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DEPARTMENT OF HEALTH AND HUMAN SERVICES
AGING AND DISABILITY SERVICES DIVISION

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Name of Organization: Nevada Commission on Autism Spectrum Disorders
Adults and Aging Subcommittee

Date and Time of Meeting: September 19, 2014
12:00 p.m.

Las Vegas: Nevada Early Intervention Services
3811 W. Charleston #112
Las Vegas, NV 89102

- I. Mr. Olson called the meeting for the Adults and Aging Subcommittee to order at 12:05 p.m.

Members Present: Mark Olson, Steven Cohen, Korri Ward, Vanessa Fessenden, Renee Portnell

Guests: Jan Crandy, Megan Crandy, Mel Johnson, Kathleen Kingston, Annette Aloiau, Lisa Watson

Staff Present: Carol Reitz

A quorum was declared.

- II. Public Comment (No action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item)

Mark Olson informed the Committee that the consumer and public surveys indicated the deadline was September 18th but they can still be submitted by the end of the day online.

Mr. Olson shared information regarding the EIs for Autism conference on October 11 which has been expanded with a morning and afternoon session. Mr. Olson also shared with the Committee that he attended the launch of the Nevada Housing Search.org. They provide services for individuals with

disabilities and elderly for available rental housing for low-income housing. Their website is NVhousingsearch.org

Mr. Olson called everyone's attention to a report that was a handout titled "Fulfilling the Promise by Senator Tom Harkin." Mr. Olson encouraged everyone to read the report since it has data regarding the prevalence of poverty among adults with disabilities.

Mr. Olson also shared with the Committee an upcoming one-day conference for supporting housing solutions for adults with developmental disabilities.

Ms. Kathleen Kingston shared her story about her son with autism who is 16 years old. He is aggressive and doesn't have conversational skills. She has had her son on a waiting list for a group home about two years ago. Desert Regional Center (DRC) got her help with Carpe Diem but now he is being placed out of state.

Mr. Olson asked Ms. Kingston if she's had his IQ level tested. Ms. Kingston responded that his IQ level was tested when he was very young and was at 40. She is unsure where his IQ level is now.

Ms. Mel Johnson shared her story about her daughter with autism who is 18 years old. She is extremely aggressive when she is experiencing PMS. She is currently working with DRC who is hiring a psychological team to observe her since she is over 18 with Medicaid. This will allow for more flexibility. They are devising a plan to stabilize her.

Ms. Korri Ward added that when her son was taken to Renown, she had a crazy experience. She commented that hospital staff, social workers and nurses need to be trained.

Mr. Olson commented that first responders and the justice system need to be trained. The system is working against us and the ADA (Americans with Disabilities Act).

Ms. Kingston added that a social worker suggested calling CPS(Child Protective Services). CPS documented that Ms. Kingston abandoned her child. Medicaid told her that he didn't meet the level of care for a residential treatment center.

III. Approval of Minutes from September 5, 2014 Meeting (For Possible Action)
Mark Olson, Chair

Steven Cohen made a motion to pass the minutes as written. Renee Portnell seconded the motion. The motion passed.

IV. Strategic Planning Discussion to Identify the Following:
Lisa Watson, Social Entrepreneurs, Inc.

Mr. Olson introduced Lisa Watson from Social Entrepreneurs (SEI) who facilitated the discussion of the strategic plan. Ms. Lisa Watson described the strategic planning process and collecting information and feedback on the vision and mission and guiding principles that the Commission has drafted.

Ms. Watson introduced herself and asked everyone else to introduce themselves. Ms. Watson has been a consultant with Social Entrepreneurs for the past year and a half.

Ms. Jan Crandy is a parent with a 21-year-old daughter with autism. Ms. Megan Crandy is a 21-year-old self-advocate. Ms. Annette Aloiau is a behavior analyst assistant who works with NEIS (Nevada Early Intervention Services). Ms. Mel Johnson is a parent of a 18-year-old daughter. Ms. Kingston is a parent of 16-year-old son. Mr. Olson is a parent of an 18-year-old daughter with autism. Ms. Vanessa Fessenden is a board certified behavior analyst. Ms. Renee Portnell is a parent of a 20-year-old. Mr. Steven Cohen is a 26-year-old self-advocate. Ms. Korri Ward is a parent of 21-year-old twin boys. Ms. Michele Tombari is a parent of a 19-year-old.

Ms. Watson told the Committee back in 2008 the Task Force developed 146 recommendations. SEI was hired to help focus the efforts over the next five years. There are three phases to the strategic planning process. They are in first phase which is collected the information of what is most important for people throughout the lifespan who are living with Autism Spectrum Disorders (ASD) in the state of Nevada. She will be meeting with all four subcommittees to gather the information. A consumer survey was also sent out and almost 400 surveys were completed. They are also doing 15 key stakeholder interviews from multiple disciplines.

Ms. Watson commented that SEI will develop priorities that are consistent across areas that the Commission can focus on. The last phase is putting all the information into a written record.

Ms. Watson began the discussion by asking what are the most significant needs or challenges facing Adults and the Aging population of individuals living with ASD who need/use services. Mr. Olson responded that housing needs are the greatest for the most challenging. There are not enough options. There are not enough specialized providers who are trained and knowledgeable to support the disabled population. Providers of services are also not paid enough so there is a high turnover rate.

Ms. Jan Crandy talked about the adequate levels of support. They need assistance with independent and community living. Ms. Megan Crandy

added there is long waiting periods for supports for college or vocational training supports.

Ms. Watson asked the Committee to talk about employment support. Mr. Olson said there is the charter for Voc Rehab (Vocational Rehabilitation) but the supports are not there to accommodate any job changes. Ms. Crandy added that the employers don't understand their disability and should work with them to be successful. Ms. Judy White said they are sometimes taken advantage of at the workplace.

Mr. Olson talked about finding appropriate medical services. He said females with autism need to find OB/GYN services and education on rights to birth control and sexuality.

Ms. Watson summarized the needs are housing, workforce opportunities as well as workforce support. This particular population needs life-skill supports. That would enhance their quality of life, transportation, advocacy network, coping skills education and access to medical services.

Ms. Watson asked how the needs have been met. Ms. Crandy said expanding what we already have. There is insufficient funding for housing placements. Mr. Olson said there is currently a state task force working on employment first but the results won't be available for at least a year.

Mr. Olson said transportation options are varied throughout the state. Transportation can be difficult to navigate and expensive. Ms. Ward said in the rural area, you have to make your appointments two weeks in advance. If you have to make any changes you are then taken off the list.

Ms. Watson asked what the three biggest challenges the Subcommittee can identify. Mr. Olson said funding that supports services for housing statewide. There is a wait list that is prioritized by the needs of the person.

Ms. Crandy said there are gaps in high functioning and low functioning needs. Ms. Michele Tombari added that there is a gap in community awareness across the board. Mr. Olson commented that Legislatures do not understand where funding comes from. They think insurance funds all these programs and do not understand that the State is funding these services as well as parents having to pay out of pocket.

Mr. Olson commented that insurance may be funding some of these services but there are not enough providers.

Ms. Watson summarized the three gaps that are unmet are housing, employment and treatment options. Ms. Crandy added support services and respite care for parents is limited.

Ms. Watson asked how well are programs and services coordinated across systems to serve the adults and aging population. Ms. Judy White responded in the rural area they are nonexistent. Ms. Crandy said there are not coordinated and you have to navigate yourself. Ms. Megan Crandy was frustrated with Voc Rehab waitlist.

Ms. White commented that the education system needs to be more aware and start earlier with the transition to start in the school system. They need to work together for that child to move forward. There is no effort that brings everything into focus and direction. There needs to be more communication and more community effort for every child.

Mr. Olson commented that there are some private programs that work directly with the school districts. The Regional Centers try to bring parents and advocates together. He added that there is not a high level of planning moving an individual through the lifespan. Ms. Crandy said it is coordinated once a crisis that occurs.

Ms. Watson summarized that there are pockets of opportunity by providers but there is not a multi-disciplinary approach. Mr. Olson said the strategic plan was designed around age groups so those specific issues were addressed.

Ms. Watson asked what current ASD programs should be continued, maintained and leveraged. Mr. Olson said that ASD is the only commission whose members have increased. ASD is the only committee addressing Autism statewide.

Ms. Annette Aloiau commented a strength that she sees is providing funding for individuals through DRC for pharmaceutical assistance. They are also providing options for vision, speech, and behavioral health.

Ms. Watson inquired about the ATAP (Autism Treatment Assistance Program) funding. Ms. Crandy said that ATAP's current age limit is 19 but they are working on expanding it. Ms. Ward added that BCBA (Board Certified Behavior Analyst) providers are traveling to rural Nevada, which is working. Voc Rehab is also available but they are not trained to work with Autism. Families collaborate with one another.

Mr. Olson said it is important to understand where government stops and nonprofit funding starts. He thinks nonprofits use their money more efficiently.

Ms. Watson asked what this subcommittee thinks is the critical needs for adults and aging. Ms. Tombari said there is a lack of knowledge among the public, providers and parents.

Ms. Ward said self-directed services need to be put back in and expanded statewide.

Ms. Crandy asked if families are protected in their evidence-based choices. Mr. Olson said the family's choice needs to be supported. Ms. Watson summarized the Subcommittee's recommendations as increase awareness, identifying services and honor and support for self-determination and self-directed services. Ms. Ward also added that there needs to be a competent and educated workforce.

Ms. Watson asked what progress has been made since the 2008 Task Force Report was produced. Ms. Ward responded that she has not seen any progress made for adults beyond the age of 22. Ms. Crandy commented that the Commission pushed Voc Rehab to do some training specific to autism but it has not been done yet.

Ms. Watson asked what policy changes need to be changed or developed to improve services for people with Autism Spectrum Disorders. Mr. Olson responded that California has a Bill that gives them a right to use money that they qualify for to choose any service and support that are not part of the regional centers. It provides a navigation network to support the access. Ms. Crandy commented that waivers should consider functional level as opposed to just their IQ level. Mr. Olson said the definition for community needs to be redefined so providers can offer these settings. Models used around the country allow people to access waiver or planned paid supports for housing.

Ms. Watson asked what practical changes are needed to improve the lives for people with ASD. Ms. Crandy responded that plans need to be designed around functional levels. Ms. Ward suggested removing the age cap on health insurance. Ms. Crandy said it should be going to age 26. The requirement that children must be in school in order to access insurance coverage should be removed.

Mr. Olson added removing barriers such as CABI (Certified Autistic Behavior Interventionist) for insurance and honoring national certifications. He said quotas need to be set for state and local government regarding hiring people with disabilities, and also addressing minimum wage disparities.

Ms. Crandy said we need more trade schools. School districts should be providing training and opportunities for students that would lead to employment.

Mr. Olson commented that Voc Rehab needs to redefine success. They need to lift barriers off what you can have. He also commented there should be pathways to post-secondary education that also has supports.

Ms. Watson asked if there are any other insights anyone would like to add. Mr. Olson said the federal government needs to change the CMS (Center for Medicare and Medicaid Services) regulations. Aging for the population with autism is a problem across housing, medical services and transportation. Mr. Olson also added first responders and law enforcement need to be trained on ASD so they can assess the appropriate action along with the justice system.

Mr. Olson brought up the issue of sexuality. There are states and providers that set their own policy as to relationships and procreating. Ms. Crandy said education on sexuality needs to be taught.

V. **Public Comment**

(No action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item. Comments will be limited to three minutes per person. Persons making comment will be asked to begin by stating their name for the record and to spell their last name and provide secretary with written comments.)

There was no public comment

VI. **Adjournment**

Mr. Olson adjourned the meeting at 3:06 p.m.