

Governor's Task Force on Autism Spectrum Disorders
Full Task Force
In-Person Meeting
Florida State University Foundation
Tallahassee, Florida
April 1, 2009
1:00 p.m.
Summary of Meeting

Committee Members

Ausley, Loranne	absent
Bailet, Laura	absent
Benson, Holly	non-voting delegate on her behalf (Leigh Meadows)
Berkman, Karen	
Block, Lance	absent
Brosco, Jeffrey	absent
DeBeaugrine, Jim	
Dowds, Debra	
Emken, Elizabeth	via conference call
Hill, Kimberly	absent
Homant, Susanne	
Houghland, Patty	absent
Jackson, Jarl	
Kanjian, Robert	absent
Kompothecras, Gary	absent
La Belle, Richard	
Llorente, Marcelo	absent
Lockman, Bambi	
Marino, Dan	absent
Perkins, Randal	absent
Precourt, Lisa	
Purvis, Kelly	absent
Ring, Jeremy	absent
Ros, Ana Viamonte	absent
Sequenzia, Ven	absent

Department of Health Staff

Casey, Megan
Howard, Catherine

Agency for Persons with Disabilities Staff

Copley, Kimberly
Demko, Tamara

Meeting was called to order at 1:30 p.m.

Ms. Demko announced that eight Task Force members were present and that Senator Ring is presenting a bill in committee, and several other members are likely downtown to testify on behalf of the bill.

Mr. DeBeaugrine noted the Patty Houghland would not be in attendance as a result of the inclement weather.

Mr. DeBeaugrine read public comment from Jennifer Morgan-Byrd. [The letter, in its entirety, is included below.]

“Dear Honored Members of the Autism Taskforce,

Thank you very much for your time and dedication over the past year. As a parent of three children with autism spectrum disorders [ASD], your attention and contributions to the various issues to improve conditions for individuals with ASD ders in the State of Florida gives me hope that we are moving in a positive direction. I wanted to share with you some of my concerns, as well as miracles, that I have witnessed as a parent and an advocate.

1. Education.

a. **McKay Scholarship needs to remain the option of last resort** – Over the past year, I have heard a lot of discussion about how to improve access education and services for children with autism. I do feel that the McKay Scholarship plays an important role in that parents who feel the local school system is not providing their child with free and appropriate education have an option to find a place that best accommodates their child. However, I am a little concerned on how much emphasis is placed on the McKay scholarship by the legislators and others in the autism community as being an option that parents should use first instead of working with the school system.

The reality is that the State Board of Education, Department of Education [DOE], Local School Boards, Individual Schools, Principals and Educators all need to figure out a solution to improve the access to free and appropriate education in the least restrictive environment for students affected by ASD, regardless of if ASD is listed as a disorder in their IEP. Parents should not have use to the McKay Scholarship without having a full understanding of their child’s rights and valid attempts with the school system to provide the needed services. The following are some suggestions for accomplishing this objective:

Educating Parents - There needs to be a better effort by the DOE and the public schools to encourage parental participation. DOE could require schools to pass information to parents about monthly educational seminars offered by FDLRS or some other community organization. It is in the best interest for the state that they educate and empower the parents to become more actively involved in a student’s educational plan. An example is having seminars about the IEP process, explaining what each section of an IEP means, transition, inclusion/ mainstreaming, etc.

Educating ANYONE who has contact with a student with ASD, as well as all who are in a managerial role over educators – DOE should consider REQUIRING each school district to provide educational seminars at the beginning of the school year for anyone who will have contact with a student with ASD. This includes educators, principals, assistant principals, school board members, resource counselors, nurses, office staff, teacher aides, bus driver, therapists, librarian, cafeteria employees, etc. This local school districts could enlist CARD to provide the trainings. This would allow schools to establish and develop a relationship with CARD, as well as learn what services CARD can provide to the schools and their students with ASD. It would also indirectly provide sensitivity training to help eliminate some of the stigma about ASD. With more and more students with ASD being mainstreamed or included in regular education classrooms, it is necessary to provide the educators with support and information about ASD so they can provide the free and appropriate education to their students.

b. Using the Correct Classification on the IEP – DOE is unable to provide the exact number of students with ASD in Florida. One reason, as you are already aware, is that it was difficult for many students with ASD prior to July 2007 to meet the criteria set by the State Board of Education. A second reason is that either the parent and/or the IEP team decide not to select the autism classification on the IEP. There could be many reasons, but one could be not wanting the child to be labeled or be viewed differently by their classmates. This is a stigma that needs to be changed through educating the schools and students. The IEP needs to accurately reflect the student's needs in order for the school to implement an effective educational plan. It also reduces any confusion if the student needs to transfer to another school with in the state. I also wonder if DOE is missing out on any federal money because they are not accurately reflecting the number of students with ASD in Florida.

c. Least Restrictive Environment/ Inclusion/ Mainstreaming – There is a school that has a few students with Asperger's Syndrome in self contained classrooms. Their reasoning is that they can provide more effective educational and therapeutic interventions for these students by placing them in a self-contained classrooms. The parents saw no problems with this because they trust and rely on the school to provide the best educational plan for their child. These are high functioning students who NEED to be either included or mainstreamed into a regular education classroom. The problem is NOT the student, but the school and its educators not having the knowledge, tools and supports in order to implement an effective plan to provide the least restrictive environment for a student with ASD. There are organizations such as Florida Inclusion Network and CARD who can provide this information and support to schools. The schools have to be aware of these resources and must have the desire to contact the organizations for assistance.

Sensitivity Training for Classmates – This is option that educators should recommend to parents. CARD can assist the educators and parents in creating a training plan for the class. With my eldest child with autism, Helon, the first grade teacher and I discussed her talking to Helon's classmates about how Helon has autism and how she is very special and may need help. It has been a very positive experience. The classmates act as Helon's older brothers and sisters making sure she is not left behind. The best part is

that they learn different techniques to communicate with Helon and are not confused about how to react to some of Helon's odd behaviors.

Buddy System – Students with ASD need to interact with typical students in order to develop their social and communication skills. Having the teachers assign buddies to help them throughout the day can accomplish this.

d. Continued Education Credits for Educators.

2. **Continuing Education Credits for Physicians, Physician Assistants [PA] and Nurses** – Florida should consider offering CEC to physicians, PAs and nurses about various issues relating to ASD. Florida should also consider requiring all pediatricians and nurses who work in pediatrics to take a certain number of hours of CEC about ASD every year or so in order to maintain their medical license to practice in Florida.

3. **Biomedical and Dietary Interventions as a treatment for the underlying health issues that commonly occur in ASD** – Florida should consider requiring the different agencies that treat or provide services to individuals with ASD to look at treating some of the health issues that may worsen the autism symptoms. Treating these health issues and educating the clients and their families about lifestyle changes will hopefully improve some of the chronic health issues they suffer from, thereby reducing the amount of medical health services paid for by the State of Florida.

I have been treating my two older children with autism with biomedical and dietary interventions for the past 3-4 years, and have recently started it on my third child when he regressed. The overall health of my children has improved significantly which allows for them to be much more receptive to their educational and therapeutic interventions. I simply ask for the state to seriously look into all or some aspects of this intervention for their clients.

Thank you.

Sincerely,

Jennifer Morgan-Byrd"

Ms. Lockman asked if a copy of this letter could be forwarded to the Task Force via email for response.

Mr. La Belle commented that he shared many of the sentiments expressed, and is distressed by the feeling on the part of many parents that they must pursue a McKay Scholarship as a resource. He reiterated that he is willing to work with the Department of Education and local school districts to reach out and assist with available resources.

Mr. DeBeaugrine turned the meeting over to Ms. Demko for next steps. He noted that the announcement regarding Task Force extension will be made tomorrow.

Ms. Demko announced the events for World Autism Awareness Day on April 2, 2009. The details of each event were provided on the meeting agenda.

Mr. La Belle noted that the Family Network on Disabilities event at Chez Pierre would last from 7:00 p.m. until 9:00 p.m., and noted that the event was actually a reception for legislators and members of the Task Force, rather than a benefit as the meeting agenda stated.

Ms. Demko reviewed the structure and content final report and appendices.

Ms. Demko directed the group to reference a document provided in the meeting materials titled "Points of Discussion for a Continued Task Force."

The group began discussion on future committee structure if the Task Force was to be extended.

She Ms. Homant stated that committee-wise, the current structure was working for broad, higher level information. She stated that specific areas per the report recommendations should be taken into consideration, for example, Assistive Technology (AT).

Mr. La Belle reiterated a need for an AT committee. He also said that dealing with education across the lifespan is an important topic. He noted that structurally he would appreciate a greater opportunity for discussion at general meetings.

Ms. Precourt stated that she agreed with Mr. La Belle. She emphasized the need for a focus on education, transition issues, and adult services.

Ms. Dowds noted that the strategic roadmap may provide a way to categorize the new committees and develop subsequent recommendations.

Mr. Jackson noted that adult support services after transition is of high importance and warrants further consideration.

Ms. Lockman noted a need for having the first committee meeting face to face. She stated that it is difficult to create united recommendations without adequate discussion.

Mr. DeBeaugrine agreed with Ms. Lockman. He highlighted the need to focus into specific issues.

Dr. Berkman acknowledged the difficulty in working with committees as they were currently structured and overlap of effort.

Dr. Homant noted the need to add training as a priority to the State Roadmap included in the final report. She stated that if continued, the TF needs to have only one committee that deals with training/professional development.

Mr. DeBeaugrine stated that a continued Task Force may not require the same number of committees.

Ms. Precourt commented that limiting the scope of priorities and the number of committees may facilitate future Task Force work.

Dr. Berkman brought up the topic of best practice evaluations for physicians and diagnosticians.

Ms. Demko stated that Dr. Viamonte-Ros was trying to develop physician-specific training for the State. She noted that there is training available with the Department of Children and Families for other entities such as early childcare workers, and that adding a course would cost \$10 per course.

Ms. Demko asked the group how they would like to vet and choose expert speakers for future Task Force meetings.

Dr. Berkman suggested that speaker suggestions originate in the committee meetings.

Ms. Precourt added that committees could develop a list of questions and forward them in advance to potential speakers in efforts to save time during full Task Force deliberations.

Ms. Dowds stated that there is a need to educate individuals serving on other committees about what each committee is learning during presentations and deliberations.

Mr. DeBeaugrine agreed and stated that it would be a good idea to have each committee chair brief the full Task Force regarding what the committee is currently working on.

Ms. Precourt suggested that digital recordings of committee meetings be disseminated to the entire Task Force.

Ms. Howard responded that all meetings are currently recorded, but that digital recordings are too large to forward via email. CD burning is an option but it is costly. She noted that staff may be able to create a website to post digital recordings of future meetings.

Dr. Homant asked about the fiscal impact of the recommendations in the final report. She asked if there will be a budget for the implementation of these recommendations and/or a budget for the continued Task Force.

Ms. Demko stated that the budget for the administrative overhead resides with the Department of Health. The Task Force recommendations may have some ideas that can be done outside of legislation that are no or low cost solutions. These options should be

explored first. Otherwise, it is likely that collaborative efforts across agencies and other organizations will be necessary for implementation.

Mr. DeBeaugrine offered a high level overview of the State budget process as it may be helpful to the members of the Task Force. There was discussion among members about concerns and options.

Ms. Demko asked the group how they would they like to select committee chairs. There was discussion regarding how to develop this process. Consensus was reached to select individuals based on interest and relative expertise.

Ms. Demko asked the group to think about the timing and duration for future meetings. She warned that many meetings may have to be carried out via conference calls due to a restricted budget.

She also asked the group if they had any preferences for the locations of in-person meetings. Central locations (i.e., Orlando and Tampa) were suggested. Tallahassee was also felt to be reasonable since many of the current members reside in or near the city. The group agreed to wait to decide how many in-person meetings should be held. They also requested that virtual technologies be investigated for future meetings.

The group briefly discussed continuing work for the Task Force. Specifically, the recommendations they made for a continued Task Force. They agreed to hold off on prioritizing these tasks until a charter for a continued Task Force is released.

Having no other business, the meeting was adjourned.

Meeting was concluded at 3:40 p.m.

Taken By: Kimberly Copley