

**Governor's Task Force on Autism Spectrum Disorders
Current and Future Outlook Committee**

Conference Call
October 14, 2008
10:00 a.m. – 5:00 p.m.
Summary of Minutes

Committee Members

| | |
|-------------------------------|--------|
| Bailet, Laura | |
| Block, Lance (Co-Chair) | absent |
| Homant, Susanne | |
| Kompothecras, Gary (Co-Chair) | |
| Perkins, Randy | absent |
| Ring, Jeremy | absent |

Department of Health Staff

Demko, Tamara
Howard, Catherine
Taylor, Lona

Call began at 10:08 a.m.

Ms. Demko stated that the purpose of the call would be to draft and agree upon recommendations that will be presented to the full Task Force during the October 30th conference call.

The committee deliberated on the topic of immunization and agreed on the following recommendations:

Recommendation: Encourage epidemiological studies utilizing existing resources in Florida (ie, using the Medicaid/Medicare data base) to look at potential relevance of ASD including but not limited to thimerosal and immunizations.

Recommendation: Explore best practices for a potential philosophical exemptions for state mandated school entrance, immunization vaccinations with required periodic renewal.

Discussion points to be included in the preliminary report regarding these recommendations are:

- Ensure that there are child protection guidelines in place.
- Pediatricians have a role in the decision to vaccinate and should discuss the risks and benefits with parents.
- Parents should review immunization with a health care provider.

Recommendation: Explore safe alternative vaccine schedules for Florida's children.

Recommendation: Explore the prohibition of the purchase and administration of all mercury containing (e.g. thimerosal) immunizations in the State of Florida.

Some committee members expressed concern about the impact of a prohibition of vaccinations containing thimerosal on the availability of flu vaccines. Some felt strongly that exemptions should be available in emergency situations.

Dr. Kompothecras stated that several states have thimerosal bans but do not enforce them. He stated that if a prohibition were implemented immediately, it would cost approximately \$1 million to remove thimerosal-containing vaccines out of the supply chain. Further, if the group recommended that the prohibition be phased in after a year's time, the fiscal impact would be greatly reduced.

Recommendation: Position Florida to stay abreast of and participate in ongoing research into causes of and treatments for autism spectrum disorders.

Discussion point to be included in the preliminary report regarding this recommendation:

- Public and private partnerships should be developed to ensure that research continues.

Recommendation: Require detailed informed consent with provider consultation prior to the administration of childhood immunizations.

The committee deliberated on the topics of treatment and research and agreed on the following recommendations:

Priority: Across the lifespan, with on-going treatment, support and providers that understand ASD.

Recommendation: Establish a statewide plan for improving access to and increasing the availability of early intervention and treatment options or Floridians with ASD.

Discussion Points:

Acceptable treatment to assist persons with ASD to reach their full potential to maximize the quality of life. Design a state plan to set up more treatment centers to screen, evaluate, diagnose and treat persons with ASD. (Possibly house in College of Medicine, Nursing or large medical centers.) Integration (Registry) specialty providers, fragmented and difficult to find.

Ms. Demko shared that The Window of Opportunity subcommittee is recommending upon suspicion, that a child is referred to an Interdisciplinary team for further evaluation and diagnosis.

Suggestion for the cost committee: more allowable, no restrictions, on the number of providers on a plan with a reasonable reimbursement rate.

Cross Recommendation for the Window of Opportunity: Health care providers to participate in training on best practices.

Cross Recommendation for the Cost Committee: Language from the Insurance Compact Workgroup on what health insurance companies can do better to serve this population.

Governor's Task Force on Autism Spectrum Disorders
Current and Future Outlook Committee
October 14, 2008
Conference Call

The committee broke for a lunch break at 12:00 p.m.

Committee reconvened at 1:02 p.m.

Safety

Support increased efforts to inform families dealing with ASD of important safety concerns and solutions across the lifespan.

Recommendation: All law enforcement agencies in Florida incorporate the Take Me Home Program and have a minimum of one public safety officer with CIT certification trained and make revisions to the curriculum for the CIT course to include a specific module for ASD.

52.10 Recommendation: support the statewide implementation Take Me Home Program

Support the statewide implementation of CIT program

Discussion Points:

Support the statewide implementation of the free training, Take Me Home Program.

Crisis Intervention Training: CIT Training for law enforcement training; available in 34 – 40 counties in Florida. Week long training. Training includes a parent living with a child with a disability and a person living with a disability (at the home level). Not every police officer is suited/or interested in becoming a CIT trained officer.

The Take Me Home Program does not train the officer to diffuse the situation. Take Me Home Program is free and would be a nice compliment to the CIT.

The Governor's Commission on Disabilities is encouraging a statewide roll out of the Take Me Home Program. Commission's Report is due out by the end of the year.

All public safety officers, EMT, school safety officers, law enforcement.

Collaborate with DJJ, DCF and DOC on these initiatives.

Ms. Demko shared information on the Governor's Executive Order: 08-211, Florida's Silver Alert. An alert system to protect senior citizens and to enhance the local or regional efforts, in cases where a vehicle is involved, the Florida Department of Law Enforcement Missing Endangered Persons Information Clearinghouse shall coordinate with the Florida Department of Transportation, and the Florida Department of Highway Safety and Motor Vehicles for the activation of dynamic highway message signs and immediate broadcast of critical information to the general public about the endangered senior citizen in accordance with the Plan.

Recommendation: under assisted technology.

Recommendation: Develop mechanisms to ease home owner association restrictions regarding home modifications to provide adequate protection of individuals with ASD.

Housing Restrictions/Home Owner's Association issues, reasonable accommodation for safety of persons with ASD.

Recommendation: Provide resources to develop extensive "tip sheets" describing major safety concerns and possible solutions, categorized by age and ASD severity level.

CARD, Website, School Systems, Interagency Committee

Review and explore acts of aggression against a of laws and penalties of dealing with the abuse of disabled child.

Review current sanctions and work/collaborate with other agencies.

Safety Restraints and seclusion

- "Time Out" Rooms
- Minimum requirements for seclusion rooms (camera, supervision)
- Consult with behavioral specialist on the process and logistics
- Interagency Council to work with DOE for recommendation implementation

Cross recommendation to the Window of Opportunity subcommittee on the safety and seclusion aspect training module for child care and early education providers to include mention of the safety and seclusion issues.

Zero Tolerance Policy – a child in the school system, 1 strike and you are out. Weapons (pencils used in the wrong way), threat to property or a teacher.

1:15 Recommendation: Special attention given to the ASD group of students.

Advanced Technology:

55.00 Encourage the use of waterproof GPS devices or other Assisted Technology at

Incorporate into the Assisted Technology Recommendation, CMS or Medicaid eligible device for purchase, educate health care providers on these safety devices.

Suggestion for the Cost Committee: Businesses to offer an incentive or tax break for participation or purchase of devices. Section 125 plan – health savings account.

Water proof GPS devices (on the website, possibly the manufacture to help with the website costs). Monthly monitoring fee required.

Discussion Points:

Cross recommendation for Putting the Pieces Together subcommittee to consider:
Assistive Technology (on the website) Blogs, Demos.

Cross recommendation for Window of Opportunity subcommittee: Ongoing interagency committee that reviews evaluates and make recommendations on what new technology advances are available to assist persons with ASD and their families. Identify model programs across the state/country.

CARD, Voc. Rehab, DOE, APD, DOH

Quality of Life

Recommendation: Develop supportive infrastructure for individuals with ASD to obtain necessary treatment and living assistance across the lifespan through adulthood.

Discussion Points:

Personal care provider program. Folks who can function 90% of the time. Assistance with daily life skills to complete their transition into society.

Suggestion for the Window of Opportunity: Home schooling, McKay scholarship program for home school programs.

How many people are we estimating treatment for? Impact on cost planning.

Specific issues for discussion by Sue Homant who will need to leave for another appointment at 2:30 p.m.

- Increased suicide rates among families with ASD children.
- Social responsibility to equip the parents so they are able to learn what they need to know to make good decisions for the family.
- Support of employers, flexibility with schedules to provide care.
- Respite care. Training shortages for respite care providers.

Cross recommendation for Window of Opportunity and the Cost of Autism subcommittees. McKay Scholarships – private school options for students with ASD, what can you use the money for? Therapies or respite care.

Medical Records – In the past minors medical records must be retained until you are of legal age, new legislation allows for the destruction of medical records after 7 years.

Children's Cabinet: Medical record sharing – integrated system of record sharing so they can better manage clients.

Aging care giver issues for the person providing care for ASD persons. Special needs trusts to help care for ASD person if something happens to the primary caregiver.

Partner with the Florida Bar and empower attorney's to provide public service, contribute pro-bono service. Needs with people with disabilities – our social cause for the year
Disability Awareness

Committee took a short break starting at 2:52 p.m.
Return from the break at 2:57 p.m.

In the subcommittee charge, current events is mentioned but we believe this can be rolled into public awareness campaigns being addressed by the Putting the Pieces Together subcommittee.

Recommendations: To be finalized by Ms. Demko at a later time.

- Long term financial planning.
- Making quality of life for ASD but everyone involved in their care.
- Respite Care, focusing of families too poor to buy help.
- Record keeping, retention.
- Free or reduced legal guidance for development of health trust funds.
- Develop special talents or encourage physical fitness, positive emphasis, productive ways to spend leisure time.
- Structured opportunities for inclusion in activities if they are so inclined, productive, fun activities. (Summer camps)
- Partner with local and faith based organizations to offer specialized care for persons with ASD for care givers to have short periods of relief.
- Transitions issues.
- Dental care (sensory issues). Brushing as well as actual dental work such as cleaning or fillings. Increase the number of dentist taking ASD patients.
- Enhance communication skills and daily living skills as part of transition to adult functional status.
- Gainful employment – training, coaching, networks of support. Review the Governor's Commission on Disabilities recommendations on employment issues.

Employment and transportation issues will be further discussed .

Call concluded at 3:39 p.m.

Taken By: Lona Taylor

Governor's Task Force on Autism Spectrum Disorders
Current and Future Outlook Committee
October 14, 2008
Conference Call