subsection for Dental under the Medical heading should be considered.

Supports for Independence:

- Those with ASD need safe housing and independent living options.
- Employment and housing are priorities that go hand in hand for those living independently with ASD.

- Some of the work needed in this area may be funded through the Office of Developmental Disabilities Services (ODDS).
- There was a work group plan drafted with the help of George Braddock regarding housing that may be archived under the Children & Families Subcommittee that may be useful.
- A subset regarding families should to be added under this section.
- Families are being removed from current rental housing due to their child's behavior challenges-this ties into law enforcement training and how they can support families when noise and behavior issues are reported by a landlord or other tenant in an apartment.
- Parents need help getting services as well as advocacy.
- Housing and basic needs seemed to be an urgent need for many who attended the focus/forum meetings.

TABLED AGENDA ITEMS

Chris Edwards mentioned that he would be resigning from the Commission, since he represented the Senate on the Commission and he no longer is in the legislature. He also noted that he would have to leave the meeting at 10:45 am.

With Chris Edwards' planned exit, there would no longer be a quorum of the Commission in attendance. With this in mind, the approval of the Commission calendar was tabled until the May 18th meeting and a Special Session was requested to approve the SIA funding request.

ADJOURN

The meeting was adjourned at 10:43 am.

Pat Sublette, Interim Chairman