

Governor's Task Force on Autism Spectrum Disorders
Full Task Force
In-Person Meeting
University of South Florida – Marshall Student Center
Tampa, Florida
September 25, 2008
8:30 a.m.
Summary of Meeting

Committee Members

Ausley, Loranne	absent
Bailet, Laura	
Benson, Holly	arrived at 9:12 a.m.
Berkman, Karen	
Block, Lance	absent
Brosco, Jeffrey	
DeBeaugrine, Jim	
Dowds, Debra	
Emken, Elizabeth	
Hill, Kimberly	absent
Homant, Susanne	
Houghland, Patty	
Jackson, Jarl	
Kanjian, Robert	
Kompothecras, Gary	arrived at 8:34 a.m.
La Belle, Richard	
Llorente, Marcelo	absent
Lockman, Bambi	
Marino, Dan	absent
Perkins, Randal	absent
Precourt, Lisa	
Purvis, Kelly	
Ring, Jeremy	absent
Ros, Ana Viamonte	
Sequenzia, Ven	

Department of Health Staff

Casey, Megan
Cozart, Thometta
Demko, Tamara
Howard, Catherine
Taylor, Lona

Meeting called to order at 8:32 a.m.

Roll call was taken by Department of Health staff member, Catherine Howard. Task Force members not in attendance are reflected above. Chairman DeBeaugrine confirmed a quorum was reached.

Chairman DeBeaugrine recognized new Task Force member, Jarl Jackson, coordinator, TASC in Tallahassee.

The first presenter of the day, Officer Jimmy Donohoe, was introduced by Chairman DeBeaugrine.

Presentation:
Take Me Home Program

Questions for Officer Donohoe:

Ms. Precourt asked Officer Donohoe if he was familiar with the Silver Alert Program that is designated for persons over 18 with disabilities or Alzheimer's.

Officer Donohoe answered that he had heard of the program and he believes there is a there is a cost associated with it.

Dr. Viamonte Ros asked where additional information can be obtained about GPS bracelets.

Officer Donohoe responded that the Association of Retarded Citizens (ARC) of Florida has information on the bracelets and that they are also supporting legislation to support protection of special populations.

Dr. Kompothecras asked if the photos provided for the Take Me Home Program are protected/secured to avoid predators of vulnerable populations.

Officer Donohoe answered that photos are uploaded onto laptops and not broadcast over any servers. Each photo update takes about 45 seconds to install and is done directly on the laptop.

Mr. Sequenzia inquired what the reason was for not including medical conditions on the child's profile.

Officer Donohoe responded that after legal review medical conditions are not listed because of possible liability issues.

Ms. Homant asked if there is an integration of training with the Crisis Intervention Teams (CIT) and the Take Me Home curriculum.

Officer Donohoe responded that the Crisis Intervention Teams are trained to deal with mental and special medical conditions. New recruits will have the Take Me Home basic training. At this time, veteran officers are not required to take this training.

Ms. Purvis asked if this training is free to Law Enforcement agencies and if one can register at any time to participate.

Officer Donohoe responded that software is provided and updated free of charge. New registration to participate in the program is on-going and site visits are made upon request to initiate or to update photos.

Officer Donohoe described the Child is Missing Program, the Amber Alert System, and Reverse 911.

Ms. Precourt stated that these are great programs to advocate for on at the local level. If grant money is available to obtain at a statewide participation we need to pursue funding for the Silver Alert Program.

Dr. Bailet asked how many law enforcement agencies are using this program.

Officer Donohoe responded that 143 departments have received the information and they have between 40 to 50 active agencies.

Mr. Sequenzia asked who enforces the training for officers.

Officer Donohue responded that all new recruits/officers are required to have 8 hours of disabilities training, however, this training is not mandated for existing officers.

Dr. Kompoethras asked if there was a growing rate of missing children.

Officer Donohue responded that he is not aware of any statistics that support more missing children. There is more media coverage so there is more awareness when children do go missing.

Task Force member Dr. Jeffery Brosco introduced Dr. Ari Brown, final speaker on the immunization issues being considered by the Task Force at this meeting.

Presentation:
Vaccine 411

Questions for Dr. Brown:

Ms. Homant asked how the Task Force could make statewide recommendations that will be viewed as for the greater good of society.

Dr. Brown responded that the recommendation is not for the greater good, no man is an island and the recommendations should protect your child as well as other people in your communities.

Ms. Precourt inquired about the number of vaccines given at one time. Specifically she wanted to know if there is a safe amount of vaccinations to administer at a time.

Dr. Brown responded that the norm is up to 5 shots administered at a time. This is strategically done if your child is behind in the immunization schedule or the client is indigent and might not be back in a physician's office for another opportunity to immunize them. There is a methodology for administering delayed vaccines that could exceed 5 shots at one time.

The Task Force was released for a break at 10:34 a.m.

Meeting resumed at 10:52 a.m.

Chairman DeBeaugrine asked the public if they had any inquiries or comments about the immunization issue.

Dr. Mobeen Rathore from Jacksonville, Florida, spoke to the Task Force about the importance of immunizations for children and the public's health. He further shared that he felt that any change to the immunization schedule will harm the children of Florida. Deferring a vaccine has consequences. He warned that the group be cautious of those who speak in absolutes.

Chairman DeBeaugrine began discussions about the voting process for the Task Force. Executive Director Tamara Demko provided a review of the charge of the Task Force and offered an outline of topics to help better define the direction the Task Force is taking for the Interim Report due in December.

Presentation:

Voting on Select Topics:

The Governor's Task Force on Autism Spectrum Disorders ("Task Force") was created under Executive Order 08-36 to advance public policy for the research, screening, education, and treatment of autism, to assess the availability of insurance coverage for appropriate treatment of autism, and to recommend a unified and coordinated agenda for addressing autism in Florida

When addressing the topics outlined in the Executive Order, each committee will consider the following overarching issues, which will be incorporated into the written report:

- recommendations regarding changes to Florida statutes, administrative rules, policies, and/or procedures relating to the purposes and duties of the Task Force;
- accomplishments in obtaining legislative or administrative change; and
- progress related to collaborative efforts with other agencies and organizations.

In addition, Ms. Demko reminded the group that there are guiding themes to utilize when considering your recommendations; lifespan approach, diversity approach, multilevel approach and the 360° approach.

Chairman DeBeaugrine brought before the Task Force the motion to include a recommendation in the preliminary and final report to address immunization as a priority of the Task Force. This motion was seconded by Dr. Kompothecras.

Chairman DeBeaugrine defined consensus as a vote of 2/3 majority.

Ms. Demko shared that this exercise is not to come up with specific language for the reports. This exercise will narrow down the direction of the Task Force and clearly

define if the Task Force will pursue this specific path related to Immunizations under the Research topic as outlined in the Governor's Executive Order.

Chairman DeBeaugrine directed the Task Force will work until 12:15 on this exercise and then evaluate the progress being made in this forum.

Formal statement of voting: Will the Task Force make any recommendation on the umbrella topic of immunizations for inclusion in the Task Force Report?

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

At the conclusion of voting on this topic, several task force members voiced concerns about the voting process and lack of time to dialogue among the Task Force members to reach consensus.

Ms. Purvis stated that the group should speak as a Task Force, as one body, to move our mission forward.

Mr. Sequenzia asked if the group could send the umbrella issues back to the subcommittee to bring formal recommendations on a specific topic back to the full Task Force for voting.

Ms. Precourt stated that she felt their recommendations should provide guidance to the legislature on how the Task Force thinks the recommendations can be accomplished, preferably in a tier effect when applicable.

Mr. LaBelle stated that the Task Force is not drafting legislation. The Task Force is making recommendations to the Governor, and that anything recommended must be substantiated and all ramifications considered. He felt the group should be able to explain how they reached their recommendations.

Ms. Purvis also mentioned that the Task Force should include benchmarks or measures of success for what they want the outcomes of the recommendations to be.

Mr. LaBelle stressed that it is important for him, and his fellow Task Force members to have the option to discuss and react with back and forth dialogue on all issues related to the recommendations. Further, without the dialogue, Mr. LaBelle shared that he does not see any other effective alternative without getting tied up on the duplicate dialogues in the future.

The Task Force was encouraged to continue the voting process to see how many issues could be resolved before the lunch break. Ms. Demko presented to the Task Force the subtopic of thimerasol for inclusion in the final report.

Will the Task Force make any recommendation on the subtopic of thimerasol for inclusion in the Task Force Report?

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

The Task Force was released for lunch at 12:15 p.m. and asked to return at 12:45 p.m.

Task Force reconvened at 12:55 p.m.

Governor's Task Force on Autism Spectrum Disorders

Full Task Force

September 25, 2008

In-Person Meeting

Ms. Demko offered a proposal to assist in moving the Task Force forward with the report recommendations. A full day teleconference and/or video conference will take place for committee work time. Ms. Demko will convert the compilation paper into the format voted on yesterday and have it available for full review prior to the scheduled conference calls.

Public Comment

Ms. Beth Kompothecras:

Ms. Kompothecras shared with the Task Force her personal story of living with two children with Autism and the hope she has for the future for her family and all children living with autism. Each Task Force member was presented a book, "The Beach" written and illustrated by Alexander Kompothecras.

Dr. Joseph Chairo:

Pediatrician who has a son with Asperberg's syndrome. Dr. Chairo shared that he was saddened by the level of discourse during this meeting, however, the debate and discussions have been good. Dr. Chairo shared that he works with Children's Medical Services that serves special needs children.

Christopher Wetts: statement read by Chairman DeBeaugrine.

"Today is my son's birthday, so I made plans to bring cookies and cake to his classroom at 12:00. This is why I cannot make this statement in person.

Matthew (my son) is 6 years old. He is on the spectrum and attends a charter school in Hillsborough County (FASCE School). I support investigating the vaccine issue, but not at the cost of providing needed support and services for these children. As a middle class parent, we (my wife and I) spend \$30,000 a year on Therapy's (speech, oral motor, social interaction, occupational, etc). We now spend \$36,000 - \$14,000 for McKay for a private school that will provide one on one therapy. As parents what we need is support from the school systems to better educate teachers to understand our children, instead of putting them in a portable in the back of the campus. We need to be able to use our health insurance to help with the costs of treatments and therapies like other illnesses.

The lucky families that can afford to cover these costs to help their children and doing the mostly by mortgaging their homes, taking out loans, forgoing retirement savings, etc.

We need support, not talk! Thank you. Christopher Wetz"

Task Force member Bob Kanjian introduced the next speaker, Dick Busto.

Presentation:

Autism Project of Palm Beach County

Questions for Mr. Busto:

Dr. Kompothecras asked Mr. Busto how many people they service and what is their budget is.

Mr. Busto responded that they have 60 children in their program, \$1.5 million budget, 80% of that from the Department of Education, which is the same amount a child with autism, would receive in a public school setting.

Mr. LaBelle commented that all children are entitled to a free education. We should offer suggestions and strategies on how the entire school system can educate our children. He believes that self-segregation is not the best strategy, but inclusion is the hope for children with special needs.

Chairman DeBeaugrine introduced the final speaker of the day, Elena Andresen, Ph.D.

Presentation:
Florida Office on Disability & Health

Questions for Dr. Andresen:

Dr. Kompothecras asked if Dr. Andresen about the feasibility of a certain epidemiological studies that could support a causative connection between immunizations and autism.

Dr. Andresen reviewed the difficulties in performing a study with that goal.

Ms. Demko announced that she hopes to have the draft preliminary report ready for review by Wednesday, October 8. The Task Force staff will work with the subcommittees to begin conference calls the week of October 13, 2008. The full Task Force will meet on October 30, 2008 via conference call.

Meeting adjourned at 2:50 p.m.

Taken By: Lona Taylor