

**Governor's Task Force on Autism Spectrum Disorders
Window of Opportunity Committee**

Conference Call
October 24, 2008
10:00 a.m. – 5:00 p.m.
Summary of Minutes

Committee Members

Ausley, Lorraine	absent
Brosco, Jeff (Co-Chair)	
Houghland, Patty	
Lockman, Bambi (Co-Chair)	
Precourt, Lisa	
Ros, Ana Viamonte	non-delegate sent on her behalf (Dr. Joe Chiaro)

Department of Health Staff

Casey, Megan
Howard, Catherine

Call began at 10:03 a.m.

Ms. Howard went over the agenda for the call including breaks and documents sent out via e-mail.

Ms. Howard discussed the format of the preliminary and final report.

The format of the recommendations for report will include four categories:

- 1.) Recommendation
- 2.) Rational
- 3.) Discussion
- 4.) Conclusion

Ms. Howard stated the goal for the call was to draft only the recommendations. The other categories of the recommendations could be drafted at a later date.

Ms. Howard stated if the committee was unable to come to a consensus on a recommendation, that a place holder can be made for it in the preliminary report and it could be addressed at a later date.

After reviewing the working documents the committee began discussion.

Based on the deliberations throughout the day, Ms. Howard drafted recommendations and shared them with the group. The group approved the draft recommendations and as follows:

Draft Preliminary Recommendations

Topic 1: Screening

Recommendation 1

Encourage screening for autism as part of routine pediatric health care visits.

Recommendation 1:1

Ensure that the “Learn the Signs, Act Early” campaign reaches all families (e.g., continuing education credits for health care provider license can encourage understanding Autism Spectrum Disorders (ASDs) and related disabilities).

Recommendation 1:1:A

Educate families on the option to self-refer to Early Steps

Recommendation 1:2

Medical educators and professional societies should ensure that primary care health providers are trained to follow the American Academy of Pediatrics guidelines on screening and to be aware of the scientific literature demonstrates that the parental concern is an accurate predictor of autism spectrum disorders.

Recommendation 1:3

Adequate reimbursement by Agency for Health Care Administration (AHCA) and third party payers for the use of formal screening tools for general developmental delay and for autism spectrum disorders

Recommendation 1:4

If there is primary care provider or parental concern regarding Autism Spectrum Disorders (ASD) (or general developmental delay), the PCP should refer to the Local Early Steps program (LES) if < 3 years old, or to the local public school program (Child Find) if > 3 years old.

Recommendation 1:5

The primary care provider should also consider referral for underlying medical diagnosis to child neurologist, clinical geneticist, or developmental pediatrician, etc.

Recommendation 1:6

Encourage Agency for Health Care Administration (AHCA) (and other health insurers) to include ASD screening at 18- and 24-month visits as part of their quality assurance plans.

Recommendation 2

Encourage screening for autism and other developmental disabilities by early care and educational professionals.

Recommendation 2.1

Encourage leaders of Early Learning Coalitions and Voluntary Pre-Kindergarten to include autism screening as part their recommendations for and training for early childcare centers.

Recommendation 2.2

Early child care centers who suspect and ASD in a child should refer them to the Local Early Steps program (LES) if < 3 years old, or to the local public school program (Child Find) if > 3 years old.

Committee dismissed for lunch at 12:00 p.m. and reconvened at 1:00 p.m.

Topic 2: Diagnosis

Recommendation 3

Families should have timely access to diagnosis and/or assessment of a child with a suspected ASD.

Recommendation 3:1

Families should expect access to an interdisciplinary team of experts (“Autism Evaluation Team”) or a single clinician with input from multiple clinicians. (Center for Autism and Related Disorders and Children’s Medical Services should explore ways to implement this state-wide).

Recommendation 3:1:A

Fund a statewide partnership between Center for Autism and Related Disorders (CARD) centers and Early Steps to establish criteria for “Autism Evaluation Teams” that would be certified and partially funded by Children’s Medical Services (just as Craniofacial teams are currently accredited and funded)

Recommendation 3:2

Early Steps and Child Find should provide access to timely assessment of children with a suspected ASD.

Recommendation 3:3

Families should have access to an underlying medical diagnosis through a child neurologist, clinical geneticist, developmental pediatrician, etc.

Topic 3: Early Intervention (Treatment)

Recommendation 4

Ensure early, intensive intervention for children with ASDs

Recommendations 4:1

Encourage disability and autism advocates to train parents to become educated consumers.

Recommendation 4.2

For child less than age of three, Early Steps personnel will educate about and train parents to provide intervention with proper intensity (25+ hours per week), duration (2-3 years), and consistency (12 months per year). The difference

between evidence and non-evidence based interventions should also be addressed.

Recommendation 4:2:A

For children who continue into public schools after age three, public school personnel shall assist with the coordination of education plans between the school and the home.

Recommendation 4:2:B

For families who do not access Early Steps, Child Find, or the public school system, the statewide entities listed in Recommendation 4.1 will serve as technical assistance for the coordination of educational and treatment plans.

Recommendation 4:3

Ensure through “Window of Opportunity Act” that an adequate list of trained providers for diagnosis and treatment is maintained and adequately reimbursed to ensure timely services.

Recommendation 4:4

Increase the number of model programs (e.g. LEAP program University of Iowa, or TEACH).

Recommendation 4:5

Improve the dissemination of progress reports of model programs.

Autism Website (Refer back to the Putting the Piece Together Committee).

Topic 4: Payment & Reimbursement

Recommendation 5

Ensure proper payment for treatment of children with ASDs.

Recommendation 5.1

Ensure through “Window of Opportunity Act” negotiations that there exists adequate reimbursement for screening, diagnosis, and a variety of treatments.

Recommendation 5:1:A

Ensure proper payment to developmental psychologist for the diagnosis of an ASD.

Recommendation 5:1:B

Ensure proper payment for Current Procedural Terminology (CPT codes) for “Team Interdisciplinary Conference” and “Family Meeting”

Recommendation 5:2 TABLED

Explore ways to increase flexibility of the use of the base student allocation to enhance parental choice.

Recommendation 5:3 TABLED – needs more research

Part-C (Early Steps) – Currently Part-C/Early Steps provide for services/therapies in the home or school setting. The theory is that this optimizes generalization skills. While this may be true, the number of providers willing to accept the Part-C rates for on location therapy/services is limited. With the increase demand, these limitations result in difficulty in obtaining timely services. Part-C should be allowed to be more flexible to working in a clinical environment if necessary or as a part of a formal treatment plan, allowing parents to choose alternative providers and paying the difference

Recommendation 5:4

Autism advocates should recognize that alliances with other Developmental Disability groups are powerful mechanisms to improve chances for increases in funding.

Recommendation 6

Prevalence studies in Florida should be conducted in collaboration with current university partnerships.

Discussion to include:

- CDC ADDM (Centers for Disease Control and Prevention – Autism and Developmental Disabilities Monitoring Network) Florida study in Miami to better gauge prevalence of autism specifically for Florida
- Children’s Health Study
 - NIH funded, 25 year study of environmental (and genetic) causes of illness in children; hope to enroll 100,000 children and follow them for 20 years; will answer many questions about the role of environmental toxins in conditions such as autism
 - Four Florida sites (Miami-Dade, Orange, Baker, Hillsborough) will join in this current funding cycle

Recommendation 6:1

Encourage families to participate in autism spectrum disorder studies.

Recommendation 7 TABLED

Long-term Strategy: Need to continue the Task Force work over multiple years.

Recommendation 8 TABLED

Encourage Early Steps personnel to develop a process for timely delivery of evaluation results to minimize duplication of services and costs to families.

To include in Cost Committee Recommendation # 9

Review and consider newly developed (October 2008) recommendations by the Autism Spectrum Disorders Guidance Workgroup to the Early Steps State Office (ESSO) for service guidelines for children with ASD (e.g., guidance to assist Individualized Family Support Plan (IFSP) teams)

To include in Current and Future Outlook Committee Section on Quality of Life:

The Window of Opportunity Committee would like to ensure that issues pertaining to the transition of individuals from the school system to “adulthood” are addressed by the Current and Future Outlook Committee.

Ms. Howard stated she will send out the discussed recommendations to committee members for edits after the conference call.

Call concluded at 3:52 p.m.

Taken By: Megan Casey

DRAFT