

Governor's Task Force on Autism Spectrum Disorders
Full Task Force
In-Person Meeting
Florida State University – College of Medicine
Tallahassee, Florida
January 28, 2009
10:00 a.m.
Summary of Meeting

Committee Members

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

Department of Health Staff

Casey, Megan
Cozart, Thometta
Howard, Catherine

Agency for Persons with Disabilities Staff

Copley, Kimberly
Demko, Tamara

Meeting was called to order at 10:22 a.m. by Jim DeBeaugrine

Ms. Demko explained housekeeping issues including location of restrooms, small café for convenience, and announced informal dinner at Harry's on Wednesday evening.

Ms. Demko announced that a quorum was present.

Mr. DeBeaugrine announced the Dean of FSU College of Medicine as host.

Dr. Fogarty gave a welcoming address to the Task Force. He also gave background information on enrollment and history of the FSU College of Medicine.

Mr. Jackson thanked Dr. Fogarty for allowing the Task Force to be hosted at FSU.

Mr. DeBeaugrine welcomed Mr. Joe Eppy as a speaker.

Presentation: Special Care Life Planning

Questions for Mr. Eppy:

Ms. Emken asked what advice Mr. Eppy had for parents to set up financial college planning funds.

Mr. Eppy responded that 529s can be transferred between to another child.

Presentation: Update: Developmental Disabilities Compact Workgroup

Questions for Ms. Senkewicz:

Mr. Kanjian asked if State employees be covered by the insurance compact.

Ms. Senkewicz answered yes.

He also asked if there would there be a paper or factsheet prepared by her office to share information.

Ms. Senkewicz answered yes.

Ms. Homant asked if the compact group addressed mental health issues.

Ms. Senkewicz stated that they had not.

Mr. Sequenzia asked about rumors that now insurance companies are not signing on to compact, that next session would try to get rid of current mandate.

Ms. Senkewicz said she was not aware of any.

Mr. Sequenzia asked when does mandate will take effect.

Ms. Senkewicz answered April 1, 2009.

Mr. DeBeaugrine mentioned that the meeting was running early, but would ensure that public comment would continue through the time allotted on the agenda.

Lauralyn Popp gave public comment. She passed along packets to all Task Force members and members of the public in attendance. She discussed awareness and advocating on behalf of change of leadership at the Northeast Center for Autism

Spectrum Disorders (CARD) in Jacksonville. She also mentioned increased training and adding additional safeguards for oversight. She asked for the assistance of the Task Force.

Mr. Kanjian shared experiences serving on the constituency board of Florida Atlantic University CARD center.

Ms. Popp mentioned that the board at the Jacksonville CARD center are handpicked and not well represented by attorneys, accountants.

Dr. Bailet commented that she was the only member from the Jacksonville area and validated Ms. Popp's issue about Jacksonville CARD Center. She expressed the difficulty of the issue and potential remedies.

Mr. Sequenzia asked Ms. Popp if she believed that Jacksonville CARD center had a situation regarding the misappropriation of funds.

Ms. Popp responded yes.

Ms. Popp mentioned that Autism Society in Jacksonville has been closed.

Ms. Purvis asked whether there were any issues with access to appropriate information and support and who would be an appropriate contact? Is there a family organization/advocacy group being worked with to improve this issue?

Dr. Bailet commented on Ms. Purvis' question. She stated that passionate, intelligent parents are working in Jacksonville and run into a brick wall even with organized efforts. She mentioned that the CARD in Jacksonville that funds medical issues rather than educational services.

Mr. Sequenzia commented that in the Jacksonville area, the Center has a medical model that is unlike any other CARD center. He added that provisions for change were supposed to be made but did not pass through the legislature.

Dr. Amy Wetherby, Executive Director of the FSU CARD center, gave public comment. She expressed her dissatisfaction with the issue at the Jacksonville CARD center. She requested advocacy on behalf of changing the statute specific to Jacksonville.

Dr. Berkman stated that University of South Florida CARD center functions with transparency, and added that all CARD centers should function in a similar fashion.

Marsha Finn from Tallahassee gave public comment. She shared her experience as a grandmother of child with an autism spectrum disorder. Her grandchild has been on the wait-list for many years and asked that the Task Force advocate for increased funding for services.

Ms. Precourt thanked Ms. Finn for her comments.

Ms. Demko began a review of the Preliminary Report.

Mr. DeBeaugrine called recess until 1:45 p.m.

Mr. DeBeaugrine called to order at 1:46 p.m.

Ms. Demko began to review the Preliminary Report in detail. She stated that there were a few issues that needed more discussion before the staff could draft certain sections of the report.

The first was a recommendation regarding the State-Level Autism Coordinating Body and its similarity to another recommendation regarding an extension of the Task Force.

She asked the group if they wanted to prioritize or combine these recommendations.

Ms. Purvis suggested that the State-Level Autism Coordinating Body (Body) fall under the Commission on Disabilities or another pre-existing group.

Ms. Demko asked Ms. Purvis if Task Force were to be extended should it be the same group as the Body. Ms. Purvis answered that she felt they should be separate entities.

Mr. Sequenzia stated that he did not see a need for both a Task Force and a Body. He suggested that Task Force be transformed into Body and noted that group should not fall under individual State agency.

Dr. Homant expressed the need for continuing Body or Task Force to be able to enforce/implement recommendations of Task Force. She added that the group should include more information regarding assistive devices in the report.

Mr. Kompothecras discussed the need for watchdog group.

Ms. Dowds described the importance of the relationships between the proposed regional collaboratives and Body. She also agreed that both a Task Force and Body do not need to exist and that the continuing Body, whether another incarnation of the Task Force or separate body, should be smaller group than the current Task Force.

Ms. Lockman stated the Task Force or Body should have authority for implementation.

Mr. DeBeaugrine stated that the Task Force or Body would have to be representative group of individuals in order to fully explore and address issues. He also suggested exploring a change in the charge of Task Force to include formal authority and oversight.

Mr. Kompothecras commented on need for legislators on the continuing Body.

Mr. Sequenzia expressed need for the Task Force to continue, but to change its focus. He would like to meet less often, perhaps every six months.

Ms. Purvis commented that it would provide continuity if current Task Force members continued on in the extended Task Force or Body.

Ms. Dowds expressed a desire for the Task Force or Body to connect with other disability advocacy and advisory groups.

Mr. Sequenzia made a motion to remove the recommendations regarding the Body from the report if the Task Force is extended. A vote was taken. The motion passed unanimously.

It was agreed that the recommendations regarding this body would be combined with the recommendation to extend the Task Force.

The group moved to the next issue: Immunizations.

Mr. Kompothecras was recognized. He wished to share article provided to Task Force members regarding thimerosal, vaccines, mercury, and autism.

He moved that a recommendation regarding philosophical exemptions be included in the final report.

After some discussion, the verbiage of the specific recommendation was "Recommend the adoption of a philosophical exemption in the State of Florida."

Moved by Dr. Kompothecras.

Seconded by Mr. Kanijan.

The group called a 15 minute recess.

Meeting was called back to order at 3:52 p.m.

Tamara recommended for grammar purposes to strike "recommend" off the recommendation.

DeBeaugrine stated that they would move forward with this recommendation if there were no objections. There were no objections.

Sue Homant expressed concern that parents would use philosophical exemptions as an excuse to not vaccinate.

Karen Berkman stated that she would like to move slowly and carefully with these recommendations while research is taking place to inform their actions.

Jarl Jackson stated that he would rather have autism than die of a vaccine preventable disease.

Ven Sequenzia stated that he felt that it was time to move on for this subject. He believes that a religious exemption is analogous to a philosophical exemption and hence, he is in support of the philosophical exemption.

Kelly Purvis stated that it is difficult as a parent to know what to do in this situation since they have been presented with so many conflicting studies. She said that at this time, she would support more research on the subject.

Gary Kompothecras stated that this is exactly the reason that FL should have the right to an exemption: for those parents who are concerned about vaccinations to be able to exempt while more research is completed.

Lisa Precourt stated that she agreed with Ms. Purvis. She stated that with a religious exemption, most pediatricians will not see her children for fear of charges of malpractice suits. She would like to switch to a philosophical exemption so her children will have increased access to medical care.

Patty Houghland stated that she did not know that information and as a result, she would no longer be opposed, but now in the middle of the road. She would like to do more research on the subject now.

Bob Kanjian asked who the “enforcer” of vaccinations: DOE or DOH? He made the point that the only way he knows that this is enforced is through school entry requirements. He stated that all have a right to a free education. However, the governing body is denying this right by compelling parents to have their children vaccinated.

Gary Kompothecras closed the recommendation.

DeBeaugrine explained that the vote would be a 2/3 majority vote. She stated that 10 out of 15 would be needed to pass. Ms. Demko called on only those who were present.

Bailet	Yes
Berkman	Abstain
DeBeaugrine	Yes
Dowds	No
Emken	Yes
Hill	Yes
Homant	No
Houghland	No
Jackson	No
Kanjian	Yes
Kompothecras	Yes
Llorente	Yes
Lockman	Abstained due to conflict of interest
Precourt	Yes
Purvis	No
Sequenzia	Yes

DeBeaugrine called a short recess to consult with legal counsel. There was question as to if a party could abstain if they did not have a reason such as conflict of interest.

DeBeaugrine decided to vote Yes.

Motion passes.

Mr. Sequenzia was recognized to discuss ASA stand on vaccinations. They committee read the ASA's interaction with the IACC. The committee reviewed the ASA website.

Ms. Demko raised the issue of discussion points for the motion just adopted. What specifics need to be included in the report regarding philosophical exemptions?

Also, Ms. Demko asked about employment, and if it should be discussed in current TF report or task to future direction.

Mr. Sequenzia noted that it could be brought up in discussion in conference calls before final report is due.

Dr. Bailet asked if there was a recommendation given to transitions? Could potentially include discussion of employment in same area as quality of life and employment within that section.

Ms. Demko raised the issue of whether or not the TF would like to include additional recommendations for oversight regarding CARD after public comment today.

Mr. Sequenzia stated that after Dr. Wetherby's comments, that issue at Jax needs to be addressed individually and not under the purview of the TF.

Mr. Kanjian stated that a statement about recognition to CARD be included in the Report, but additional scope of treatment and available services requires increased funding.

Ms. Demko stated that the Report already lists such comments.

Dr. Bailet noted that she is in support of increased funding for CARD. She stated that increased CARD funding in Jax could result in further problems. She stated that it is not within the purview of the Task Force – but if not TF, then who addresses?

Ms. Precourt – stated that perhaps the TF draft a letter more specific to the Governor regarding the current state of CARD centers. Mention issue that has arisen with single center that needs resolution and increased oversight.

Mr. DeBeaugrine stated that he would like to have staff look into and investigate issue about where jurisdiction and purview lies.

Mr. Sequenzia retracted his previous comment and moved to reinsert a sentence into statute prohibiting use of CARD funds for medical and pharmaceutical purposes.

The motion was seconded.

Ms. Houghland was recognized, and asked that the chair as research is conducted that more research be done as to what has already been done and investigate the university in question.

Ms. Precourt asked for logic as to why legislature removed clause last session and requested background information.

Mr. Sequenzia asked to reiterate his earlier point regarding Senator Wise and last minute statutory changes.

Vote:

Bailet – yes

Berkman – yes

Dowds – yes

Hill – yes

Hammond yes

Houghland – yes

Jackson – yes

Kanjian - yes

Kompothecras – yes

Llorente – abstain

Lockman – yes

Precourt – no

Sequenzia – yes

Vote passes. 11 in favor, 2 abstentions (including chair) and 1 opposed.

Mr. Kanjian brought up FS.112.311 regarding abstentions and voting.

Mr. Sequenzia asked if it would be an appropriate time to discuss Autism Awareness Day.

Dr. Gary asked if the License Plate had been considered.

Mr. DeBeaugrine turned the chair over to Ms. Demko to discuss logistics and plans for tomorrow.

Reconvene at 9am. Presentation on bills filed to date. Dr. Brosco will be in attendance. Discuss State roadmap for development.

Mr. DeBeaugrine closed the meeting at 4:52.