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**MINUTES**

Name of Organization: Nevada Commission on Autism Spectrum Disorders  
Early Childhood Subcommittee

Date and Time of Meeting: September 17, 2014  
1:00 p.m.

Carson City: Aging and Disability Services Division  
3416 Goni Road  
Suite D-132  
Carson City, NV 89706

- I. Ms. Tombari called the meeting of the Early Childhood Subcommittee to order at 1:07 p.m.

Members Present: Michele Tombari, Nicole Cavanaugh, Nicole Kalkowski, Debra Vigil, Charles Marriott

Members Absent: Toni Richard, Shannon Crozier

Guests: Ken MacAleese, Jan Crandy, Valerie Soto, Lorri Unumb, Dan Unumb, Johnette Oman

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)

Mr. Ken MacAleese informed the Committee that he spoke with Lisa Watson, the strategic plan facilitator on September 16<sup>th</sup>.

Mr. MacAleese expressed his concerns about the State wanting to use the Early Start Denver Model (ESDM) at Early Intervention. Mr. MacAleese has

only found one outcome study on the Model and in his opinion we don't yet have the scientific reliability for this work to come in.

Mr. MacAleese referenced the Eldevik 2010 research study which was a meta-analysis. This is out of 309 participants across 20 years of research studies in Applied Behavior Analysis (ABA) outcome. He encouraged everyone to read it and will be added to the ADSD website.

Ms. Crandy asked Mr. MacAleese if he can tell the Committee a floor of intervention treatment for that age group that we can be supporting. Mr. MacAleese responded that 26 to 30 hours per week for children under three years old.

Ms. Tombari read from the Behavior Analysts Certification Board (BACB) document, "Children who are under three years of age with an Autism Spectrum Disorders (ASD) diagnosis have better outcomes when they receive 25 to 30 hours a week and it is not uncommon for children in this age group to receive 30 hours of treatment or more as they approach three years of age."

Ms. Crandy asked Mr. MacAleese if he supports the document. Mr. MacAleese responded that yes, it's published by the American Association on Intellectual Developmental Disabilities.

Ms. Valerie Soto asked Mr. MacAleese if he found an article that was against Early Intervention training on the Early Start Denver Model. Mr. MacAleese clarified that the article is not a comparison study between ABA and Early Start Denver Model. It is a study suggesting that we provide intensive levels of therapy of ABA to children younger than three years old. He commented that there is no external body accrediting the certification of the interventionists for the ESDM.

Ms. Crandy asked if the ESDM utilizes ABA. Mr. MacAleese responded that it is not fully ABA and that question would have to be answered by them. Mr. MacAleese is concerned if the ESDM practitioners would be able to implement with fidelity.

Ms. Crandy commented that as new science comes along, we should be open to new ways coming in that can help our children.

Mr. Charles Marriott echoed Mr. MacAleese's point. Mr. Marriott commented that our focus should be on the most efficacious treatment models with outcome studies that are well entrenched in peer-reviewed scientific literature. ESDM has good value but we need more treatment outcome studies before we devote the resources to the training and implementation of ESDM.

### III. Discuss Other States' Autism Programs (For Possible Action)

Michele Tombari, Chair

Ms. Tombari introduced Lorri and Dan Unumb who work with Autism Speaks in states all over the country.

Ms. Unumb is Vice President of state government affairs for Autism Speaks. She travels around the country to pass Autism insurance mandates in all 50 states. They have been to 37 states so far. Mr. Unumb is the executive director of the Autism Speaks Legal Resource Center. He deals particularly with access to healthcare for children. They are also the parents of a 13-year-old who is severe on the spectrum.

Ms. Tombari asked if they have seen in other states where they are switching away from funding and delivering treatment after a failed screening instead of waiting for a multi-disciplinary diagnosis. Ms. Unumb responded that in California the Regional Centers would offer treatment upon a positive screening for Autism. It will only improve outcomes if therapy starts early.

Ms. Tombari asked what other states are doing to get pediatricians to screen. Ms. Unumb asked if the pediatricians in Nevada are following the American Academy of Pediatrics (AAP) guidelines. Ms. Tombari responded that they are not looking at the risk factors and the pediatricians aren't get paid enough to do the training or don't have the training to educate the parents on starting early intensive treatment.

Ms. Debra Vigil commented that there was a recent study in the pediatric journal that the length of time that the pediatricians are seeing the children has decreased to seven minutes. It is not enough time to do a screening and provide education to parents identifying problems.

Ms. Unumb commented that no state has solved the dilemma. Autism organizations that are parent driven are educating the pediatricians at the pediatric conferences within the state.

Ms. Vigil asked what states are doing the screening that would be helpful. The pediatricians in Nevada do not have enough time to do the screening and insurance companies don't reimburse for the screening. Ms. Unumb responded that pediatricians need to be informed that insurance companies are now required to reimburse for the screening. It is written in the mandate that screening, diagnosis and treatment must be covered.

Ms. Unumb talked about the reimbursement rate for pediatricians to do the screening from Medicaid. Modified Checklist for Autism in Toddlers (M-CHAT) is a 20-question survey that can be performed quickly. There's a lot of education that needs to be done around the reimbursement opportunities. The EPSDT obligation has been in federal law for several decades.

Ms. Crandy asked if there are any cities that are holding conferences just to educate doctors on the law. Ms. Unumb responded that if you can generate the interest to get pediatricians to come to an Autism workshop. There is plenty of material to go over. Mostly it's advocates that are pushing themselves into the gatherings that are already scheduled. The medical community is yearning for more information about Autism.

Ms. Tombari asked about the treatment services. Speech and occupational services are still being denied in Nevada. Ms. Cavanaugh added that they're calling providers to get more information. Ms. Unumb responded that not only should they be covering evidence-based treatment but also therapeutic care such as services provided by a licensed speech or occupational therapist. Ms. Cavanaugh also added that most insurance companies consider speech and occupational therapy to be approved for acute conditions. Autism Speaks Legal Resource Center is looking out for insurance policies that are making the assertion that speech and occupational therapy is only covered for acute care.

Ms. Crandy commented that because of the Affordable Care Act (ACA), it is an essential benefit that habilitative and rehabilitative that the number of visits had to match in Nevada to the plan that they chose which is 60 visits a year. She asked if that should be something that is addressed. Mr. Unumb responded that under CMS you can have a value of limits based on the dollar value of essential health. You cannot have quantitative treatment of benefits for mental health conditions unless you have the same quantitative limits that are applied substantially for all of the physical coverage. There is a dollar value limit in mandate for Autism in ABA therapy. It has to be determined solely by medical necessity. Ms. Unumb added Nevada law says an insurer shall not limit the number of visits.

Ms. Crandy asked if it shouldn't apply to the number of visits for speech and occupational therapy if it actually points to the ABA piece. Ms. Unumb responded that Nevada's visit prohibition says that insurers shall not impose visit limits except as to ABA. Mr. Unumb added that you can't have a visit limit in the sense of the dollar cap. Ms. Unumb also added between the ACA and the federal mental health law, you can defeat those visit limits but you have to challenge it.

Ms. Unumb commented on Nevada's mandate that says Autism spectrum disorders means a neurobiological medical condition. No other state has it written into the definition that Autism is a medical condition. Mr. Unumb commented that the Mental Health Parity Act refers to the Diagnostic and Statistical Manual of Mental Disorders (DSM) as evidence of a physical mental health condition.

Ms. Tombari asked about what other states are doing to serve children who are under the age of three. Ms. Unumb responded that they are trying to persuade the policymakers to start treatment right at screening. Many states have expanded their birth to three program to cover ABA and other therapeutic services. The states are serving the children through the Medicaid state program. EPSDT is a mandate that is applicable from birth to 21. The minute the child fails the screening, they need to get them through the Medicaid system. Mr. Unumb commented that there are financial and efficiency incentives to go through Medicaid.

Ms. Tombari expressed the concern that the school districts would be billing Medicaid for the services provided within the school district. Ms. Unumb responded that the school district cannot use EPSDT Medicaid funds unless the parent authorizes it. Mr. Unumb commented they would be different obligations and they would have to provide medically necessary care. In some of the plans, there's a reference that Medicaid is not responsible for IDEA services but there's a clear demarcation between what school districts are delivering and what is medically necessary care under Medicaid. Ms. Unumb commented that the standard that the treatment is measured by is higher under Medicaid than under IDEA.

Ms. Crandy asked if they're allowed to bill for ABA. There's a concern that they'll use up the child's balance to use outside of school hours. Ms. Unumb responded, once again, the schools cannot bill unless you give them that right.

Mr. Charles Marriott commented that school districts do ask for parent authorization for the reimbursement. The parents do have the opportunity to decline. Ms. Tombari commented that parents don't quite understand that it is optional. Mr. Marriott suggested educating parents of their rights for billing Medicaid would be beneficial.

Mr. Unumb commented that if parents are aware that an after-school program funded by Medicaid is available, that may immediately inform them that they should preserve their ability to use their Medicaid funding for that. The obligation under EPSDT is to deliver all medically necessary care to correct the deficits and conditions that have been uncovered by a screening. It is not limited in any way; it is whatever is medically necessary.

Ms. Unumb commented that this is a whole mindset shift. There's no dollar cap, no waiting list, whatever the child needs that is prescribed as medically necessary by the doctor. That is what Medicaid must pay for.

Ms. Crandy asked when they're building the Medicaid policy, if they should not have any hourly caps then. Ms. Unumb responded that you cannot and should not have any hourly caps. Autism Speaks has built a model state plan

amendment for coverage. Mr. Unumb said that California is providing coverage and they don't have a plan in place.

Ms. Tombari asked about rural services in other states. Ms. Unumb said some states are doing TeleMed. Ms. Unumb went on to say providers have been able to receive enhanced reimbursement rates when they're servicing rural clients.

Ms. Tombari asked if Ms. Unumb has noticed pop-up clinics or any increase in providers driving out to the rural areas. Ms. Unumb responded that there are some that go into underserved communities to do pop-up clinics, which seems to be working well. Ms. Unumb suggested contacting Josh Cobbs in Iowa and Mike Wasber (sp) in Kansas for more in-depth rural services.

Ms. Tombari asked what other states are doing to develop their workforce. Ms. Unumb responded the more you pay them, the faster your workforce will develop. It has a lot to do with the reimbursement rate.

Ms. Unumb asked how much the ABA provider pool expanded since the insurance mandate passed. Ms. Crandy responded that it has grown. Nevada has 75 BCBA's and not all of them are practicing in Autism. The rates are very low for interventionists. The insurance companies are not paying for a level of supervision that is appropriate for the amount of hours that are being provided.

Ms. Unumb commented that North Carolina created several coursework mechanisms that lead to the ABA certification. Mr. Marriott commented that Nevada does not have appropriate coursework that leads to certification. There currently isn't a mechanism to recruit, educate and then transition to the workforce that creates a career for people.

Ms. Unumb said that she and her husband went to the psychology and special education department at the University of South Carolina. They advised them on the consistent funding streams available for the University to join. Ms. Unumb suggested the Task Force make education in Autism a responsibility and urge the universities and colleges to create coursework. This is the most solid career choices for people to make.

Ms. Crandy asked Ms. Unumb to talk about RBT training and transitioning to that. Ms. Unumb responded that many states aren't cognizant of it yet. Ms. Johnette Oman commented there are a lot more hours and there are big changes that the BACB have put out of their website.

Mr. MacAleese commented that there are a number of trainings available online. Eight hours of training are required. Mr. Marriott offered his help to inform and educate about the requirements.

Ms. Tombari asked about the community awareness to identify the children as early as possible. Ms. Unumb said in order to make contact with childcare providers, you have to go to each center and leave them information for any possible future references.

Ms. Crandy asked if Autism Speaks thought about educating families to accept the diagnosis right away. Ms. Unumb commented that Autism Speaks has an initiative called Early Access to Care. They have been targeting the underserved community.

Ms. Tombari asked if other states are educating childcare workers as part of getting their license. Ms. Unumb said this is not happening currently.

Ms. Vigil, representing tribal issues, said the tribes follow tribe laws and not state laws. The tribe that Ms. Vigil has been working with feels that their early childhood educators are being educated. The tribes do not have pediatricians either. Ms. Unumb suggested reaching out to Autism Speaks' Early Access to Care initiative to get the education out to the tribes with pop-up clinics.

Ms. Tombari asked what recommendations can Ms. Unumb make about community awareness and how to counter the stigma associated with Autism. Ms. Unumb commented that Autism Speaks has amazing resources that's been developed in multiple languages and materials of literature that is freely shared. The Task Force can work on a dissemination plan and Autism Speaks can supply the materials.

Ms. Tombari asked if Autism Speaks offers material that helps with the stigma of Autism. Ms. Unumb said they have material that address how common Autism is. Ms. Crandy commented that Nevada's Early Intervention gives out the 100-Day Kit. Ms. Unumb added that the 100-Day Kit is the single most effective and utilized tool that Autism Speaks has ever come up with.

Ms. Tombari asked if transition between Early Intervention and school district happens smoother in other states. Ms. Unumb responded that the transition process is not seamless in other states. School districts are entitled to evaluate on their own. EPSDT Medicaid coverage should solve the whole problem.

Ms. Crandy commented that children in Nevada can get Katie Beckett. Ms. Unumb added that Autism is a qualifying disability under Katie Beckett. You qualify by meeting ICF level of care which is if you weren't getting the services you would need care in an intermediate care facility.

Ms. Crandy commented that Early Intervention offers families four to five hours of therapy a week. They are educating the parents. She asked if they

should be trying to change the floor and increase the hours. Ms. Unumb commented that there shouldn't be any numbers written into the Medicaid policy. The number of hours is different for every child and it should be determined by the child's doctor.

Mr. Unumb commented that a child is entitled to medically necessary care. The guidelines come in to play because the guidelines are what inform the standard of care.

Ms. Tombari asked if the primary physician told Early Intervention that the medically necessary standard of care for that child is 25 to 30 hours, would Early Intervention have to provide that. Ms. Unumb responded that under the Medicaid context under EPSDT, Medicaid is to provide what is medically necessary for that child.

Ms. Crandy commented that we need to make some level of care for Early Intervention. She suggested having a Best Practices for Early Intervention but don't use a level for Medicaid. Ms. Unumb commented with the availability of EPSDT coverage, a child may not elect to get services in Early Intervention.

Mr. Unumb talked about the standard under IDEA Part C. He suggested contacting a lawyer.

Ms. Tombari asked what other states are doing with their ABA programs through the school districts. Ms. Unumb responded that it varies from state to state. Ms. Unumb also commented that there's a lot of tension between insurance companies and school districts as they figure out whose responsibility it is to pay for therapy. The obligation of the schools under IDEA is to accommodate children with disabilities. Ms. Unumb believes it's the healthcare system's obligation to remedy the medical deficits and Autism is a medical issue. There should be a shift away from school district funding to Medicaid and insurance funding.

Ms. Tombari asked how they can get the teachers and aides trained. Ms. Unumb responded that some states have passed laws specific to the training that teachers must have in ABA. Mr. Unumb commented that to make any changes in the schools you must find out how engaged the Department of Education is to make the changes. There has to be a continuing commitment on the part of school officials.

IV. Discuss Nevada's 2008 Strategic Plan Recommendations (For Possible Action)  
Michele Tombari, Chair

This item was tabled to the next meeting.

V. Discuss Strategic Plan Process  
Michele Tombari, Chair

This Item was tabled to the next meeting.

VI. 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.)

Ms. Crandy advised everyone in the group that the meeting on September 24<sup>th</sup> with the facilitator, Ms. Lisa Watson will be addressing all the goals the subcommittee wants to achieve for their age group.

Ms. Tombari stressed how important it is to attend in person. Ms. Tombari will be sending out information and ask some of the voting members of the subcommittee to talk about where they are on some of the different issues.

VII. Adjournment

Ms. Tombari adjourned the meeting at 3:19 p.m.