

**MINUTES
of the
Autism Council**

- DATE:** May 15, 2006
- LOCATION:** Madison, Wisconsin
- MEMBERS PRESENT:** Nissan Bar-Lev, Heather Boyd, Terri Enters, Vivian Hazell, Rose Helms, Paula Petit, Paul Reuteman, Glen Sallows, Pam Stoika, Michael Williams
- ABSENT:** Milana Millan, Joan Ketterman
- FACILITATOR:** Kris Freundlich
- STAFF PRESENT:** Sandy Blakeney, Beth Wroblewski

The meeting came to order at 10:10 AM.

No public comment was received.

Prior to commencing with the established agenda, there were these updates:

- Katie Sepnieski, new Children's Services Specialist in DHFS, was introduced to the Council. Katie will be working directly with the Children's Long-Term Support Waivers as well as other programs administered by the Children's Services Section.
- Paula Petit let the Council know that she has a new email address: pmp@hughes.net.
- The Council discussed council member replacement due to Deb Mandarino's resignation:
 - ❖ Reviewed what the Bylaws say about resignations.
 - ❖ Discussed suggestions regarding membership; e.g., parent of a child currently receiving intensive services under the waiver as well as the DHFS' desire to increase diversity representation on the Council. The Governor's Office has a list of applicants, but none would meet the need to add diversity representation.
 - ❖ There were three related **Motions** on this topic:
 - **Motion (Heather Boyd):** That the Department of Health and Family Services request that Governor Doyle appoint a new Council Member to fill the position vacated by Deb Mandarino.
Seconded: Nissan Bar-Lev
Approved by unanimous voice vote.

- **Motion (Paula Petit):** That, in appointing a new Council member, the Governor appoint a parent of a child currently receiving intensive in-home autism treatment services, who first began receiving services through the CLTS Waivers (that is, they did not switch from Medicaid Fee For Service to the Waivers)

Seconded: Paul Reuteman

The motion was Approved by voice vote with 1 member in opposition. Heather Boyd opposed this motion based upon earlier discussion about diversity considerations.

- **Motion (Nissan Bar-Lev):** That, in appointing a new Council member, the Governor give consideration to increasing minority representation on the Council.

Seconded: Heather Boyd

The motion was Approved by unanimous voice vote.

- Nissan Bar-Lev had a number of updates on the agenda:

April is Autism Awareness Month: In response to a proposal by the Autism Council, Governor Doyle proclaimed April as **Autism Awareness Month**. The announcement was published around the state in newspapers and by other sources of media. It was also a focus at the annual Autism Society of Wisconsin Conference which Nissan attended.

Autism Society of Wisconsin (ASW) Conference: The ASW Spring Conference was held in Milwaukee the last weekend in April. There were approximately 600 participants who participated in raffles, exhibits and contests. The Department of Public Instruction sponsored an essay contest promoting April as Autism Awareness Month. Over 800 students submitted essays describing what it meant to them to have a friend with autism. Winners won gift certificates to Amazon.com. DHFS Secretary Helene Nelson spoke at the Friday luncheon and was well received. Nissan (a member of the ASW Board of Directors) reported there was a strong sense of appreciation for the work that DHFS has done in the area of autism.

Motion (Nissan Bar-Lev): That the Autism Council commend the Department of Health and Family Services for its efforts and professionalism in meeting the needs of families with children with autism, and building positive relationships in the process.

Seconded: Heather Boyd

Discussion: Nissan stated that he has been highly impressed by his experience both with DHFS staff as well as DHFS Secretary Helene Nelson, and wants the Council to formally recognize the work the Department has done and the Department's efforts at building partnerships to work on meeting the needs of children with autism and their families. He said he was especially impressed by Secretary Nelson's interest and involvement at the Autism Society of Wisconsin Conference. He sat at her table and heard her asking many questions about how Wisconsin can improve its efforts as well as what other states are doing. In addition, Secretary Nelson followed up after the conference with e-mails requesting additional information as well as contact information for people in other states who are working on the issue of services for children with autism.

The motion was Approved by unanimous voice vote.

Approval of Minutes: The Council reviewed the draft of the February 20, 2006 Meeting Minutes. A few minor edits were requested.

Motion (Nissan Bar-Lev): That the Autism Council approve the February 20, 2006 minutes with the corrections made.

Seconded: Terri Enters

The motion was Approved by unanimous voice vote.

EXCEPTIONS POLICY WORKGROUP REPORT

Volunteers for the workgroup: Terri Enters, Milana Millan, Pam Stoika, and Glen Sallows (represented by Eric Lund). Beth Wroblewski provided a written summary of the workgroup meeting and their recommendations to the Council. At the Autism Council meeting on February 20, 2006, the Council had decided to stay with the current policy, but charged the workgroup to consider other types of circumstances or criteria under which there should be an exception to the three year limit on intensive in-home autism treatment services.

The workgroup's recommendation was that a child may be considered for an extension of intensive services if the child meets the following criteria:

- 1) The child has just begun to show substantial progress, or the child's progress has substantially increased. This would be determined and defined through norm-referenced testing showing a substantial shift in developmental level. The workgroup would define **substantial** based upon the criteria for each norm-referenced test. This testing would need to be completed prior to the final six months of treatment so that appropriate planning for continuing services would occur, or appropriate planning to the ongoing level would occur if the child does not meet this criterion. The child's progress would be compared to their own previous evaluation which must be within the previous six months or less.
- 2) The child would have to be no more than seven years of age at the anticipated end of intensive services in order to be considered, and the child would have to be under an age when full-time school attendance is expected.

In addition to the above criteria, the extension would **not exceed six months** and the team must submit a comprehensive plan indicating specific treatment goals for the six month timeframe, as well as specific transition steps which are planned at the close of the six months.

DISCUSSION:

- Question about earlier suggestions for extension? The workgroup had looked at all the suggestions made at the earlier meeting and decided that some of them could not be used as reasons for an extension.
- At what age is full-time school attendance is expected? While there is a "mandatory school age," this may not be the same as full-time school attendance. This is why the group

specified that the child be **under seven years old and under an age when full-time school attendance would be expected.**

- On the requirement that a child be under seven years old, Beth noted that there are several ways in which we have already stretched the idea of “early and intensive” intervention. The workgroup focused on younger children because they were concerned about how much benefit there would be for an older child, or a child in school full time. Additionally, an overly broad policy would not be cost neutral.
- Homeschooling: Family is not limited to a specific school schedule and perhaps more able to accommodate intensive treatment. The workgroup specifically did not want to make a proposal that might create a conflict between the Department of Public Instruction (DPI) and families (i.e., would families register as homeschoolers simply in order to access intensive treatment services?). The workgroup’s age criterion was worded specifically so that it would not be an advantage or a disadvantage to homeschooling families. Instead, it looks more at the development of the child.
- Nissan suggested that it would be useful to invite Pam Foegen (autism consultant with DPI) to discuss this issue and any creative methods to address it. There are different approaches among different school districts, some more flexible than others. The workgroup agreed that they might invite Pam to one of their subcommittee meetings.
- The workgroup acknowledges that there is work still to be done on this topic, but they brought these initial recommendation to the Council to find out if the Council supports it before they begin working on identifying the appropriate tests.

Motion (Paula Petit): That the Autism Council accept the recommendations of the workgroup and direct the workgroup to continue its work to define “substantial improvement” and to identify appropriate norm-referenced tests for measuring “substantial improvement.”

Seconded: Nissan Bar-Lev

Discussion: Michael Williams wondered how many tests the group should look at. Beth said that DHFS is currently in the process of defining acceptable tests. Pam suggested that the group might end up defining certain minimum requirements that need to be present in any test in order to be an accepted test. Heather pointed out that “norm-referenced” is standard. Beth said the workgroup wanted to be sure any test had gone through validity testing and could be expected to **measure** something. Nissan mentioned the current issue of *Time Magazine* had a useful article dealing with testing.

The motion was Approved by voice vote with 10 Ayes and 1 Abstention (Heather Boyd).

TRANSITIONS WORKGROUP REPORT

Volunteers for the workgroup: Joan Ketterman, Paula Petit, Paul Reuteman, Pam Stoika. Beth provided a written summary of the workgroup meeting and their recommendations to the Council. The workgroup recommended several steps and policy clarifications related to transition:

- Provide further clarification that during the last six months of treatment, the limitation of 25% of the service out of the home may be waived with local county approval when it is consistent with the child's planned outcomes and treatment goals. This adds flexibility to meet the child's needs, and could be especially helpful for children and families in rural areas.
- DHFS should collaborate with DPI in defining "best practice" for transition of children receiving intensive autism services.
- Permit parents to use some of the funding for intensive autism services to support their training and skills, while still maintaining at least the minimum intensive level of treatment. Goal to promote active parent involvement and intervention throughout the treatment and during transitions. Activities would have to be waiver allowable; the waiver would only pay for registration and materials (not room and board, etc.).

DISCUSSION:

- The Council discussed the importance of parent involvement in all stages of treatment. Considered ideas for developing materials to actively promote more parent involvement. Also important to always be clear on what issues are within the scope of the Council.

Motion (Nissan Bar-Lev): That the Autism Council accept the recommendations of the workgroup and direct the group to work on developing a checklist for parents to prepare for transition for review by the Council at their next meeting.

Seconded: Glen Sallows

The motion was Approved by unanimous voice vote.

STAFF SUFFICIENCY WORKGROUP REPORT

Volunteers for the workgroup: Terri Enters, Nissan Bar-Lev, Vivian Hazel, Pam Stoika. Beth provided a written summary of the workgroup meeting and their recommendations to the Council. The workgroup reviewed several recommendations made by the earlier Autism Task Force and responded to those with their own recommendations:

- Create a workgroup that would take a systematic approach to (1) identifying the core knowledge and competencies needed to support children with autism spectrum disorders and their families and (2) establish a curriculum based upon these identified competencies and a plan for how any funding that is located could be used to advance training related to this curriculum. The workgroup did note that some concerns about the burden of the cost of training had been alleviated by up to one-half of the training hours being claimable under the waiver if the child receives treatment concurrently with the staff training.
- DHFS should collect information needed to review the current rate setting and rate structure and share this with the Council at a regular Council meeting. In advance of this, the Council should generate questions and concerns they would like to address through this process.
- Changing Lead Therapist Requirements: the workgroup made no specific recommendation, since DHFS currently reviews and, where appropriate, grants variances related to qualified

lead therapist. Any changes made to the Service Code would depend upon agreement of the federal Centers for Medicare and Medicaid.

- There were two Task Force recommendations: (1) create a state certification for Behavioral Analysts and Associate Behavioral Analysts and (2) introduce legislation for loan forgiveness to encourage students to pursue degrees with emphasis on behavior analysis. In both cases, the workgroup felt these recommendations were not of a scope that could be appropriately considered by the Council at this time.

DISCUSSION:

- Clarification that the primary goals of the workgroup are to address the problems of insufficient staff availability and children not able to receive the minimum level of services.
- Need to address staff sufficiency both for **rural areas** as well as for **urban** areas. Suggestion to look at alternative or flexible forms of service delivery, such as center-based treatment or webcasting. Beth noted that DHFS has directed Milwaukee County to explore variations on in-home delivery of intensive services due to a variety of factors including availability of staff, availability of families at home, etc. The state can approve variances on a child-by-child basis. Perhaps should look at some sort of statewide variance, so that it is not incumbent upon the family to request the variance.
- National certification of providers is not within the scope of the Council and there is no need to review it. For information about national certification go to www.basb.com
- The Council should take some time before the next meeting to review these recommendations and think about other issues and/or recommendations they would like the workgroup to consider. Members are reminded that shifting too far away from the current model of service requirements and service delivery, as that could require budget proposal and legislative action. Any new proposals must meet Medicaid and waiver requirements.
- Michael Williams and Milana Millan both agreed to join the workgroup

REVIEW OF UPCOMING ISSUES

- Alternative forms of treatment & service delivery models (rural issues): this will be addressed by the Staff Sufficiency Workgroup.
- Children's functional screen / Level of care: This has been on the list of priority issues for the Council for some time. Kris asked the group for clarification on what the issue is, why is it rated so high in the Council's priority list. Discussion among the members:
 - accuracy of the Functional Screen depends upon accuracy and availability of records; e.g., results of provider testing
 - children disqualified at annual recertification because they are making gains
 - Beth gave an overview of the process of doing a Functional Screen: service coordinator obligated to do a strong interview with the family; screen is never based on a single source of information; screen should be a comprehensive picture of how the child is doing across various environments.
 - There is a quality monitoring process in place; DHFS watches for patterns. There is **no quota** of how many children are found eligible.

- Access to information for parents; e.g. guidance on how the waiver process works:
 - Suggestion of a checklist of materials for counties to track what information is needed prior to referring a child for waiver services.
 - Information regarding what is needed for a valid diagnosis.
 - Pamphlet, booklet, etc., for parents describing intensive in-home services.
 - Suggestion that each Council workgroup should have **information for parents** woven into their discussions.

UDPATES

- DHFS will pilot a mediation system for the Children's Long-Term Support Waivers. A broad group of stakeholders met in March to give input about the system. This group included state advocacy agencies, county representatives, providers, parents, as well as three members of this Council (Nissan Bar-Lev, Joan Ketterman and Heather Boyd). The group was concerned about creating a successful roll-out of the new mediation system. Marquette University is contracted to do the mediations. The pilot program will include approximately 50 mediations the first year. Target date for rollout is July 1, 2006. DHFS is developing a pamphlet to be distributed with information about the pilot and a statewide Wisline will be held to inform counties about the program.
- Sandy distributed information regarding the numbers of waiver slots released for intensive in-home autism treatment services during State Fiscal Years 2005 and 2006 (to date), organized by county.
- Waiting Lists: Discussion of the current length of wait for a slot, as well as best practice for service coordinators. Service coordinators can have contact with families while they are waiting a slot, and the services coordinators should be giving families information about available resources.
- Confirmation of Diagnosis: Recently DHFS has required counties referring children for intensive in-home autism treatment services to include copies of documentation supporting a verified diagnosis of autism, Asperger Syndrome, or PDD-NOS. Since counties had been expected to have already confirmed that the child had a verified diagnosis, this request was expected to be simple. However, the response, and the materials submitted, demonstrated that there were many difficulties getting evidence of acceptable diagnoses based upon clinical and DSM-IV criteria. This is a significant issue, leading to concerns that children without the necessary diagnosis were being awarded waiver slots while children with the necessary diagnosis remained on the wait list. These state-funded slots are a valuable "commodity," because a child who completes the required minimum of treatment may transition to an ongoing slot that they could hold for many years. Since these slots are a limited resource, it is DHFS' responsibility to ensure that they are awarded to children who are eligible for them.

NEXT STEPS

Work groups looking at all three current issues will meet once or twice prior to the next Council meeting and report back at that time.

Minutes of the Autism Council Meeting
May 15, 2006

Next Meeting The next Council meeting is scheduled for August 21, 2006 in room 751 of the 1
W. Wilson St. Office Building.

Minutes Respectfully Submitted by
Sandy Blakeney
August 21, 2006