

**Governor's Task Force on Autism Spectrum Disorders  
Putting the Pieces Together Committee**

Conference Call

Wednesday, October 15, 2008

10:00 a.m. – 4:30 p.m.

Summary of Minutes

Committee Members

Berkman, Karen (Co-Chair)

Dowd, Debra

Jackson, Jarl

Llorente, Marcelo

Marino, Dan

Purvis, Kelly (Co-Chair)

non-delegate sent on his behalf *Lonnie Laveda*  
absent

Department of Health Staff

Cozart, Thometta

Demko, Tamara

*Call began at 10:06 a.m.*

Ms. Demko informed the committee she will be moderating the call for today.

Ms. Demko went over the agenda for the call including when other Task Force members could join the call and documents sent out via e-mail.

Committee began to sort through documents in their e-mail.

Ms. Demko discussed the format of the preliminary and final report and informed the committee members that the Disabilities Council Report had be selected as a guide for the Task Force preliminary and final reports.

Recommendation format for report

There will be four categories

- 1.) Recommendation as a one sentence punch line
- 2.) Rational or reasoning
- 3.) Discussion
- 4.) Conclusion for the reader

Ms. Demko stated the goal for the call today is to come up with the recommendations for each section of the executive order tasked to the Putting the Pieces Together Committee – the Website, Collaboration and Outreach & Awareness.

Ms. Demko stated if the committee can not come to a consensus the item can be tabled and a place holder would be listed under the recommendation in the preliminary report.

Before getting into the recommendations, Ms. Berkman informed the committee that Center for Autism and Related Disabilities (CARD) Directors would like to create and submit a memo to the Task Force regarding the role of CARD and their current initiatives addressing autism throughout the State of Florida, in efforts to shorten some of the recommendations in the Task Force's preliminary and final reports.

After reviewing the working documents the committee began discussion.

The committee reviewed the recommendations for their committee at the beginning of the conference call and made the following edits to the recommendations:

## **Section A – Statewide Autism Website**

### **Section Recommendation**

Create a Statewide Autism Website to serve as a centralized point of entry into the information, services, supports and other resources that would assist families and individuals with ASD.

Discussion to include: non-duplication of effort; understanding the scope of the issue; focus on individuals and families; but helpful to all

### **Recommendation 1:**

Design the Statewide Autism Website to provide multiple methods of information searching.

#### **Recommendation 1.1:**

Design the Statewide Autism Website to include Site Map

#### **Recommendation 1.2:**

Design the Statewide Autism Website to include Navigation Bar

#### **Recommendation 1.3:**

Design the Statewide Autism Website to include a User Tree Function

### **Recommendation 2:**

Design the Statewide Autism Website to meet compliance standards for persons with disabilities.

Discussion to include: ADA, Bobby compliant

### **Recommendation 3:**

Design the Statewide Autism Website to address considerations of informational integrity.

Discussion to include: external links, disclaimers, informational checks, monitoring

**Recommendation 4:**

Design the Statewide Autism Website in a user-friendly format that maximizes the ability of Floridians to easily locate and use information.

Discussion to include: plain language, FAQs,

**Recommendation 5:**

Design the Statewide Autism Website to provide (external) linkages to statewide resources.

**5.1 Family/Parent Information Sharing**

**5.2 Types of Entities**

Discussion to include: List of existing websites on page. Opportunity to promote parent-to-parent contact/information

**Recommendation 6**

Design the Statewide Autism Website to provide Florida-specific information.

Discussion to include: Developed content; flowchart; state agency org chart; Task Force information; ongoing Interagency Council;

**Recommendation 7 - advertising for the website - hold**

Promote the Statewide Autism Website to Floridians.

Discussion to include:

**Recommendation 8**

Design the Statewide Autism Website to include a searchable online database of Florida resources for ASD.

Discussion to include: collaborate to pull baseline database information from the Clearinghouse on Disabilities, United Way/211

**Recommendation 9 – HOLD- TABLED – Place holder**

Provide a Statewide Autism Information Call Line.

Discussion to include: collaborate to pull baseline database information from the Clearinghouse on Disabilities, United Way/211

1-800-9-AUTISM (Statewide CARD number)

**Recommendation 10**

Explore collaborative efforts across private, public, and governmental organizations to partner in the creation and maintenance of the Statewide Autism Website.

Discussion to include: Promote, work with us, update info, provide info, part of it, and believe in mission

**Recommendation 11**

Design the Statewide Autism Website to include a mechanism for Florida's families and individuals with ASD to provide feedback on services and supports.

Discussion to include: feedback on website; feedback channeled back to relevant agency

**COLLABORATION**

Intro – being with second sentence of 1<sup>st</sup> paragraph on page 1

**Recommendation 1**

Extend the Task Force on Autism Spectrum Disorders...

Discussion to include:

**Recommendation 2 – HOLD- TABLED – Place holder**

Create a state-level ASD advisory council to enhance partnerships among state agencies and private organizations

Discussion to include: Reports to/shares information with the Task Force if extended; purpose and rationale--to address barriers to collaboration and collaborative planning and; State-level group would work with regional collaborative and review surveys (annual – survey like on p. 3-4)

**Recommendation 3**

Develop regional-level ASD collaboratives through CARD as central points for information sharing, gap reduction, collaborative planning and service delivery.

Discussion to include:

Through each CARD center – describe; survey regional collaboratives for barriers and efforts

- The regional collaborative should be given a uniform charge to include, but not be limited to, the following:
  - Identify the ASD related services and resource in the region;
  - Identify the gaps and duplications in services;
  - Inform the state level autism committee of barriers to effective collaboration that are due to state laws, policies and practices;
  - Partner on how to reduce the gaps and duplication of services through collaborative planning and delivery of services.

Purpose and rationale--to address barriers to collaboration and collaborative planning; regional collaborations to feed into state-level discussion

**Recommendation 4 – HOLD- TABLED – Place holder**

Conduct an annual survey of state agencies AND regional collaboratives to gauge activities and accomplishments that impact Florida’s individuals and families with ASD.

Discussion to include: free survey

**COMMUNITY AWARENESS AND OUTREACH**

**Section Recommendation**

Create a Statewide ASD awareness and outreach plan for individuals with ASD, and their families. (secondary would be the general public)

Discussion to include: Should include people with marketing experience and ability

**Recommendation 1**

Content

**Recommendation 1.1**

Signs and symptoms

**Recommendation 1.2**

Early identification for better outcomes

**Recommendation 1.3**

Accessing the Statewide Autism Website

**Recommendation 1.4**

Information for families to Get Started

Discussion to include: Getting Started Pamphlet (cross Window of Opportunity Committee – questions for provider)

**Recommendation 1.5**

Safety Information across the Lifespan/Gender

Discussion: Pamphlet (cross Current and Future Outlook Committee)

**Recommendation 1.6**

Enhance general knowledge of ASD in Florida (church, business, dining, medical home)

**Recommendation 1.7**

ASD --- good for business/community – how families are treated

**Recommendation 1.8**

ASD --- awareness targeting health care providers especially with signs and screening (e.g., talking to parents who raise concerns)

### **Recommendation 1.9**

ASD --- individual/family empowerment (self-advocacy, etc.)

*Karen - Regulatory piece, mandate, accountability*

### **Recommendation 2**

Develop plans for annual awareness events for Autism Awareness Month and World Autism Awareness Day in April.

Discussion: through state-level council and regional collaboratives; through school; CHDs, CMS, APD regional offices; DOE school boards; county commissions; post plans to website ---- success inspirational stories

### **Recommendation 3 – The How**

Media: Public service announcements

Delivery mechanism – opportunity to deliver autism awareness through multiple media formats

Rationale to include: need across multiple spectrums: language, gender, culture, ethnicity, SES, rural, suburban, urban; underserved populations

Connecting to existing community activities

Working campaigns through regional collaboratives

Umbrella campaign---single, uniform message, new theme annually (awareness month)

Develop marketing strategy to address the most effective ways to reach target population

Cross back to Window of Opportunity committee – trainings/tutorials for medical professionals and others (maybe external link for training opportunities for anyone ---autism library on Autism Speaks)

Dissemination plan: faith-based, libraries, etc.

Need to have incentives (outcome, benefit to organization) to achieve buy-in; what do the players want? Sometimes just taking the lead.

Don't overwhelm. Suffering from lack of resources/funding-----collaboration for Florida funding and grant dollars;

Issues of ownership: state agencies; organizations; considered a mental health/medical/neurological/behavioral/educational issue? Where to house?

You can make a difference.

What do people need help with?

Project Lifesafer to the Tampa area (Cross to current and future outlook cmte re: Take Me Home)

Older undiagnosed adults just finding out – information

Common system for defining what autism spectrum is (across the State of Florida)---linked to benefits --- goal to achieve more equity

Employment rate for ASD

Long-term view of autism in older Floridians --- past young adulthood ---what happens as people with ASD age (housing, care, needs---perhaps research/study)

From recommendations to action --- Task Force work meaningful to create systems change

More efforts to include adults in the process of determining what is needed and how to provide it

Service coordinators in the state train in planning process (system) and implement it with integrity----include person/family in the process of their planning and care [PERSONALIZED INTERACTION] broadening of experience so people don't lose dreams on the way

Management components of people on waiting lists ----reaching out, connecting to helpful resources while waiting, personal communication

Ms. Dowd joined the call at 2:04 p.m. and had to leave at 2:57 p.m.

Ms. Purvis had to leave the conference call at 4:08 p.m.

*Call concluded at 4:36 p.m.*

Taken By: Thometta Cozart