

Governor's Task Force on Autism Spectrum Disorders
Full Task Force
In-Person Meeting
University of South Florida – Marshall Center
Tampa, Florida
September 24, 2008
10:30 a.m.
Summary of Meeting

Committee Members

Ausley, Lorraine	absent
Bailet, Laura	
Benson, Holly	
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	
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 was called to order at 10:30 a.m.

Mr. DeBeaugrine welcomed the group, went over housekeeping rules such as placing phones on vibrate and reiterated to the Task Force members to be respectful of each other's points of view. He thanked the University of South Florida, Center for Autism and Related Disorders for hosting the meeting.

Roll call taken by Ms. Demko.

Ms. Demko opened the meeting discussions with an overview of the Task Force, including the purpose: The Governor's Task Force on Autism Spectrum Disorders ("Task Force") was created by Executive Order 0836, 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

She stated that a preliminary report is due to the Governor's Office in December 2008.

She reminded the group that when addressing the topics outlined in the executive order, each committee should 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.

The themes and guiding considerations across committees:

1. Lifespan Approach - As autism is not limited to any specific age, discussions should contemplate and facilitate solutions across the lifespan.
2. Diversity Approach – Proposed solutions should consider diversity across the autism spectrum, needs, functionality/abilities, and impact across individuals of various races, ethnicities, languages, genders, and socioeconomic status.
3. Multilevel Approach – Proposed solutions should consider needs and impact at multiple levels such as individual, family, community, state, and nation.
4. 360° Approach – Proposed solutions should consider each issue carefully, after recognizing diverse viewpoints, risks/costs and benefits, and potential impact beyond the group benefiting. Discussion should also explore the potential for unintended consequences and the creation of incentives or disincentives. Other considerations may include economic impact, social/societal impact, public health concerns, individual/family concerns, sustainability, and feasibility of implementation.

Ms. Demko provided an overview of each committees work, focus and goals.

Putting the Pieces Together

- Statewide website
- Collaboration
- Community Awareness and Outreach

Window of Opportunity

- Early identification of individuals with ASDs
- Early implementation of an intensive treatment plan
 1. Screening for autism as part of routing pediatric health care visits
 2. Screening early care and educational professions

3. Facilitate evaluation by qualified professionals (adequate reimbursement)
4. Ensure early intensive intervention for children with ASDs (25 + hours per week, provider reimbursement)
5. Payment for treatment of children with ASDs
6. Prevalence of autism in Florida (difficult to gauge. Insurance coverage, cost for needs) Children's Health study, CDC collaboration, state agency surveys, private insurers.
7. Long-term strategy: Need to continue the Task Force work over multiple years. (multi-year, multi-tier approach)

Current and Future Outlook

- Support research to identify causes of ASD and potential avenues for prevention.
- Support evidence-based, person-centered approach to intervention options across the lifespan.
- Support increased efforts to inform families dealing with ASD of important safety concerns and solutions across life span.
- Support enhanced efforts to address quality of life issues for individuals with ASD and their families.
- Possible mechanisms to accomplish these priorities.

Cost of Autism

- Estimating short term and long term costs to individuals, families and state (direct, indirect, hidden costs)
- Short term funding/long term funding (private insurance, tier waiver implementation, need for care across the lifespan)
- Alternative funding sources (health councils, fundraising, specialty license plates.
- SB 2654 impact/changes (Medicaid waivers/state plan, Window of Opportunity Workgroups, Insurance mandate)
- Employment (training, placement, vocational rehabilitation, mentoring, ASD friendly work environment, transportation)
- Review and consideration of other state practices

Ms. Demko also mentioned the following considerations for report writing:

1. Governor's Plain Language Initiative
2. Structure and recommendations committee work presentation
3. Appendices (scientific documentation)
4. Additional resources (news articles, Glossary of Terms)

Ms. Demko answered questions from the task force members about the structure of future work time and assignments of the subcommittees.

Mr. DeBeaugrine dismissed the task force for lunch at 11:36 a.m. to return and begin work at 12:30 p.m. Mr. DeBeaugrine reminded the group that they must adhere to Government in the Sunshine Law and not discuss Task Force business outside of the meeting forum. MC

Meeting resumed from the lunch break at 12:34 p.m.

Ms. Demko announced that Senator Ring was unable to attend the meeting due to illness. She reminded the group to respect each other's opinions, and to wait to be recognized by Mr. DeBeaugrine before they made comments and/or asked questions.

Mr. DeBeaugrine introduced the first speaker, Dr. David Berger, Medical Director, Wholistic Pediatrics.

Presentation:

The Biological Plausibility of a Relationship between Vaccines and Autism Spectrum Disorders.

Questions for Dr. Berger:

Ms. Homant asked if there were other suspected environmental factors in the etiology of autism spectrum disorders (ASD) that were not included in his studies.

Dr. Berger answered that there could be other factors but pharmaceutical companies specifically are not supporting financially of any studies on their products.

Lisa Precourt asked if a test was available to screen for autoimmune disorders that would increase the likelihood of an adverse reaction to an immunization.

Dr. Berger stated that a test similar to the PKU (Phenylketonuria) heel stick, was available.

Dr. Kompothecras asked how long Dr. Berger has been seeing autistic children.

Dr. Berger answered that he has seen over 1500 children with an ASD in the last 10 years of practice.

Dr. Kompothecras asked if Dr. Berger recommended delaying certain vaccinations

Dr. Berger answered that vaccination could be delayed for diseases for which there is a very low risk of contracting during infancy, such as Hepatitis B.

Dr. Brosco stated that this discussion brings forth a series of questions and concerns about abandoning the vaccination schedule. He noted that there is a wealth of information available on the positive impact vaccinations have in saving lives.

Mr. Kanjian inquired about studies that identify optimal weight/sizes for children when they immunized?

Dr. Berger stated that a developed immune system was more important than size or weight.

Ms. Emken asked if Dr. Berger has performed any efficacy studies on his patients that have opted for a delayed vaccination schedule.

Dr. Berger answered that while this would be a good investigation funds were not available to pursue this research.

Dr. Kompothecras introduced the next speakers, Dr. Mark Geier and Mr. David Geier.

Presentation: The Genetic Centers of America
Thimerosal and its role (link) in Autism.

Questions for Dr. Geier and Mr. Geier:

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Ms. Purvis asked for the speakers to verify which states use thimerosal-free vaccines?

They answered California, Delaware, Maryland, Iowa, Missouri, New York, and Washington.

Ms. Purvis inquired if Mr. Geier was aware of studies on pregnant women with group B strep and Autism?

He answered that some studies suggest immune problems with children.

Dr. Bailet asked why thimerasol is used in vaccines.

The presenters answered that the chemical is used because it is cheap, easy to work with and manufacturers are used to working with it.

Mr. Sequenzia asked why the pharmaceutical industry still uses thimerasol in vaccines and vaccine production.

The presenters answered they believe that is has not been removed because the chemical is cheap and there in no enforcement to do so.

The group and presenters engaged in additional discussions about research findings related to thimerasol and vaccines.

The Task Force took a short break and reconvened at 3:18 p.m.

Mr. DeBeaugrine reminded the group to be respectful of each other as they progressed through the agenda and that all speakers would be given time to make their full presentations even though the meeting was behind schedule. He asked speakers to share affiliations and/or financial conflicts of interest as they introduced themselves.

Dr. Kompothecras introduced the next speaker, Dr. Boyd Haley.

Presentation:
Amalgams and Mercury Toxicity

Questions for Dr. Haley:

Dr. Brosco asked Dr. Haley to list some other neurotoxins that are common in the environment.

Dr. Haley answered heavy metals such as mercury, lead and pesticides.

Dr. Jeff Brosco introduced the next speaker, Dr. Saad Omer.

Presentation:
Vaccine Refusal and Risk of Vaccine Preventable Diseases

Questions for Dr. Omer:

Mr. DeBeaugrine asked if Dr. Omer could explain the difference between easy and hard to obtain immunization exemptions.

Dr. Omer explained that requirements for exemptions could vary from easy (e.g., a parent simply signs an exemption form), to difficult (e.g. clergy is required to verify the exemption).

Ms. Precourt inquired about the concern that a ban on thimerosal in all vaccines in the state could affect immunization coverage and possibly trigger a shortage.

Dr. Omer stated that policy changes such as this would likely have consequences.

Dr. Bailet agreed that policy changes would have consequences. She asked what benefit thimerosal provides.

Dr. Omer stated that the chemical acts as a preservative.

Ms. Emken stated that there seemed to be a concern about increasing the number of exemptions granted. She asked what the odds were for a child becoming ill or dying if they did not receive a vaccine on the vaccination schedule.

Dr. Omer answered that local clustering of exemptions/incidents is the concern. Infectious diseases spread and then morbidity and mortality becomes an issue.

Mr. Sequenzia asked if there is a risk of a child getting a disease if there is a delay in vaccine administration.

Dr. Omer answered that the consequences of a delayed immunization scheduled have not studied in detail. He stated that there is a high risk of preventable disease in infants and children.

Mr. Kanjian asked if there is any truth to the possibility that the vaccines could be a cause of autism, and if Dr. Omer supports a change in the vaccine schedule.

Dr. Omer stated that if there was evidence supported by the mainstream scientific information then he would recommend a change.

Mr. DeBeaugrine introduced the next speaker, Dr. Russell Eggert, Director of the Division of Disease Control at the Florida Department of Health.

Presentation:
Protecting Individual and Public Health through Immunization

Questions for Dr. Eggert:

Ms. Purvis asked if childhood vaccines are now available thimerosal-free.

Dr. Eggert answered that children 6 years of age and under can obtain thimerosal-free immunizations from their health care provider. He stated that there is an economic issue in that thimerosal-free vaccines are more expensive. Policymakers must address how to protect children while managing a limited budget.

Dr. Kompothecras asked where Florida buys its vaccines.

Dr. Eggert answered that vaccines are purchased from the manufacturers under a contract negotiated by the Centers for Disease Control and Prevention (CDC). The CDC purchases the vaccine for the Vaccine For Children (VFC) program, and then provides them to the states.

Dr. Viamonte Ros asked Dr. Eggert what his concerns were regarding philosophical exemptions.

He answered that his concern begins with states such as Texas and Arkansas where there are clusters of children at risk for contracting diseases because of philosophical exemptions.

Ms. Precourt asked if there are any studies on how many vaccines can be safely given at one time.

Dr. Eggert answered that he was not aware of any specific study but stated that when a vaccine is approved, it is administered in human subjects in the context that all individuals would be receiving the same immunizations in the same sequence.

He also stated that contemporary vaccines are much more pure than old vaccines.

Mr. LaBelle asked if children receiving exemptions are being tracked to see if the autism rate is impacted or if it was possible to get this information from the Department of Health.

Dr. Eggert answered that there is not a registry that he was aware of but mentioned a current study sponsored by the Centers for Disease Control with the University of Miami that may produce prevalence data.

Ms. Emken asked Dr. Eggert what office within the Department of Health was responsible for combating autism in Florida.

He answered that autism is under direction of Children's Medical Services.

Dr. Bailet shared that she is concerned about health equity. If a family on Medicaid goes to the local county health department can the request a thimerosal free vaccine?

He responded that parents can request thimerosal-free vaccines from any provider. The Department of Health provides thimerosal-free vaccines for Vaccine for Children (VFC) clients.

Dr. Brosco shared that the group must understand the value of immunizations and they should remember there are significant risks for not giving our children vaccines.

Mr. DeBeaugrine introduced the next speaker, Kimberly Haws of Christopher Connections, Inc.

Presentation:

Water Safety for Children with Autism

Ms. Haws asked the Task Force to think of the following issues when making recommendations to enhance the work that Christopher Connections is doing to help children with water safety.

- Clarify language in FS 514.072 (Special Needs VS Disabilities)
 - Disabilities omits those who are visually or hearing impaired.

- Specialized – what does this mean?
- May be certified – does not say MUST
- Dan Marino Foundation only one to certify?
- Who owns it? What State agency is for enforcement?
- Consider fencing bodies of water, not just pools.
- Homeowner exemptions for fence – safety of special needs children

Questions for Ms. Haws:

Mr. DeBeaugrine clarified that the statute being referenced is the definition for Developmental Disabilities.

Mr. DeBeaugrine introduced the final speaker of the day, Janet Crawford, Vice President for Autism Services for Youth Advocate Programs, Inc.

Presentation:
Youth Advocate Programs, Inc.

Questions for Ms. Crawford:

Dr. Bailet asked, where the funding come from to run Youth Advocate Programs.

Ms. Crawford answered that for direct services, the funding comes from behavioral health or the Agency for Persons with Disabilities.

Ms. Demko made closing announcements.

Mr. DeBeaugrine asked the group to vote on the ratification of the minutes that were included in the meeting binders. The Task Force ratified all minutes with no objections or requested changes.

Meeting concluded at 8:01 p.m.

Taken By: Lona Taylor