

**Governor's Task Force on Autism Spectrum Disorders**

**Full Task Force**

Conference Call

February 26, 2009

1:00 – 2:00 p.m.

Summary of Minutes

*Committee Members*

Ausley, Loranne  
Bailet, Laura  
Benson, Holly  
Berkman, Karen  
Block, Lance  
Brosco, Jeffrey  
DeBeaugrine, Jim  
Dowds, Debra  
Emken, Elizabeth  
Hill, Kimberly  
Homant, Susanne  
Houghland, Patty  
Jackson, Jarl  
Kanjian, Robert  
Kompothecras, Gary  
La Belle, Richard  
Llorente, Marcelo  
Lockman, Bambi  
Marino, Dan  
Perkins, Randal  
Precourt, Lisa  
Purvis, Kelly  
Ring, Jeremy  
Ros, Ana Viamonte  
Sequenzia, Ven

*Department of Health Staff*

Howard, Catherine  
Taylor, Lona

*Agency for Persons with Disabilities Staff*

Copley, Kimberly  
Demko, Tamara

*The call began at 1:04 p.m.*

Ms. Demko provided an overview of the revisions to the report. She stated that the report is still in the revision process. She referred the Governor's Task Force on Autism Spectrum Disorders  
Full Task Force  
February 26, 2009  
Conference Call

group to an email she earlier in the day including current changes to the report as well as the items that were to be voted on during the current conference call.

Revisions made to date include:

- Language change in the Editorial Note to ensure that the listing of disabilities could not be interpreted by the reader as inclusive.
- Term “care-taker” was replaced with “care-giver” throughout the report.
- Instances where CARD was incorrectly referenced as “Center for Autism and Related Disorders” were changed to “Center for Autism and Related Disabilities.”
- Success stories from the seven CARD centers will be incorporated into the final report.
- More specific language regarding the use of the internet and the proposed Statewide Autism Website was added to the Awareness section.
- A footnote will be added to the Research section in reference to the cited prevalence rate of 1 in 150. It will explain that the rate of 1 in 150 was derived from a population that only included children aged eight. Prevalence studies that are currently underway will also be cited.
- The report mentions a number of treatments, but does not comment on whether these treatments are evidence-based. A footnote will be added to explain that discussion on the evidence-based treatments vs. non evidence-based treatments is beyond the scope of the report. It will also refer the reader to other sources to learn more about these treatments.
- More verbiage will be added to the report regarding genetic influences on the etiology of autism
- The citation for the 1987 Lovaas study has been corrected.
- A disclaimer has been drafted stating that although many organizations, treatment methodologies, etc. are mentioned in the report, the Task Force does not endorse one over any other. This disclaimer was forwarded out to Task Force members for their review. Ms. Emken requested that Ms. Demko add comment to the disclaimer to specifically cover the Task Force members individually instead of as a group.

- As far as the request to reference and endorse specific bills in the body of the report, Ms. Demko stated that after a conversation with the Governor's Office, the advice was to include this as an appendix since the language may change.
- The recommendation to delete the medical model provision in the CARD statute that was voted on during the last in-person meeting was not included in the preliminary report. This recommendation will be added to the final report.

After the overview of the current modifications to the report, Dr. Brosco asked Ms. Demko if the Task Force's preliminary recommendations were influencing on bill language or sponsors. She stated that she was not aware of any influence to date.

Ms. Demko provided an update on the progress of the Developmental Disabilities Compact Workgroup administered by the Office of Insurance Regulation (OIR). She stated that there were no signatories to the insurance compact, and that the insurance mandate will go into effect on April 1<sup>st</sup> of this year. She stated that OIR was made aware of insurance provider intentions to place extra burdens placed on practitioners and families in order to qualify for the benefits to be provided per the mandate. One example is requiring extra paperwork from diagnosing/treating physicians in order to receive reimbursement for services. Ms. Demko asked the Task Force to forward any reports similar to this to OIR.

Ms. Emken stated that other states are releasing clarifying regulatory notices that prevent misinterpretations of statute such as this.

Dr. Brosco stated that he believes that the Task Force has done incredible work and that he fully supports most of the recommendations. However, he has concerns about the way the report may be used, and cannot in good conscience fully endorse the report. As a result, he will be writing a letter to the Governor explaining his views. He plans to send a copy of this letter to the group through Ms. Demko and asked that a portion of the next conference call be dedicated to discussing it.

After all announcements and opening discussion, the Task Force moved forward with voting on substantive issues.

The first item requiring a vote was for approval of minutes. Copies of the minutes were provided to the Task Force members at the last in-person meeting in Tallahassee on January 28<sup>th</sup> and 29<sup>th</sup>. The minutes were adopted without objection.

Ms. Demko stated that three issues regarding the final report were submitted before the previously stated deadline of Friday, February 20<sup>th</sup>.

Issue 1:

Dr. Brosco moves that the Task Force include the following statement from Federal Department of Health and Human Services to be included in "Research" Section:

Three rulings related to autism and vaccine injury compensation cases were issued by the Special Masters of the U.S. Court of Federal Claims. The rulings were part of the Omnibus Autism Proceeding created by the National Vaccine Injury Compensation Program to handle the large volume of claims that vaccines induce autism. In order to ensure that the over 4,900 cases were dealt with in a timely manner, the U.S. Court of Federal Claims divided the claims into three different theories:

Theory 1: MMR in combination with thimerosal-containing vaccines can cause autism

Theory 2: Thimerosal-containing vaccines alone can cause autism

Theory 3: The MMR vaccine alone can cause autism

In three separate rulings issued today, each of the Special Masters ruled that the measles-mumps-rubella vaccine, whether administered alone or in conjunction with thimerosal-containing vaccines, were not causal factors in the development of autism or autism spectrum disorders.

The specific rulings can be found at:

<http://www.uscfc.uscourts.gov/node/5026>

He also recommends the inclusion of the Statement from the Department of Health and Human Services Regarding the Decisions of the U.S. Court of Federal Claims in the Omnibus Autism Proceeding:

As these cases illustrated, there's no doubt that autism and autism spectrum disorders place a heavy burden on many families. That is one reason why the U.S. Department of Health and Human Services continues to support research to better understand the cause of autistic disorders and develop more effective methods of treatment. The medical and scientific communities have carefully and thoroughly reviewed the evidence concerning the vaccine-autism theory and have found no association between vaccines and autism. If parents have questions or concerns about childhood vaccines, they should talk with their child's health care provider. Hopefully, the determination by the Special Masters will help reassure parents that vaccines do not cause autism.

More information about autism and autism spectrum disorders can be found at

[www.hhs.gov/autism](http://www.hhs.gov/autism)<<http://www.hhs.gov/autism>>.

More information about the National Vaccine Injury Compensation Program can be found at

<http://www.hrsa.gov/vaccinecompensation/>."

Discussion:

Mr. Sequenzia stated that he felt this verbiage would fit better in the appendix than in the body of the Research Introduction section.

Dr. Brosco agreed.

Mr. Kanjian asked Dr. Brosco how this information would add to the report. Dr. Brosco answered by explaining that the court spent the last two years hearing testimony and interviewing experts, whereas the Task Force spent only two days with limited testimony to make their recommendations. He believes that it is significant that the court came to such a strong conclusion, and should be included.

Dr. Kompothecras stated that he was against the inclusion of the language.

Ms. Emken asked if we were referencing any other cases supporting vaccine injury. Ms. Demko responded that there is a reference to the Hannah Polling case in the Research Introduction section.

Dr. Brosco reviewed history of vaccine court and the Polling case. He stated that this ruling is for 5000 other similar cases. He stated this is not just another court ruling, and that people have been waiting for it.

Mr. Kanjian compared vaccines to cigarettes. He stated that before scientific literature supported a causal role in cancer and many other health outcomes, they were thought to be safe. He believes that simply because the literature does not support a causal link between vaccines and autism at this point, that it may in the future.

Ms. Dowds stated that if the federal court ruling is not included in the report, then the Polling case should not be referenced either.

The Task Force voted.

Ausley, Loranne	Absent
Bailet, Laura	Yes
Benson, Holly	Absent
Berkman, Karen	No
Block, Lance	Absent
Brosco, Jeffrey	Yes
DeBeaugrine, Jim	No
Dowds, Debra	Yes
Emken, Elizabeth	No
Hill, Kimberly	Left call
Homant, Susanne	Absent
Houghland, Patty	Yes
Jackson, Jarl	Yes
Kanjian, Robert	No

Governor's Task Force on Autism Spectrum Disorders  
Full Task Force  
February 26, 2009  
Conference Call

Kompothecras, Gary	No
La Belle, Richard	Absent
Llorente, Marcelo	Absent
Lockman, Bambi	Yes
Marino, Dan	Absent
Perkins, Randal	No
Precourt, Lisa	Absent
Purvis, Kelly	Absent
Ring, Jeremy	Absent
Ros, Ana Viamonte	Yes
Sequenzia, Ven	No

The motion failed on a tied vote.

Issue 2:

Dr. Brosco moved that the Task Force delete all issues except immunizations in the Recommendation Process section. He stated that in the original vote, the group decided to only include immunizations. The current passage reads as follows:

In developing the recommendations for this report, the twenty-five (25) member Task Force spent many hours gathering information from state agencies, community organizations, health professionals, and Florida families. In carefully deliberating the broad scope of issues, the Task Force found it challenging to reach consensus on topics such as immunizations, McKay Scholarships, and insurance coverage.

Dr. Brosco withdrew this recommendation.

Issue 3:

Dr. Brosco moved that the Task Force include this discussion in the final report”

Any future incarnation of the Task Force should focus on autism and leave vaccine questions to a different (parallel?) group. Creating a road map for a system of services for people with autism and their families is an awesome responsibility and should be the full-time focus of any autism advisory group. Questions about vaccines and autism are also important but deserve a separate group to focus just on those issues.

Discussion:

Dr. Brosco felt that the Task Force was charged with numerous tasks, but were not able to address them all equally because deliberations regarding vaccines consumed most of the Task Force’s time.

Dr. Kompthecras stated that it was important to have all voices in any autism advisory group.

Mr. Kanjian stated that a spirited debate was important and that the charter for the Task Force should not be changed.

Ms. Emken stated that there is significant parental concern about this issue. As a result, it needs to be addressed.

Mr. Sequenzia agreed that discussions about vaccines did consume a good amount of the Task Force's time. He recommended that the group implement time limits to prevent this from happening again, but he does not think the subject should be omitted from.

Dr. Bailet agreed that vaccine discussions were too lengthy, but they were necessary for holistic approach.

The Task Force voted.

Ausley, Loranne	Absent
Bailet, Laura	No
Benson, Holly	Absent
Berkman, Karen	No
Block, Lance	Absent
Brosco, Jeffrey	Yes
DeBeaugrine, Jim	No
Dowds, Debra	No
Emken, Elizabeth	No
Hill, Kimberly	Left call
Homant, Susanne	Absent
Houghland, Patty	Yes
Jackson, Jarl	No
Kanjian, Robert	No
Kompothecras, Gary	No
La Belle, Richard	Absent
Llorente, Marcelo	Absent
Lockman, Bambi	No
Marino, Dan	Absent
Perkins, Randal	No
Precourt, Lisa	Absent
Purvis, Kelly	Absent
Ring, Jeremy	Absent
Ros, Ana Viamonte	Yes
Sequenzia, Ven	No

The motion failed 11 to 3.

Ms. Demko revisited Issue 2. She stated that after reviewing the minutes that Dr. Brosco was correct that the Task Force just voted on including Governor's Task Force on Autism Spectrum Disorders  
Full Task Force  
February 26, 2009  
Conference Call

immunization. She asked if he would like to bring forward his motion again.

The motion was brought forward.

The Task Force voted.

Ausley, Loranne	Absent
Bailet, Laura	Yes
Benson, Holly	Absent
Berkman, Karen	Yes
Block, Lance	Absent
Brosco, Jeffrey	Yes
DeBeaugrine, Jim	Yes
Dowds, Debra	Left call
Emken, Elizabeth	Yes
Hill, Kimberly	Left call
Homant, Susanne	Absent
Houghland, Patty	Yes
Jackson, Jarl	Yes
Kanjian, Robert	Yes
Kompothecras, Gary	No
La Belle, Richard	Absent
Llorente, Marcelo	Absent
Lockman, Bambi	Yes
Marino, Dan	Absent
Perkins, Randal	No
Precourt, Lisa	Absent
Purvis, Kelly	Absent
Ring, Jeremy	Absent
Ros, Ana Viamonte	Yes
Sequenzia, Ven	Yes

The motion was passed 12 to 2.

In closing, Ms. Demko reminded group to continue sending edits to her regarding non-substantive issues.

She also stated that full-text copies of research articles will not be included in the report due to report size and copyright issues.

*Call concluded at 2:05 p.m.*

Taken By: Catherine Howard