

State of Nevada Autism Task Force

MINUTES

Thursday, May 22, 2008

Nevada State Legislative Building / Carson City – Video-conferenced to:
Great Basin College / Elko
Grant Sawyer State Building / Las Vegas

Members Present: Ralph Toddre, Mary Liveratti, Patrick Ghezzi, Flo La Roy, Korri Ward, Cynthia McCray, Matt Tincani, Jan Crandy, Johanna Fricke, Senator Warren Hardy / **Members Absent:** Assemblywoman Francis Allen, Senator Bernice Mathews, Elizabeth Moore, Assemblyman James Ohrensall / **Staff:** Todd Butterworth, Paul Haugen / **Guests:** John Flamm, Randy Figurski, Jane Gruner, Toni Richard, Jan Marson, Diane Branson, Wendy Hruska, Angela Flora, Julie Gagen, Nancy Sylvania, Kathy Patten, Laurie Handen

WELCOME AND INTRODUCTIONS, QUORUM CALL

The meeting was called to order by Chair Toddre at 1:09 p.m. Introductions were made by all present for the record; it was established that a quorum was present.

APPROVAL OF MINUTES FROM THE JANUARY 2008 AND MARCH 2008 MEETINGS

A motion was offered by Ms. Crandy to approve the minutes of the January 2008 and March 2008 meetings. The motion was seconded by Vice-Chair Liveratti and unanimously approved.

UPDATE ON THE WORK AND TIMELINE OF EACH OF THE 7 SUBCOMMITTEES

Financing Comprehensive Systems of Care – Mr. Butterworth stated the subcommittee has a draft completed and is waiting on individual feedback from the subcommittee members. At their next meeting on June 9th the subcommittee will take a vote to finalize the draft report. He will then distribute the report by email to the taskforce members. If the taskforce members have any corrections, they can reply back to Mr. Butterworth directly and, when the taskforce meets again, they can deliberate those changes.

Screening and Diagnostic – Mr. Figurski stated as of May 14th the subcommittee has finalized their recommendations and will now email their report to the individual taskforce members. In addition, he was asked to complete Sections 4 and 5 of the Suggested Report Format. Once he drafts these sections he will email them to the individual taskforce members.

Best Practices Guidelines – Ms. Crandy stated the subcommittee has met and developed and finalized their definition of Evidenced-Based Practices which has been distributed to the taskforce members. The subcommittee will be completing a list of recommendations, and who would be responsible for funding and making it happen. The subcommittee should have their document finalized by June 3rd.

Training, Certification and ABA – Dr. Ghezzi stated the report is about 75% written and the plan is to circulate it amongst the subcommittee members.

Transition, Employment and Community Inclusion – Ms. LaRoy stated the three topics they have for the subcommittee turned out to produce quite a volume of information.

Workforce Development – Dr. Tincani stated the subcommittee met on May 20th and approved a final draft report pending a couple of minor revisions.

Education – Ms. Ward stated they did not have a quorum at the subcommittee’s last meeting, which kept them from finalizing their recommendations. The subcommittee will be meeting again June 5th and June 12th.

DISCUSSION AND POSSIBLE DELIBERATION AND DECISION ON THE FORMAT FOR THE ROUGH DRAFT OF THE FINDINGS AND RECOMMENDATIONS

Chair Toddre distributed an example of a report from Washington State that has good flow and is easy to read. If all the subcommittees have a copy of this format before they put their draft reports together, maybe they could base their draft report on this.

Chair Toddre stated the subcommittee drafts should be sent directly to each task force member by June 16th. Each taskforce member should reply directly back to the chair of each of the subcommittees with any comments, and not to the task force members as a whole.

UPDATE ON THE STATE FUNDING APPROPRIATED FOR AUTISM SERVICES

Mr. Butterworth stated the program is currently serving 73 kids with Autism. Of the 73 children enrolled, 60 are actively receiving services and the remaining 13 are close. He analyzed the medical expenses for only those families with a co-payment and their average out-of-pocket expenses are \$21,000 per year.

Ms. Crandy stated once all the kids are picked up in the South they are going to end up serving about 50 kids which includes one child in Mesquite. Ms. Ward stated Rural Nevada will be serving 9 children. Mr. Butterworth stated in the North they have 29 children in which 27 of them are actively receiving services.

Chair Toddre asked if there is any way to have another meeting with Early Intervention Services (EIS) personnel to get clarification on the diagnosis issue and go over the reports he is receiving that EIS is telling parents not to do ABA. Mr. Figurski replied there was a meeting facilitated by Mr. Richard Whitley where it was more than recommended that each of regional Early Intervention programs provide diagnosis. **Vice-Chair Liveratti stated she will set up a meeting with the Health Division to discuss these issues. Mr. Figurski recommended if they do set up a meeting to include the lead supervisors of each of the regional programs.** Dr. Ghezzi and Ms. Crandy would also like to participate in this meeting.

DISCUSSION OF THE IMPACT OF THE STATE OF NEVADA BUDGET CUTS AND THE BIENNIAL BUDGET ON AUTISM SERVICES

Mr. Mike Willden, Director of the Department of Health and Human Services, reviewed a document regarding: 4½ % Budget Cuts, Additional Cuts, Sierra/United Health settlement, and Round Three. He talked about how all this impacts the FY10 and FY11 budgets which need to be submitted to the Governor by September 1, 2008.

Mr. Willden stated that, over the biennium, the 4 ½% cuts resulted in a General Fund reduction of \$80 million for DHHS. As the General Fund is reduced, the Department is also going to lose about \$45 million in federal matching funds. Mr. Willden stated that the Sierra/United Health settlement will replace the \$87,600 budget cut from the Autism funding. The Department did not take money as part of the budget cuts from the Early Intervention Services.

Mr. Willden stated the bottom line is the Department may be forced to look at another \$30 to \$60 million in cuts. Whatever additional cuts need to be made will be very difficult. The forecasters have indicated the amount of revenue that they are seeing available in FY10 and FY11 to provide basic services for the Department’s share is going to be about \$920 million, compared to the \$1.07 billion DHHS currently

receives. Chair Toddre asked if there is any way to cut something else, instead eliminating Autism Services from ODS. Mr. Willden replied the Department will try and look at the best ways to make the budget cuts and welcomes any advice or guidance in this matter.

PRESENTATION ON THE AUTISM DATABASE AND ANALYSIS PROJECT WITH STAFF FROM THE NEVADA CENTER FOR HEALTH STATISTICS AND INFORMATICS, UNR

Dr. Wei Yang presented through PowerPoint, information on the Autism Database and Analysis Project. The pilot project tries to give a broader picture of the real data in Nevada. The Autism data had challenges because of unclear diagnoses, the young ages of the children, and difficulty in accessing the data. There is not an Autism registry. The department only has some projections or estimates based on the CDC's 1 in 150 children estimate. This pilot project is trying to check several systems and, if possible, to cross-check them. The systems the department plans to check are the Education system, Early Intervention, and hospital in-patient records. To-date, the Education system has received individual records without individual names. There are 320 cases reported from the Washoe School District and 1990 cases from the Clark County School District. From Early Intervention they have 156 cases with clear diagnosis. The department tries to cross match between the birth certificates and the Early Intervention database. Another search was done on hospital discharges, which revealed 1623 cases.

Chair Toddre stated Autism Speaks is getting permission from the parents and there may be a way the task force could help Dr. Yang get this information out to the Nevada parents. Dr. Yang stated they need help with getting the permission and continued funding. The department is currently searching for Federal funds. Ms. Crandy asked if it would be beneficial for one of the task force recommendation to be an Autism registry for the state of Nevada. Dr. Yang replied definitely yes.

Ms. Debra Vigil FERPA doesn't allow them to get some of the needed data. Chair Toddre stated he will be meeting with Greg Olmstead who has a tracking program. Ms. Vigil stated what he doesn't have is the actual children who are in the school districts and going from a transition in Nevada.

Ms. Ward asked if there was a problem getting the data from Elko. Dr. Yang stated they are working on getting the Education data from Elko. Ms. Vigil stated they will be getting additional information from other school districts.

Dr. Yang stated he was involved in establishing several registries when he worked for the Nevada State Health Division. The technical challenge of creating an Autism registry is not that big. Once you have a good registry it's not hard to do the analysis on other factors but they have to have the data. Dr. Ghezzi suggested a second kind of registry on outcomes. Ms. Vigil stated once they are able to get their hands on these statistics, then they will be able to show what's happening. Vice-Chair Liveratti stated Mental Health and Developmental Services does track their children that have gone through the Self Directed Autism Program. Ms. Crandy stated they are collecting good data now with the children receiving Autism services. Ms. Vigil stated her department will be in contact with task force members.

PUBLIC COMMENT

Ms. Wendy Hruska stated she has a son who has been in the Autism program for a month and a half. He was completely nonverbal before entering the program and within two weeks of being in the program spoke to her.

Ms. Jan Marson stated there is a lot of confusion concerning the Defensive DIR Model. There is data involved in this model to make decisions. The evidence is still not strong and doesn't have the history that ABA has.

SET NEXT MEETING DATE

A motion was offered by Dr. Ghezzi to set the next Autism Taskforce meeting for Friday, June 27, 2008, at 1:00PM. The motion was seconded by Vice-Chair Liveratti and unanimously approved.

ADJOURMENT

The meeting adjourned at 4:01 p.m.