

State of Nevada Autism Task Force

MINUTES

Wednesday, September 26, 2007

UNR, School of Medicine / Reno – Video-conferenced to:
Great Basin College/Elko – Teleconferenced to:
CCSN/Las Vegas

Members Present: Ralph Toddre, Mary Liveratti, Jan Crandy, Matt Tincani, Patrick Ghezzi, Flo La Roy, Korri Ward, Johanna Fricke, Assemblyman James Ohrenschall / **Members Absent:** Senator Warren Hardy, Senator Bernice Mathews, Assemblywoman Francis Allen, Elizabeth Moore / **Staff:** Todd Butterworth, Winny Simmons / **Guests:** John Flamm, Randy Figurski, David Luke, Jane Gruner, Toni Richard, Janice Lee, Debra Vigil, Jennifer VanTress, Angela Flora, Jan Marson, Scott Craigie, Michael Hackett, Ralph Sacrison, Machismo Rodriguez, Judy White, Deborah Ferguson, Don Jackson

WELCOME AND INTRODUCTIONS

The meeting was called to order by Chair Toddre at 1:40 p.m. Introductions were made by all present for the record; it was established that a quorum was present.

DISCUSSION OF ROLE OF THE TASK FORCE

Vice-Chair Liveratti distributed copies of AB629, which was the legislation that formed the taskforce and also appropriated the \$2 million for services. There are fourteen members who are appointed, ten from the Governor and four from the Legislature. The Task Force has five main duties and is required to have not more than six open meetings each year. Responsibilities are:

- to review the available literature and consult with experts to gain an understanding of the causes of Autism and its incidence in Nevada,
- to assess the availability of services currently provided for early screening, diagnosis, and treatment,
- to review the effectiveness of programs and services currently provided to individuals with Autism and their families,
- review any other issues or concerns that the taskforce believes would be helpful in arriving at sound policy recommendations and
- to submit a report to the Legislature and Governor regarding the findings of the task force and to make recommendations. The report is due August 1, 2008.

DISCUSSION OF PLAN FOR PROVIDING AUTISM SERVICES

Ms. Crandy stated the proposal was approved by the Interim Finance Committee on September 6th with the hope to begin funding services for children in October. Mr. Butterworth stated his agency has an existing program that helps people to live independently and over the years it has provided some limited Autism services. It made sense to offer the new Autism services through the existing program Independent Living Program to save on administrative expenses. For the general structure of these Autism services, it was decided to mimic what is currently being done through the Self-Directed Autism Program at MHDS.

Ms. Crandy suggested the first item for discussion be the specific eligibility criteria. She asked if they are going to consider using the IEP, or certified professionals or does it have to be a medical diagnosis. Dr. Fricke stated the first point of clarification is whether or not this funding is restricted to children with classical Autism. Mr. Figurski suggested using the Nevada Administrative Code (NAC) to define the term Autism to include Autism Spectrum Disorder. It is in the NAC for the Department of Education.

Dr. Fricke asked how do they standardize the assessment for Autism and do they adhere to the dictum that it is a medical diagnosis.

Vice-Chair Liveratti reminded everybody that \$2 million may sound like a lot of money but this amount will only serve about 64 kids. She suggested having a broad definition and refine down when they start looking at prioritization about who the target groups are because the money is limited. Chair Toddre expressed concern with the money being limited at this point, but if there is any possibility of additional funds coming in and if they make the definition too broad it is going to be a free for all.

Dr. Fricke suggested the definition remain with Autistic Spectrum Disorders as diagnosed by a professional. The next item on the agenda may be to define which professionals. Mr. Figurski stated his workgroup is capable of diagnosing kids in the birth-to-five age range and can be used as a resource.

It was discussed what fell under Pervasive Developmental Disabilities and a motion was made to include: Autism, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder.

Ms. Crandy stated Autism Spectrum Disorders should include Autism, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder. Dr. Ghezzi stated what Autism is for their purposes should be approached from an operational definition, that is, scores received on a psychometrically acceptable inventory that assesses Autism. Chair Toddre asked if this comes down to who is qualified to make a diagnosis and what instrument are they using.

Ms. Crandy stated the taskforce should consider families who are going to come to get this funding that already have a diagnosis and shouldn't have to go get one. She asked what paperwork will be taken as a valid diagnosis of Autism.

Ms. VanTress stated there are two routes to go for the diagnosis of Autism in the school district. There is medically based where a professional comes in with a diagnosis. There is an educationally-based diagnosis when the school site eligibility team completes their eligibility assessment. Up until age six any district in the state can use the category of developmentally delayed which is not always specified as Autism.

Dr. Tincani suggested using a diagnosis from a clinician for whom diagnosing is within their scope of practice. Mr. Jackson commented on the diagnosis issue from the standpoint of the state's developmental services system. In having to decide whether a child qualifies with Autism or another diagnosis for services and for Autism monies, he suggested an oversight in the process that is in-house.

A motion was offered by Dr. Tincani: "the program will accept a diagnosis from a clinician whose scope of practice allows them to make such a diagnosis of Autistic Disorder, Aspergers Syndrome, or Pervasive Developmental Disorder, not otherwise specified with the test results and report available for review by the caseworker, and the diagnosis has to made with at least two validated instruments." The motion was seconded by Ms. Crandy and unanimously approved.

Ms. Ward stated her concern over a state program like this setting a precedent over future programs. She is concerned the rural children have not had access to early diagnosis and it is not uncommon for rural children to be diagnosed at twelve years old. Even children who receive early intervention are likely to need ongoing services. She suggested the policy that the taskforce is making does not stop at the age of ten. Chair Toddre stated the legislation does not specify age limitations so it could go up to eighteen.

A motion was offered by Ms. Ward “to amend the plan to go through the age of eighteen on the monthly allotment and remove the wording that says older children will be considered on a case by case basis, that only one behavior will be addressed, or that severely aggressive behaviors must be present.” The motion was seconded by Dr. Tincani and unanimously approved.

Ms. Crandy stated the next item to discuss was the scoring system. It is assumed there will be a waiting list due to the demand for services, so ODS created a scoring system to prioritize children. Mr. Butterworth stated the reason the younger group was given extra points was on the presumption that services would be more effective. He asked if the task force wanted to prioritize those younger kids.

The discussion moved to the proposed scoring system to be used by the ODS Autism program (see attached).

A motion was offered by Ms. Crandy: “Critical behavior issues would receive five points if a child is at risk of being removed from home or school to a more restrictive environment.” The motion was not seconded. Dr. Ghezzi stated all the other criteria are relatively more objective. This second one is subjective and could be used to get into the system quicker.

Dr. Fricke stated for Medicaid to fund an inpatient admission the criteria are “documentation of danger to self or others.” If that criteria were provided by a psychiatrist or professional qualified to do so, then it would make that five extra points more objective. Ms. VanTress stated if you take a child with Autism to the mental health facilities, they won’t take them because of that diagnosis. If you put that as a criterion, they are not going to consider it. Dr. Fricke suggested instead of “regularly violent towards others, or self-abusive” use “documented behavior that is potentially harmful to self or others.” Ms. Ward asked if they are looking at attacking other family members as the level of aggression or self abusive. Ms. Crandy stated everything on the list needs to be documented and proven. Mr. Butterworth stated this can be refined over time if the Task Force accepted it as it were today; it is by no means set in stone. What ODS primarily wanted from the taskforce was to identify any missing or incorrect criteria. Chair Toddre stated there should be points for the older age group. They should just leave three points for eighteen months to four years.

A motion was offered by Dr. Fricke to change the wording of “regularly violent” to “documented aggressive and potentially harmful behavior towards others or self.” The motion was seconded by Ms. Crandy. Ms. VanTress suggested moving the term “documented” up to the actual question so that it is for both issues. Dr. Fricke amended her motion to reflect this and Ms. Crandy concurred. The motion passed unanimously.

A motion that the phrase “high level of self-stimulatory behavior” be eliminated was offered by Dr. Ghezzi. The motion was seconded by Vice-Chair Liveratti. Ms. Crandy stated if a child has such a high level of self stimulatory behavior that they are unable to do work at school, she would like them to get more points. Dr. Ghezzi asked what constitutes a high level, moderate level or low level. The motion was passed unanimously.

A motion to amend the document to say “other documented disabilities” instead of “other disabilities” was offered by Ms. Ward. The motion was seconded by Ms. Crandy. Mr. Butterworth stated they need to trust their case managers at some level to make judgments. Vice-Chair Liveratti asked if they could have a range of one to three points depending on severity. Chair Toddre stated under the second bullet point other disabilities could be zero to three points. Vice-Chair Liveratti offered a friendly amendment to change the “other disabilities” scoring to zero to three points for each additional child. Ms. Ward accepted the amendment and the motion passed unanimously.

Ms. VanTress asked about question one, where it says “our behavioral intervention services,” what if the child is receiving speech, OT, or other therapies? Ms. Crandy stated if the child is getting Medicaid and they ask for funding to use it to pay for those services, it won’t be allowed. Mr. Butterworth stated they are only looking at behavioral intervention services here. They could form a core team that would consist of the case managers from the North and South and someone from his office who could collectively look at the information and make a decision.

A motion to accept the proposed scoring system with the changes that have been made in this meeting was offered by Ms. Crandy. The motion was seconded by Vice-Chair Liveratti and passed unanimously.

Ms. Crandy stated they will have coordination of services. There has been a question about if Greenspan and SCERTS should be kept on the list of evidenced-based services. Ms. Marson commented when it says approaches which are evidenced based, OT, PT, and Speech are really disciplines and are not approaches. The DIR (Developmental Individual Difference Relationship) approach has some evidence to support it. There needs to be a number of workgroups formed. Dr. Tincani stated they need to support approaches that are going to be evidenced based. They are not funding disciplines but approaches. He thinks they should remove the “evidenced-based but not Autism specific” category.

A motion to remove the section titled, “Approaches which are evidenced-based, but not Autism specific” was offered by Dr. Tincani. The motion was seconded by Dr. Fricke. Chair Toddre stated the biggest complaints he hears, especially with the school districts, is they could only get one to two hours of speech therapy a week from the school, which is not enough. Ms. Crandy asked if they could just change the wording to say “and paid for.” Mr. Figurski stated he is concerned they are going to limit which licensed professional can practice the strategies. Ms. Crandy stated how this is written they are saying that DIR is evidenced-based and it is not on this list. Chair Toddre stated this was to make sure this funding was self-directed and would give the parent the opportunity to make the decision.

Dr. Tincani stated he doesn’t think they will be able to wrap up today the discussion about what’s evidenced based and what’s not. He suggested moving forward with the document as it is today but the Task Force needs to put effort into identifying what evidenced based approaches are and what they will include on this list and be prepared to amend it in the near future. Dr. Fricke suggested since there is a Health and Human Services list that includes the approaches that have been chosen that they stick with what is the national standard. Mr. Figurski stated they are missing the focus that parents using their power to self direct services for their children are going to be better than a panel of professionals. Ms. Crandy stated there has to be some protection that if the state is funding this, they shouldn’t fund things that are not evidenced based.

Mr. Butterworth stated if you take no action this item will stay as it is. Chair Toddre stated for the time being they are leaving this item as it is and will discuss it later because they don’t want to hold up the funding. The motion failed. At the next meeting they will discuss the evidenced based services further to come to some agreement.

PUBLIC COMMENT

None

SET NEXT MEETING DATE

Vice-Chair Liveratti reminded everyone the Task Force could have up to six meetings before the end of June. One is today so there are five more meetings they could hold. She suggested at the next meeting

the task force look at how they are going to get the report done. Chair Toddre would like to put mandated insurance coverage on the agenda for the next meeting. The second issue is the progress that needs to be made in the school systems. He has already talked to Paul Dugan who is happy to come to this meeting and talk about what the schools need to be doing. Dr. Fricke would like to start discussing integration into the community.

Chair Toddre asked Vice-Chair Liveratti to contact the Attorney General's office and get information on what the Task Force can and cannot do in accordance with the Open Meeting Law.

ADJOURNMENT

The meeting adjourned at 3:40 p.m.

Applicant Scoring System

Independent Living Autism Services

Choose one option for each question:

Are behavioral intervention services currently being received?

- No known funding source available (5 points)
- Limited services received (3 points)
- Services available but not being accessed (1 point)
- Substantial services received (1 point)

Are there documented critical behavior issues?

- Documented aggressive behaviors harmful to self or others (3 points)
- Documented risk of removal from home or school placement (5 points)

Is the applicant at the low end of the age range?

- Age 18 months to 4 years (3 points)

Is this a single-parent household?

- Yes (5 points)
- No (0 points)

Does the family have multiple children with disabilities?

- Autism (5 points per additional child)
- Other disabilities (0-3 points per additional child)

What is the projected TOTAL cost of the family's Autism services, divided by their NET monthly resources (Gross Income, less Medical Expenses, less 200% of Poverty)

- 76% or more (5 points)
- 68% - 75% (3 points)
- 33% - 67% (1 point)
- 0% - 33% (0 points)

Prioritization:

If a family has 0-7 points, services will be made available within 90 days of their application, if funding is available at that time.

If they have 8-15 points, services will be made available within 60 days of their application, if funding is available at that time.

If they have 16 or more points, services will begin as soon as possible.