



STATE OF NEVADA
DEPARTMENT OF HEALTH AND HUMAN SERVICES
AGING AND DISABILITY SERVICES DIVISION

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

Date and Time of Meeting: September 24, 2014
1:00 p.m.

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

Las Vegas: Public and Behavior Health HCQC
4220 S. Maryland Parkway
Las Vegas, NV 89119

- I. Ms. Tombari called the meeting of the Early Childhood Subcommittee to order at 1:10 p.m.

Members Present: Michele Tombari, Nicole Cavanaugh, Nicole Kalkowski, Debra Vigil, JonPaul Saunders, Toni Richards, Shannon Crozier

Guests: Johnette Oman, Adryon Ketcham, Thomas Kapp, Robin Kincaid, Ken MacAleese, Robert Johnson, Jan Crandy, Lisa Watson, Jennifer Davidson, Charles Marriott

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)

Ms. Tombari thanked all the committee members for all the work and time.
Ms. Nicole Kalkowski said she was concerned with comorbidities associated

with autism. She said there are no proper diagnostic tools for the comorbidities which can affect the intervention to have the best possible outcome.

III. Strategic Planning Discussion to Identify Recommended Priorities and Strategies

Lisa Watson, Social Entrepreneurs Inc.

Ms. Tombari referred the Subcommittee to the handouts that are posted on the ADSD website. Ms. Tombari introduced Ms. Lisa Watson who will facilitate the strategic planning discussion.

Ms. Watson introduced herself and told the Subcommittee about the strategic planning process. She said she will provide the information about the process, collect the information from the Subcommittee regarding the issues that affect this age group, and then she will develop a plan with goals that can be achieved and how to modify the approach.

The collection phase of the strategic plan included 400 consumer surveys that had been completed, 71 provider surveys, and 15 key stakeholder interviews.

Ms. Watson asked what the needs are for this age group which is 0 through 6. Ms. Tombari stated that there were 15 items that the subcommittee had compiled. The first point that Ms. Tombari brought up was earlier screening. Once children fail a screening, they should be identified at risk and receive treatment. Ms. Debra Vigil said they should be receiving services in a timely manner. It is a bigger problem in the rural community. Ms. Crandy said children need access to treatment as soon as they fail a screening and then they can get a diagnosis.

Ms. Kalkowski said the speed in receiving effective evidence-based services from a parent's perspective is most important. Ms. Crandy added there is a lack of awareness.

Ms. Watson summarized early screening and diagnosis using evidence-based tools, access to treatment immediately after a failed screening, and parent access to information that is reliable.

Ms. Crozier added access to treatment should include appropriate intensive dosages. She said they need to look at the prescreened population and the identified which have different needs. Ms. Crandy added referrals for comprehensive medical evaluations to identify comorbidities.

Ms. Tombari said more training for pediatricians is needed. Ms. Toni Richard said parents need assistance in navigating all the systems such as Medicaid, SSI (Social Security Insurance), ATAP (Autism Treatment Assistance

Program), and Regional Centers. Ms. Crandy added families need integrated coordinated help with qualified ASD (Autism Spectrum Disorders) providers. Families need access to information and links to screening tools on a web-based program.

Ms. Vigil said the transition from Early Intervention to the school district needs to be seamless so there is no break in services. They need help with coordination.

Ms. Crozier said case management across the lifespan. Ms. Kalkowski said the most pressing concern as a parent is the access to research-based therapy that is effective at the proper intensity and having that therapy transition forward to the school district. Ms. Kalkowski said parents have a difficult time until they know their child is receiving the appropriate intervention.

Ms. Crozier said there is an existing gap between what are evidenced-based levels of intervention in early childhood and what children actually get in schools. There is an artificial gap created by government systems that needs to be addressed. Ms. Crandy said there should be more parent education the 100-Day Kit. Ms. Crandy added that the law in Nevada says that ATAP is supposed to educate the parents as well as Early Intervention and the school districts.

Ms. Kalkowski said once the parents receive the diagnosis, they are so overwhelmed with grief. They need someone to help map out what their next steps are. The 100-Day Kit is a great resource but they need someone to sit down with them and go through all the information.

Ms. Tombari said parents need to be educated on funding that is available. Mr. JonPaul Saunders said parents need support. Ms. Crandy said parents should be given hope, but they also need to be told the truth. Ms. Tombari added that an adequate workforce is needed that are competent.

Ms. Richard said it would be a benefit for a seasoned parent to meet with a newly diagnosed parent to help them fill out forms. Ms. Crozier suggested adding a medical home under the continuity of care system.

Ms. Watson asked what is and what is not working. Ms. Crandy said the majority of children are identified through Child Find. She added children can be diagnosed at 12 months old. If they go to Early Intervention, they can be screened and diagnosed but not everyone knows about Early Intervention.

Ms. Vigil said there are groups of people at Early Intervention and school district that were trained using the ADOS (Autism Diagnostic Observation Schedule). The ADOS is evidence-based and is the gold standard in the

nation for a diagnosis. There were 50 people in 11 different groups across the state that were trained in the ADOS.

Ms. Crozier said most other providers are not screening children. Ms. Kalkowski said pediatricians are not educated in autism and unless the child presents with severe red flags, they are not doing the screening.

Ms. Vigil said the Milestone Moments booklets by the CDC (Center for Disease Control) is good at outlining what children should be doing and what parents can be asking their pediatricians. This is an example of what has been done and they need to be disseminated to more parents.

Ms. Watson summarized that there is not a consistent use of tools or timing by pediatricians. She went on to ask why this is happening. Ms. Crozier answered that there is an insufficient workforce to provide quality diagnostic services. Ms. Crandy said parents can't access their insurance until they get a diagnosis. Ms. Crozier said there is a reluctance by providers that exists to diagnose children under the age of three. Ms. Crandy said that there is an apprehension by the parents wanting the diagnosis as well.

Ms. Crozier said the number of hours of treatment that is provided is far below the levels of intensity that they need across services. Ms. Crandy said the model by Early Intervention is parent education instead of direct treatment. Children need direct services.

Ms. Crozier said that case management is spotty and fragmented. The systems are not integrated. Ms. Crandy said collaboration is inconsistent among providers.

Ms. Watson asked what the three largest gaps of services in the early childhood age group were. Mr. Saunders said early screening before 36 months by a competent professional and then immediate initiation of evidence-based therapy. Ms. Adryon Ketcham asked what definition was being used for evidence-based therapy. Ms. Watson answered therapy that has research behind it that has achieved outcome.

Ms. Ketcham said the only evidence-based therapy is ABA (Applied Behavior Analysis). Ms. Crandy told Ms. Ketcham the definition is in the 2008 Task Force Report. Ms. Watson asked if ABA was the only treatment that children with ASD are not getting. Other therapies only treat symptoms and not autism itself.

Ms. Crozier said the gaps in service for speech, occupational, physical therapy and ABA are not being rendered at the required intensity.

Ms. Tombari said there is a gap in getting all children in Nevada screened at the earliest time possible. Ms. Crandy said they want early screening to start treatment and then diagnosis. Insurance will not pay for treatment unless there is a diagnosis. Early Intervention will start treating once they fail a screening and before a diagnosis. Ms. Crandy added there is a gap in comprehensive diagnostics to treat comorbidities such as seizures or intestinal issues.

Ms. Crandy said other family health needs are family counseling, respite care and advocacy in IEPs (Individualized Education Plans).

Ms. Watson asked what works well in other systems. Mr. Saunders said that ATAP is working well. Ms. Crandy said it is not working well for younger than three years old. Ms. Vigil said the amount of children that ATAP is servicing is problematic because there are a lot more kids not receiving the funding. Ms. Vigil suggested having ATAP provide training for the interventionists that can provide services to a broader population. Ms. Tombari said ATAP is working well with the kids that are accessing the funding.

Ms. Crozier said the multidisciplinary assessment teams such as the UNLV (University of Nevada Las Vegas) and UCAN (University Center for Autism and other Neurodevelopment) are working well. The children have access to comprehensive multidisciplinary assessments.

Ms. Crandy said that treatment is provided in Elko but not in other outlying rural areas.

Mr. MacAleese said there are a number of funding sources to access services in Nevada. Both universities in Nevada have doctoral-level behavior analyst programs providing training and supporting individuals in the schools and home-based programs. Ms. Vigil added that the child psychiatry fellows are part of the UCAN team and are in the school districts.

Ms. Cavenagh said UNLV and Touro University are training pre and post-doctoral level neuropsychologists. This is helping address some of the shortages of diagnostic availability. Currently Nevada is 47th in the country in per capita psychologists. Ms. Vigil said one of the advantages is that we are small state and we can effect changes.

Mr. Tombari added that we have access to legislators and they are listening to us.

Ms. Watson asked what the priorities should be for the next five years for the State. Ms. Vigil said screening, diagnosis and training of professionals. Ms. Tombari suggested paying the pediatricians more so they can spend more time doing an adequate screening.

Ms. Crandy said the insurance bill needs to be opened up. The insurance companies need to follow the BACB (Behavior Analyst Certification Board) Guidelines. The focus needs to shift from the insurance companies to the care providers.

Ms. Tombari said childcare workers need training on how to screen. Ms. Crandy said the law could be changed to mandate childcare workers receive training as part of their license. Ms. Vigil said the Nevada Registry requires childcare workers to do screening twice a year. Head Start is required to do screening as well. If it is mandated by legislation, it will be stronger.

Mr. MacAleese said the Commission should consider incentive funding for provider programs to grow. Ms. Crozier said professional development for providers is critical.

Ms. Watson summarized ensuring insurance companies including Medicaid is paying for screening. Ms. Crozier said the Commission would like to move the locus of control for determining the appropriate care to the providers of the individual. The insurance company should not be defining what appropriate care is for the individual.

Ms. Crandy said aligning with the Affordable Care Act and Medicaid will remove the \$36,000 annual benefits cap. She said there should be a collaboration between all systems including universities and nonprofits. She also added that the State should access federal money to get the state to match. The promotion of the dissemination of the best practices that has already been created should be implemented.

Ms. Tombari said customization of the 100-Day Kit should be specific to Nevada. Ms. Crozier agreed that the navigation guide should be specific to Autism in Nevada.

Ms. Crandy commented that Pennsylvania has an Autism Bureau. ATAP can be expanded and provide more funding to add a navigation tool.

Ms. Vigil said there should be an education component when doing outreach so the parents are educated in early intervention. Ms. Vigil said there was a concern that parents are not getting their kids immunized and there has been an outbreak of polio.

Ms. Crandy said the Commission could ask to expand public and private financing outside of insurance. ATAP can get more money. There needs to be adequate levels of supervision and for legislation to support treatment with fidelity. Mr. Marriott said outcomes need to be replicated with methodology.

Ms. Tombari said funding for services has to come first. Ms. Crozier said that part of the problem is that providers are showing up but they are not qualified to work with children with Autism. Mr. Marriott said there should be marketing for a career for behavior analysts. Ms. Crozier suggested a vertical career path. Workforce development is critical and nationwide does not have the capacity. Ms. Vigil said if the state has quality and fidelity, people would want to come here to work.

Ms. Crandy said there needs to be a priority for the ATAP waitlist. Mr. Marriott said science has answered that question that it is the most effective resource for early intervention.

Ms. Watson summarized that early screening and diagnosis, access to care and workforce development are the top priorities from this subcommittee.

Ms. Tombari will send Ms. Watson the progress that has been made since the 2008 Autism Task Force Report.

Ms. Watson asked what policy or practices are in place that prevent services for people with ASD. Ms. Crandy said prioritizing early intervention for children under a certain age for ATAP funding. Ms. Crozier added children at Early Intervention only receive three to five hours a week of behavior services. Ms. Richard said in the past Early Intervention provided 25 hours a week and parents should not have to fight for services.

Mr. Kapp said there is no policy in place at Early Intervention for the number of hours provided. The Early Start Denver Model is being looked at which is a 20-hour program. The 20 hours is broken down to 15 hours by a trained professional and five hours is by the parent.

Mr. Marriott said there is an understanding of the workforce problem of recruiting and retaining quality interventionists to provide quality treatment. Interventionists should be offered full-time employment. He added there should be a collaboration with school districts and Early Intervention for interventionists that also work in homes.

Ms. Vigil said there is a barrier with FERPA (Federal Educational Rights and Privacy Act) for the educational employees to work outside of the school district. This Act needs to be looked at.

Ms. Watson thanked everyone for their feedback. She asked the Committee to rate the vision and mission statements that are the guiding principles.

*See Attachment A for photographs of Ms. Lisa Watson's notes taken during the discussion.

IV. **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.

V. **Adjournment**

Ms. Tombari adjourned the meeting at 3:58 p.m.

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#1

• Early Screening +

Diagnosis (using the best tools)
evidence-based

- Access to treatment immediately after ~~Diagnosis~~/failed screen
↳ Especially in Rurals
- Speedy service access throughout need.
- Parents → access to information that is reliable.
- Access to appropriate levels of treatment./evidence-based.
- Comprehensive Medical exams as part of an ASD Diagnosis.
- Pediatricians who are knowledgeable + informed about ASD so they can accurately ~~diagnose~~ screen + refer + discuss treatment w/families

Transitional Supports

How to get into, and out of, how to access services, navigate systems & benefits.

- Families need transitional supports (system of care)
 - ↳ Continuity of care, to assist w/ transitions between systems + within/between service providers
- Medical Home: / due to complexity of need
- Case Mgmt that spans the lifespan
- Parents need to know how to find, & get evidence-based services/treatment. They need to know how to work with the various systems that serve their kids. (support attached to 100 day kit)
 - ↳ Parents need to feel/be supported in empowerment

Programs. Family Support + self-advocates. Case (Mental Health Care)

#2. ~~Screening - kids need to be screened prior to 30 mos of age~~
~~40% of kids screened + who had @ 48 mos~~
~~are have been screened using evidence based tools. Other providers are not using evidence based.~~

There is not a consistent approach (use of tools / timing) to conducting ASD screenings by Medical Community, School or Early Care System.

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Timely diagnosis & access

Gaps Screening / ^{Early Screening} ^{Timely Comprehensive} ^{Diagnosis & Referral} to Treatment

- ① Early Diagnosis / Referral to Treatment & comprehensive
- ② Treatment rendered immediately & with the required intensity
↳ Specifically there is insufficient access to ABA services
- ③ Co-occurring treatment which is inclusive of ABA type of services.

④ Gap in Care

⑤ Family Supportive Services
↳ Counseling, Respite, Advocate

~~Primary diagnosis of autism~~

(6)

What is working well

- ATAP as an approach is working well for the clients who are accessing care.
 - ↳ might be a good venue to provide training to field.
- Access to log. because of Commission
- Multi-disciplinary Diagnostic teams
 - Center for Autism @ UNLV } expansion
 - UCAN - Reno } opportunity
- Small state → can affect change.
- Treatment in Elko (although not in all Rurals)
- TARRO
- Funding sources to access care (public: State/Fed)
- University Efforts to Address ASD Research + Services/Supports
- UNR - child ^{psychiatrists} psychologists fellows going through UCAN Team + present in School Districts.

~~What is screening used~~

Magic Wand

↳ Legislate ~~to~~ to support
Pediatrician screening using
specified tools @ necessary
intervals ↳ tie it to payment
for well child checks.

↳ consider adding
language which supports
financial incentive
supported by funding
sources (Medicaid/uninsur)

↳ Health Insurance has to follow
BACB~~®~~ Guidelines.

↳ Remove CAP

* Alignment to ACA / Medicaid
EPSDT

~~Family diagnosis of access~~

~~What is working well~~

② Work with QRIS process to
Advocate/encourage use of
ASD screening Tools in
ECE Environments. Partnership

③ Explore opportunities for
legislation shift the locus of control
from Insurance Company
to care provider.

④ Funding Advocacy
Funding a system that supports
development of a professional
workforce for ASD and
training across disciplines
plan/legislate BUILD PROVIDER
CAPACITY

~~Final step of process~~
~~Initiative~~

⑤ Promote the dissemination of Best practices + guidelines
↳ Utilize CEAs as a venue.

⑥ Customize 100 day Kit for NV.
↳ Establishment of Navigational Guides or State Autism Bureau.

⑦ Develop an Outreach + Education Campaign (Parents, Public, Providers)

↳ Info / Education / Reduction of Stigma / dispel myths / Resources + funding available / outcomes associated w/ Treatment

⑧ Legislative advocacy to support more \$ to fund Researched based treatment of care to current caseload

~~Tuesday 11/11/2020~~

~~What is the role of the...~~

8 cont → Ensure treatment fidelity w/ public funded services.

Workforce Development → encourage a career in ABA

↳ Grow our own community of providers

- Train existing cadre of providers.
- Support, Train + Incentivize Career in ASD services.

Prioritize Early Intervention based on scientific proof that ~~these~~ appropriate supports result in long-term outcomes.

Policy

- \$36,000 Cap on benefits.
- School District prevents ~~ABA~~ Behavioral Interventionists from going into class with kids, which lessens the amount of hours they have available to provide services.
Low hours, doesn't support workforce retention.
↳ opportunity to collaborate between service systems to support full-time employment + sense of belonging to an employer.

Practices

- ATAP
Date of Application drives when services are rendered (establishing waitlists)
↳ children who are younger get priority care.
- § Generic Standard of care that is often inadequate @ NELS.
- NELS framework of parent ed vs. direct service.



Policy

- Interventionist could be payed by school
- to support home-based services + on-site educational supports.

↳ Federal

(~~SEPA~~ FERPA) Barriers exist that prevent this from occurring.

↳ Idea that kids cannot be screened until 3 yrs of age.

Statewide practice vs family by family fight

Practice

OR service provider (similar to CA Model)

↳ In case of transition into different systems
NHS -> Schools

↳ between what research states works + what services are offered.

Solutions
↳ Peer Support System.

Strengths
Milestone Moments
Booklet

assist
stems -
providers
to 10 year
lifespan

to
d
red
in
- serve
(100 day kit)
ported