

**MINUTES
of the
Autism Council**

- DATE:** February 19, 2007
- LOCATION:** Madison, Wisconsin
- MEMBERS PRESENT:** Nissan Bar-Lev, Heather Boyd, Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Paula Petit, Paul Reuteman, Glen Sallows, Pam Stoika, Michael Williams
- ABSENT:** Milana Millan
- FACILITATOR:** Kris Freundlich
- STAFF PRESENT:** Sandy Blakeney, Beth Wroblewski

The meeting came to order at 10:00 AM.

PUBLIC COMMENT

Speakers included Renee Martin, Peggy Helm-Quist, David Mulligan, Glen Angus, and Wendy Vorpahl (via email).

Renee Martin described for the council the long draining process her family has experienced since her child was diagnosed with autism. Renee is concerned with the length of the wait for a slot for intensive in-home services and feels that Wisconsin should make funding available immediately. She feels autism is not taken as seriously as other disabilities. She encouraged the council to meet more often to discuss how to better help families and to have more influence on the governor.

Peggy Helm-Quest provided information from a committee meeting she attended regarding transitions and recommended Jan Serak of WI FACETS as a potential resource for the council as they develop a transition checklist. Peggy also provided a chart developed by the CDC regarding the prevalence of autism in a metropolitan area and discussed her concerns with the study. She explained that Wisconsin only used Medicaid data for this study and no data from schools (Department of Public Instruction did not participate). She encouraged the council to ask DPI to reconsider their decision not to participate. Peggy also reported that she is a member of a group looking at seclusion/restraints, and that they are considering a day-long event for parents, providers, etc.

David Mulligan discussed the impact on his family of their son's diagnosis, and their concern that the "clock is ticking" regarding the time period when services are likely to be most effective. He encouraged the Council to think about the difficult choices that families face and to "do the right thing" and put an end to the wait lists.

Glen Angus, a father of a 2 year old with autism, spoke in support of the Governor's proposal to require insurance companies to cover the cost of autism services. Glen voiced his concern that his son will lose eligibility for waiver services if he shows great improvement.

Wendy Vorpahl sent her comments to the Council by email and Council members were provided with a copy of the original email. Her comments had to do with the long wait for services for her son, as well as concerns about communication between DHFS, county waiver agencies, and families regarding a child's status on the wait list. She stressed the importance of early intervention for children with autism and that the long wait could be detrimental for a child.

TRANSITION PLANNING

Beth Wroblewski distributed and reviewed the handout, "Transition Planning for Parents." This documents the important points that the Transition Sub-Group had identified when they had last met: (1) the importance of planning ahead; (2) families are vital members of the child's team; (3) the team should be discussing the upcoming transition at least three months prior to the transition date; (4) an Individual Service Plan (ISP) needs to be developed prior to transition and based upon identified outcomes; (5) a child's needs may change throughout the year and the parents and service coordinator need to monitor these changes and revise the ISP as needed to support the child.

Discussion:

- The intent is for transition planning to be a collaborative process that includes the family, providers, support and service coordinator. It is important for families to understand and be part of the process, and it is important to include providers in the planning.
- The timing of the process (e.g., when a provider has been identified for ongoing services) will vary for each individual child and family.
- A transition checklist should be broader than simply moving from intensive to ongoing services. It could include suggestions for services available while *waiting* for transition. In addition, it should including planning for a transition that is due to a discontinuation of eligibility or due to a last-minute decision to end intensive services and move to ongoing services.
- There should be guidelines regarding what providers can or should offer at transition time, as well as guidelines for the support and service coordinator.
- Key goals of a checklist is to assure more continuity between counties in how transition is handled, and to ensure that the important decision makers are present for the planning.

- A transition checklist should include a resource listing (e.g., WI FACETS, the Waisman Center, Health Ready to Work, all have people and/or publications that can be valuable resources).

The Council encouraged the workgroup to continue to meet in order to finalize the transition checklist.

APPROVAL OF MINUTES

The Council reviewed the draft of the November 20, 2006 Meeting Minutes. A minor edit was requested.

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

Seconded: Vivian Hazell

The motion was Approved by unanimous voice vote.

INFORMATION TO FAMILIES AND PROVIDERS

- Neal Minogue of the Bureau of Long-Term Support presented an overview of the DHFS initiative to ensure that service and support planning is based upon *outcomes* identified as important for the individual. All county staff working with individuals will be expected to become familiar with outcomes-based planning. The first wave of trainings are designed as “Train the Trainer” opportunities to which counties should send 1 to 3 key staff who will be able to help train other staff on this process.
- DHFS has partnered with the UW School of Nursing to create an on-line training to supplement the in-person training.
- The Children’s Waivers have required outcomes-based planning since their inception in 2004, but the new training will provide more in-depth information than has been available up to now.
- Council members are invited to attend these trainings in order to become familiar with the process. It will be important for Council members to be familiar with this process in order to best advise DHFS on related issues.
- The outcomes planning process provides the opportunity to think critically; e.g., define outcomes, make a plan, review and evaluate, revise as needed.
- Over time we will find out how the process is going through results from family surveys.
- All training materials regarding outcomes planning can be made available to families and providers, including examples of plans and outcome statements. Council members could advise DHFS on other suggestions for how to get this information out to families.

AUTISM 101

The purpose of this project is to have a standard “basic” orientation curriculum for line staff, county staff, and school personnel that all providers could agree upon. It would not be based on one specific modality or another. This could potentially save provider time and resources. The training could be web based. Diana Adamski from the Children’s Section in the Bureau of Long-Term Support has been the lead on this project. A sub-group of interested Council members will be meeting in March to begin development of this curriculum.

2007-2009 BUDGET PROPOSAL BY GOVERNOR DOYLE

Beth provided information about the Governor’s budget proposals, including the proposal to require insurance companies to cover the cost of autism services. Key points of discussion:

- The insurance proposal covers plans specified in the document. It will not cover self-insured plans not specifically identified (e.g., a large corporation may have its own self-insurance plan).
- Insurance coverage is NOT linked to waiver eligibility. If approved, it may help address the needs of children waiting for a waiver slot, not involved with the waiver program at all, or terminated from the waiver program due to improved functioning. We cannot know what impact, if any, it might have on the wait list time for intensive services. If this bill is passed, it will take some time to see what kind of impact there might be.
- If approved, the insurance requirement would be effective seven months after the date the budget bill is published.
- It does not appear that the Governor’s proposal included funding specifically for new slots for intensive in-home treatment. However, after the close of 2006 books, DHFS will know if there is underspending to apply to new slots for 2007. Also, the Medicaid Base Re-estimate shows there will be additional funding overall.
- The council discussed encouraging and supporting families in expressing their opinions to the Joint Finance Committee as they deliberate the budget bill.
- Concern about available slots in upcoming biennium for intensive in-home treatment services. DHFS will know after the 2006 reconciliation process is complete if there were underspent funds, and if those funds can be applied to additional slots. Otherwise, new slots will become available as children exit the program.
- Viv reported on her discussion with the Governor. She indicated that the Governor explained that the state cannot cover the cost of these services alone and hopes to have insurance companies share the responsibility.
- Discussion on how the Council might address their concerns to the Governor and to the Joint Finance Committee. Glen suggested including Senior Therapist costs to the insurance proposal. Glen said that in Minnesota private insurance covers half the cost of services, the state pays more per child than Wisconsin, and insurance covers line staff in Minnesota.

- Paula suggested that families need to be told that the wait for a slot will be of indeterminate length. Nissan and Rose expressed concern about causing a panic among families. The Council could assist families or advocates for families by developing language that would be useful for communicating their concerns to the Joint Finance Committee.

Motion (Paula Petit): We, the Autism Council, recommend that counties begin immediately informing families that the current wait list for intensive in-home autism services is potentially indefinite. Currently, the Governor's 2007-2009 Biennial Budget Proposal does not allow for any new waiver slots for the 2007-2009 biennium."

Seconded: Glen Sallows

The motion Failed by a voice vote – 3 aye's and 7 nay's.

- The Council discussed drafting a new letter from the Council to the Governor and to DHFS Secretary Kevin Hayden expressing their concerns about the budget and the length of the wait list, and giving specific recommendations.

Motion (Vivian Hazell): That the Council consider contacting the Secretary, Governor, and other important parties to address the issue of insurance coverage, and drafting a separate letter of introduction from the Council to the Secretary.

Seconded: Rose Helms

The motion was Approved by unanimous voice vote.

It was decided that Glen Sallows would draft the letter and distribute for comments by the Council. The letter should include the points that the Council feels are most important for meeting children's needs.

Update on the Children's Long-Term Support Functional Screen

- In response to critiques from screeners, DHFS has updated the Behavior screen. Questions were expanded to get at a broader depth of behavior information. Also, items were split to show both frequency of a behavior (e.g., how many times a week) as well as what kind of intervention was required.
- An important point for the Council to know is that if a child is *not* exhibiting a behavior *because of the intervention*, then the screener enters what behavior(s) was happening *absent the intervention*.
- The changes to the screen were effective on February 7, 2007. DHFS has a process in place for monitoring the results closely.
- Changes will correct some "mistakes" made in the past to account for age-typical behaviors. For example, typical 2-year-old behavior can include tantrums. Not every 2-year-old who has tantrums would automatically have a mental-health diagnosis on that basis.

New Department Proposal

- Part of the budget proposal was to create a new state Department of Children and Families. Beth reviewed the proposal and clarified that Children's and Adult Long-Term Supports would not be moved to this new department. The Department of Health and Family Services would become the Department of Health.
- There could be new lines of communication and coordination between the two departments for certain children; e.g., a child in foster care and receiving waiver services would be connected to both departments.
- There was also a proposal for splitting the Division of Disability and Elder Services (DDES) into two separate divisions: Division of Long Term Care and Division of Mental Health and Substance Abuse Services. At this time, we are not sure of the impact of this change on children participating on CLTS waivers.
- Joan Ketterman said the counties have concern about coordinating services administered by the new department and/or division. If children's services were moved to the Department of Children and Families, the link to Medicaid services would be broken and this could create coordination issues. On the other hand, there is a positive component to having a cabinet-level position focused on children's needs.
- As proposed, the new department structure would not happen until the second year of the biennium. If it is approved, we would work to create a well-defined way to coordinate between departments.
- This is a budget proposal, so there is the opportunity for people to address it now as part of the budget approval process. If approved, there will be opportunities afterwards to address a process for implementation. So the Council could look at their priorities and decide to address now, or to address it after the budget is passed. The overall costs impact appears to be neutral.

Meeting was adjourned at 3:00 PM

Remaining 2007 Meeting Schedule

May 21, 2007
August 20, 2007
November 19, 2007

Minutes Respectfully Submitted by
Sandy Blakeney
May 21, 2007