

**MINUTES
of the
Autism Council**

DATE: November 1, 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

ABSENT: Michael Williams

FACILITATOR: Kris Freundlich

STAFF PRESENT: Sandy Blakeney, Beth Wroblewski

GUESTS: Pam Foegen, DPI

The meeting came to order at 10:00 AM.

Kris Freundlich welcomed the Council and took some time to introduce herself and briefly discuss her role as Facilitator. Three visitors were welcomed. No public comment was received.

The Council reviewed the draft of the September 26, 2005 Meeting Minutes.

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

Motion was Seconded

Vote: All were in favor.

EXCEPTIONS POLICIES

Beth Wroblewski reviewed the background of the Interim Policy, **Extensions beyond 3 Years of Service for Intensive In-Home Autism Treatment Services**. This document was created as an “interim” policy in March, 2005, in response to Governor Doyle’s directive that DHFS respond to concerns raised by the former Autism Task Force; the hope was that the Autism Council would be able to look at this interim policy and provide guidance to the Department regarding finalizing the policy. Issues with the policy include:

1. Children needing to transition to ongoing services just when they are making good progress with intensive treatment, and
2. Developing criteria for extensions that would be fair, consistent, clearly defined (for monitoring purposes), and budget neutral.

Rose Helms raised the question as to hours of treatment received and cost. For example, if a child was authorized to receive 35 hours per week, but received well under that amount, would there be a savings during the first three years that could offset the cost of an extension? Beth Wroblewski addressed this question explaining that the original budget for intensive in-home autism treatment services was based upon the average hours received by children under the Medicaid fee-for-service system, which was 27.5 hours per week. Waivers are developed using a capitated budget - a specific dollar amount based upon the fee-for-service average. At this time, children receiving services through the waiver are receiving closer to 30 hours per week on average, which is above the expected amount. DHFS' ability to manage within the capitated budget comes from those who do not use all of the authorized hours.

Although families tend to see the authorized hours as an individual "bank account" of hours, the overall budget is not based upon each individual family. In effect, it is not an individual "bank account," it is a **group** account. If DHFS instead considered it as individual family accounts, the exceptions policy would not be cost neutral.

Beth explained that an additional issue is the concern of providers and others that they do not want families to be encouraged to use sub-clinical hours for their child simply to get a fourth year of service.

Nissan Bar-Lev pointed out that an extension would never be cost neutral because there will be additional administrative costs (support and service coordination, evaluations and testing, etc.) during that extension.

Glen Sallows raised a question regarding children being discontinued from intensive services because the child no longer meets Level of Care requirements. The example was given when a child's IQ has increased substantially after a year of service, the child is found not functionally eligible for the waiver and is discontinued prior to completing the 3 years of intensive services, and then the child regresses. Beth responded by reviewing Level of Care and federal requirements for waiver eligibility, and clarified that in this example a child is not being denied 3 years of service, or an extension of services; instead, the child is being evaluated based on eligibility criteria and found to be not eligible. This eligibility review is an annual requirement which must be completed for all children participating in the waivers or receiving Medicaid through the Katie Beckett Program. In addition, eligibility is not determined by one area of functioning alone (e.g., IQ). In fact, a child has to have improved substantially across 3 domains in order to no longer be functionally eligible. If DHFS were to say that once a child is diagnosed with autism, that child should have services for life regardless of his or her functioning, Wisconsin would be out of compliance with federal regulations and waiver services would have to be 100% state funded.

Beth further clarified that the Children's Functional Screen (used to determine functional eligibility) is a process by which a full assessment is done in order to get the most complete understanding of the child. Eligibility is not based upon just a single day in a child's life, or a single test result.

Terri Enters pointed out that her agency, and others who work closely with families, work diligently to ensure that they develop an accurate picture of the child as they proceed with the eligibility determination process, including determining functional eligibility.

The Council asked that they receive information regarding how many children have been denied eligibility due to not meeting Level of Care requirements after having started intensive services. Sandy will get that data for the next meeting.

Kris asked the Council whether or not they consider the 3-year exception policy to be as good as it can be. The general answer was "no." Council members agreed that there were issues to be addressed with all the Exceptions policies; e.g., beginning intensive services after age 8, or transitioning to ongoing services if requirement of at least 12 months of services at an intensive level has not been met, or extending intensive services beyond the 3 years.

The Council members felt that additional data would be helpful in addressing the issue of the exception to the 3-year policy. They asked that the following data be provided by the next meeting:

1. Number of children who have applied for an extension, and the number approved/denied.
2. Number of children who request to transition to ongoing services after just 1 year of intensive services.
3. Number of children not approved to transition to ongoing services due to receiving less than intensive level of services.

STATUS OF THE BY-LAWS

The final draft of the By-Laws was distributed to the Council and members were asked to take the document with them for review. The document will be finalized at the next meeting.

The Council did decide to elect the 3-person Support Committee at this time. Following a nomination and secret ballot ranking process the Support Committee members were determined to be: Nissan Bar-Lev, Rose Helms, and Joan Ketterman.

A meeting schedule was determined for 2006. Members wanted one more meeting for getting up to speed, and then will go to quarterly meetings. They agreed upon a quarterly schedule that will start with February of each year, and the day will be the third Monday of the month. The 2006 schedule is:

January 9, 2006
February 20, 2006
May 15, 2006
August 21, 2006
November 20, 2006

STATUS OF MEDICAID AUTISM INDEPENDENT DIAGNOSIS

Beth reported that a letter is going to be distributed to providers from Mark Moody, Administrator of the Division of Health Care Financing. DHFS Secretary Helene Nelsen was

pleased that this Council reviewed the materials and gave feedback on it. When we have the letter, we will provide it electronically to all agencies and providers of intensive in-home autism treatment services. We expect that by January 2006, we should know about the interested provider response and whether or not we can begin to establish evaluation teams.

REVIEW OF DATA RELATED TO SERVICE HOURS LESS THAN 20 HOURS/WEEK

The Children's Services Section did an informal survey to try to get an understanding of whether or not a significant number of children are receiving intensive services at a less than intensive level (i.e., less than 20 hours face-to-face per week). Since only thirteen counties responded to the survey, the Children's Services Section hopes to give counties another opportunity to respond and provide additional data, in order to be able to draw better conclusions. One method is to make this a more formal survey, which would come to the counties from the Department and they would be required to respond.

Beth noted that the Children's Services Section staff is planning to draft a new survey, which they will share with the Council by email for feedback. After the questions have been finalized, staff will then create a formal survey through the DHFS Action Memo procedure, which includes review by the Wisconsin County Human Services Association prior to finalization and distribution. It is hoped that this will happen in 2006.

The question was raised as to whether or not there would be consequences to the counties at annual reconciliation time, if they reported that they had a number of children at the intensive autism service level who did not receive services at an intensive level. Beth explained that counties would not be penalized for responding accurately to the survey. The point of the survey is to find out if intensity of services is an issue that needs to be addressed. If it turns out that it does, then the Department will address it with counties and find resolution over time.

DPI REPRESENTATIVE

Pam Foegen, Consultant For Autism Spectrum Disorder (ASD) at the Department of Public Instruction (DPI), addressed the Council and responded to many of the questions that the Council had sent to her prior to the meeting (list of questions is attached). Pam first provided an overview of her position in DPI, how her position came to be, and her responsibilities. She also provided an overview of autism within the K-12 system. Prior to June 2004, ASD issues were included within the job responsibilities of a different DPI consultant position. In June 2004, the ASD Consultant position was created to work 100% on autism issues. Pam was hired into the position at that time. She averages 50-60 emails per day and at least 60 phone calls per day. Her goal is to respond to all contacts within 2 days.

Within the K-12 system, DPI has provided some general training about autism statewide, but local CESA's (Cooperative Educational System Agencies) and local school districts have developed more advanced training for their own areas. Many CESA's and local districts have also hired consultants. The roles of these consultants vary from district to district because the educational system is one of local control. If there is no consultant, the area has identified a person with advanced training in the field of autism. These autism consultants and experts are Pam's "eyes and ears" in the local area.

Pam addressed several of the Council's questions.

The first question was how will the public schools handle the growing numbers of children diagnosed with autism. Pam responded that DPI is developing a program to address this issue. Each district must develop its own response, so not every community will have a program for children with autism. The requirements of a Free Appropriate Public Education (FAPE) under the Individuals with Disabilities Education Act (IDEA) do not allow a "one size fits all" approach. Each child's IEP determines what is appropriate for a child. DPI's focus is on the **individual** child, and the parent's understanding of the child's needs is integral to the development of the IEP.

The next question was how the public schools could provide "oversight" of educators by the autism specialists in each school district. Pam clarified that the local autism experts do not in any way monitor staff in the schools. In fact, the district's Special Education Director oversees staff, and any concerns or issues come back to the IEP team.

Another question referred to children who have a treatment program which is not part of their education, and how to meet both the treatment and educational needs of children within the school system. Pam suggested that the first thing to do is to talk about the needs of the child and the characteristics of the treatment that are working well for child. Then the IEP Team can talk about how to bring those **characteristics** of treatment to the child's educational plan.

The common theme of Pam's talk is that "It is all about the IEP." She also passed around a DPI booklet, *An Introduction to Special Education*, which contains helpful information for families in IEP development and other decision making. She will provide the staff with booklets which will be sent out to Council members.

WRAP-UP/NEXT STEPS

Kris wrapped up the meeting and discussed next steps with the Council. It was decided that after this meeting, staff would identify what items remained unfinished from this meeting's agenda. Kris will also send out a request to Council members to submit by email their questions or issues that are high priority. Combined with the priorities that the Council identified in their first meeting, staff will put together a list of potential agenda items for the next meeting, share that with the Council for feedback, and then staff and the Support Committee will develop the next agenda. If any of the data that was discussed during this meeting is available prior to the next meeting, it will be sent to members as it is available.

NEXT MEETING

The next Council meeting is scheduled for Monday, January 9, 2006, Room 630 of the 1 W. Wilson State Office Building, Madison.

Minutes Respectfully Submitted by
Sandy Blakeney
November 29, 2005