

**MINUTES
of the
Autism Council**

DATE: September 26, 2005

LOCATION: Madison, Wisconsin

MEMBERS PRESENT: Nissan Bar-Lev, Heather Boyd, Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Debra Mandarino, Milana Millan, Paula Petit, Paul Reuteman, Glen Sallows, Pam Stoika, Michael Williams

STAFF PRESENT: Sandy Blakeney, Beth Wroblewski

GUESTS: Elaine Gundlach, Marge Pifer, Donna Wong

The meeting came to order at 10:00 AM.

The Council reviewed the draft of the August 17, 2005 Meeting Minutes and corrected two misspellings. Members indicated that they were satisfied with the format and style of the Minutes.

Motion: (From Nissan Bar-Lev): To approve the Minutes with the specified corrections.

Second: Rose Helms

Vote: All were in favor.

Department of Public Instruction Donna Wong reported on the results of a discussion with the Department of Public Instruction (DPI) regarding the recommendation from the Governor's Task Force on Autism. This recommendation stated:

“Create a committee to examine the role of schools in providing services to children with autism. Include representation from DHFS, DPI, parents, providers and other stakeholders.”

Donna reported that DPI responded to the Governor's office that there are already advisory structures in place, including the State Superintendent's Council on Special Education, to address the educational needs of children with Autism Spectrum Disorders (ASD). This is a federally required group and creating a separate group would in fact be inconsistent with federal requirements. DPI also indicated that it is important that there be a clear division between Medicaid and the school's responsibility.

DPI is very interested in being responsive to the needs of children with ASD and in fact now has a full-time staff consultant who works with schools related to educational

services for children with ASD. This staff person is Pam Foegen, phone (608) 266-3928. Pam's role is to assist public instruction professionals with autism-related issues. She helps school districts with identification of needs, services, and development of Individual Education Plans (IEP's). She has also worked with a group to update the curriculum and training modules for children with ASD and is implementing a statewide training schedule

There was discussion among the Council about how to better interface with DPI. The Council would like to invite Pam Foegen to a regular meeting of the Council to share more details about her role and to respond to their questions and concerns. The Council agreed that it would be best to provide Pam with time to speak about her role and DPI activities, as well as to respond to several questions from the Council members. It was agreed that Deb Mandarin would collect input from all Council members and then compile the list of proposed questions. There was also clarification from Council members that this Council does not have an advisory role to DPI.

It was decided to invite Pam to attend the next meeting of the Council, if she is available, during which (1) Pam would be asked to give a short presentation on her role and any current projects related to autism, school districts, and DPI and (2) the Council would let Pam know that they have questions/concerns and would offer assistance to her if she would welcome that.

By-Laws Subcommittee Members of the By-Laws Subcommittee reported back from their September 7, 2005 meeting. The subcommittee met by telephone with Kristina Stuart and Kris Freundlich of DHFS to discuss the structure and decision-making process of this Council. Members reviewed the minutes from the subcommittee meeting. The Council had determined last time that they do want to have a facilitator for each meeting, and that facilitator will be Kris Freundlich of the DHFS Office of Strategic Finance.

The first two issues, "Agenda Setting" and "Defining a Quorum," were generally accepted by the Council as described by the subcommittee report. The issues of "Participation" and "Voting" were clarified in a couple aspects; e.g., Council members may participate and vote by teleconference participation, however, there will be no **proxy votes** and no votes by **e-mail**, and that the Facilitator of the meeting will call the vote. Special Meetings of the full Council may be called by the "Support Committee" and would need to meet all the requirements of the Public Meetings Law and proper notice to Council Members.

After a thorough discussion on the issue of process for having Public Comment, the Council made the following decisions:

- A 30-minute period of time will be set aside at the beginning of each Council Meeting for Public Comment. If there is no Public Comment, the meeting may commence.
- Individuals wishing to speak would be asked to register at least 15 minutes prior to the meeting and speakers would be called in the order in which they registered. Speakers would be asked to register as either an Individual or a Group.
- Each speaker would have up to 3 minutes for their comments, regardless of whether they are speaking as an Individual or representing a Group.

- Individuals wishing to comment who cannot attend the meeting in person may send written comments by e-mail or by US mail to Sandy Blakeney. Written comments received at least 3 business days prior to the Council Meeting will be forwarded to all Council Members by e-mail. Written comments received less than 3 business days prior to the meeting will be distributed at the meeting. Written comments will be included as part of the record.
- The Council puts a high priority on keeping this process simple, accessible, and flexible, so the registration process is meant to help streamline the Public Comment period, but if a potential speaker arrives at a different time, the Council will do their best to allow them 3-minutes for comment.
- There was clarification that this pertains to *Public Comments*, which is different from a Public Hearing. If the Council were to hold a Public Hearing, this would be structured very differently from a regular Council Meeting.

Additional discussion on the structure of the Council included the following points:

- Guest Speakers are not the same as individuals providing public comment. Guests will be “experts” attending at the request or invitation of the Council. The Council still needs to consider how they want this to work.
- Meeting Minutes are not made public until the Council has approved the final version; therefore, minutes are not published until after the **next meeting**.
- Information about upcoming meetings will be published on the Web and in the Wisconsin State Journal.
- The “Support Committee” will set the Council Meeting agenda following the steps outlined in the proposed by-laws. Council members must submit agenda suggestions to the Committee at least 3 weeks prior to the meeting. The agenda will be finalized and published to the Web 2 weeks prior to the meeting.

A draft of Council By-Laws based on this discussion will be provided to the Council for the review at the next meeting. The Council will wait until their next meeting to elect members of the “Support Committee.”

Exceptions Policies Beth Wroblewski reviewed the Exceptions Policies for the Council for the purpose of familiarizing the Council with the interim policies that were established following the Governor’s letter to Secretary Nelson following up on the final report of the Governor’s Task Force on Autism. The Council will have an important role in reviewing these policies and making recommendations to DHFS for final, budget-neutral policies on the following issues: the requirement for a minimum of 20 hours face-to-face for intensive in-home autism services; the 3-year timeline for intensive services; and the relationship between waiver services and the schools. While it was clear from enthusiastic discussion that the Council is anxious to begin addressing these issues, the intention for this half-hour overview was to present the issues as preparation for future in-depth discussions.

ASD Diagnosis Elaine Gundlach and Marge Pifer of the Bureau of Health Care Financing returned to continue the discussion of the document, *General Approach for Establishing a Specific Diagnosis of Autism Spectrum Disorder*. Beth clarified that since **diagnosis** and **Level of Care** comprise the “gateway” to the Children’s Long-Term Support waivers, there is concern that children without the necessary diagnosis will inappropriately gain access to the waivers. If this happens, it could cause a situation where children with true ASD diagnoses are excluded from services. In addition, the existence of questionable diagnoses would undermine the Department’s ability to administer the waivers, and the Legislature set expectations that this type of process would be in place.

The reality is that no one actually knows if there is a problem with diagnoses. Therefore, a random review would allow us to document what is happening and determine whether or not accurate diagnoses are an issue.

Motion: (From Nissan Bar-Lev): That the DHFS send a letter to potential providers indicating a change in scope related to independent evaluation and assessment and explaining that the Department is interested in a review of a random sample of approximately 10% of the children receiving intensive in-home autism treatment services. The letter would also explain that no child-specific repercussions of inaccurate diagnoses will occur as part of this sampling process. Rather, the process will identify potential issues related to diagnosis.

Second: Milana Millan

Vote: All were in favor.

Level of Care/Children’s Functional Screen Beth demonstrated the new web-based Children’s Long-Term Support Functional Screen, which is a tool that determines *functional eligibility (level of care needs)* as required by various children’s programs. The Functional Screen uses the same level-of-care criteria as those required by the Katie Beckett Medicaid Eligibility Program. A copy of the two most relevant levels of care: Developmental Disabilities and Severe Emotional Disturbance, were distributed to the Council. The Web-based Functional Screen provides more statewide consistency and reduces a child and family’s waiting time for results.

Next Meeting The next Council meeting is scheduled for November 1, 2005 in room 950 of the 1 W. Wilson St. Office Building.

Minutes Respectfully Submitted by
Sandy Blakeney
November 1, 2005