

**MINUTES
of the
Autism Council**

DATE: January 9, 2006

LOCATION: Madison, Wisconsin

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

ABSENT: Heather Boyd, Rose Helms, Joan Ketterman

FACILITATOR: Kris Freundlich

STAFF PRESENT: Sandy Blakeney, Beth Wroblewski

The meeting came to order at 10:05 AM.

Kris Freundlich opened the meeting and there were brief introductions of the individuals present. No public comment was received.

Approval of Minutes: The Council reviewed the draft of the November 1, 2005 Meeting Minutes. Beth noted that, despite efforts by staff to meet the promised deadline to provide draft minutes to the Council within five working days after a meeting, this has not been possible due to the demands on staff time. Members noted that they will be satisfied so long as they receive the minutes prior to the next meeting and since the draft minutes are not published to the Web site, there was little concern about the timing.

There was a **Motion to Approve** the minutes which was **Seconded**, and **All were in Favor**.

Kris Freundlich reminded the Council of the Prioritization Tool that had been distributed by e-mail prior to the meeting and asked that members submit their finalized form no later than Thursday, January 12, 2006.

SMALL GROUP WORK

Kris discussed the agenda for the day and the plan to have the Council break into small groups to work on the topics. Council members reviewed how the process was intended to work and shared comments and suggestions until all were clear on what was expected.

PROCESS: The Council would be divided into three groups. Beth Wroblewski would provide an overview of the topic at hand, the full group would discuss until it was clear to all what the

issues were, and what sort of guidance the Department of Health and Family Services (DHFS) was hoping to receive on the topic. Following that discussion, the three groups would meet separately, identify their own process for discussion and development of recommendations. Following the small group work the full group would come back together and each group would report out on their discussion and their recommendations (if any).

The three groups were:

Group A: Nissan Bar-Lev, Vivian Hazell, Deb Mandarino, Paul Reuteman

Group B: Mike Williams, Milana Millan, Glen Sallows

Group C: Terri Enters, Paula Petit, Pam Stoika

EXCEPTIONS POLICY

Council Members were provided with a copy of the Interim Policy Revision for Extensions Beyond 3 Years of Service for Intensive In-Home Autism Treatment Services. Beth reviewed the policy and the Governor's specific requirement that any policy regarding this issue be "budget neutral." There was discussion regarding the definition of "budget neutral." Service costs reported to DHFS by the counties are currently available for 2004. The costs for 2005 will not be finalized until later in 2006. Costs for 2005 will be a better baseline for looking at actual costs of the program, since 2004 was the first year and there were variations due to implementation of the new waiver. Beth pointed out, however, that there is no underspending in the budget.

Members asked for clarification on the costs of county administrative costs and service coordination costs. According to the waiver rules, county administrative costs may not exceed 7%. Some counties may not claim the full 7%, but for planning purposes, administrative costs are most likely at the 7% level. Terri Enters noted that Lutheran Social Services (which administers the autism waivers for several counties around the state) budgets for the 7% administrative costs, but they bill for the actual costs. This tends to work out to 7%, considering the ebb and flow of need, such as during transition of services.

Service Coordination (also known as case management) costs are based on actual service provided. Actual costs are only available at this time for 2004. Counties tend to include service coordination on the child's Individual Service Plan (ISP) as a percentage of the plan costs, but they bill actual costs. Deb Mandarino suggested that the Council might want to look at the costs of case management. Paula Petit indicated that she would recommend cutting case management costs.

DATA: Prior to breaking into their small groups, the Council discussed the report that was provided in their packets answering several of their data-related questions from the last meeting. Members were interested in the information about children who were denied eligibility due to not meeting Level of Care requirements. They wanted to know who determines level of care, how it is determined, and what information is used. Beth specified that level of care is determined based upon what we told the federal Center for Medicaid and Medicare Services (CMS). If we serve children who do not meet the Level of Care requirements, we would risk

losing the 60% federal match dollars. While there may be children who have significant needs, if they do not meet the Level of Care, then they are not eligible for the program. This is similar to the situation in the Katie Beckett Program; children with very high medical needs, but who do not meet the functional (level of care) requirements, are not eligible for that program. It in no way diminishes the need of the child, but Wisconsin does not have the state dollars that could replace the federal dollars that would be withdrawn.

Beth clarified that the policy regarding exceptions to the 3-year rule for intensive services is not affected by level of care determinations. This policy has to do with a lapse in service. If a child has accumulated at least 12 weeks during which service dropped below the minimum 20 hours of face-to-face service, despite the family and child being ready and willing to accept services during those weeks, then an extension of time can be considered. The lapsed weeks do not have to be contiguous. The actual billing record is considered for determining the actual lapsed time. The service coordinator also keeps records and notices when lapses occur and keeps in communication with the family and the provider if there are questions about the billed time.

SMALL GROUP RECOMMENDATIONS

Each group reported on their discussion and ultimate suggestions/recommendations for addressing the issue of the extensions to the 3-year timeline of intensive services. There were common themes among all three groups:

Flexibility based upon child need: Council members felt that it would be helpful to be able to have some degree of flexibility as to the end date in order to accommodate the specific child's needs. Examples included:

1. A child who will start school in the fall but has an end date in August
2. A child who has a serious illness or is undergoing a med "washout" and is not able to have intensive services for a month or more - how might the provider manage that month if they had some flexibility with hours
3. A child who needs a longer period of time for transitioning to ongoing autism services than the typical one or two months spent on this.
4. A child who cannot tolerate an intensive level of services on top of school, but might benefit from less services during the school year and a very intensive plan in the summer.
5. A child who is just beginning to show great progress with intensive services at the time that the 3 years is coming to an end.

Manage a total number of budgeted hours of intensive services vs. a total number of years of intensive services: All three groups spoke of this concept as something they would want the Council to explore further. Instead of allowing a child to have 3 years and only 3 years of intensive services, the suggestion is to attempt to determine a total number of hours of intensive services that a child could receive under the waiver and allow that child to use those hours over a longer (or shorter) period of time. The issue would be to determine what number of hours would be effective, meet best practice requirements, and achieve budget neutrality.

Discussion included the issues of how to maintain budget neutrality, how to determine an end date if more flexibility is going to be permitted, and how to determine a number of hours, in the

“budgeted hours” recommendation, that would be effective. Paula Petit noted that a change to the extension policy could have the potential of saving money if it prevented the need for the process of a formal request for an extension.

In terms of the budget, Beth clarified that as the services moved out of Medicaid fee-for-service and into the waiver, there were three separate budget constructs:

1. 250 new intensive autism treatment slots per year
2. supporting children at the intensive level
3. supporting children at the ongoing service level

The requirement for “budget neutrality” in the discussion of the Exceptions Policy pertains specifically to the money for intensive autism treatment services. However, the budget for each separate category needs to stay neutral within that category; any changes made must not negatively impact the other categories. Therefore, when looking at the possibility of each individual child having a set budget of hours to spend on intensive in-home autism treatment services, that number of hours would either need to be less than 35 hours per week, or, if it were at 35 hours, then the total amount of time available would be less than 3 years.

Discussion revolved around some pro’s and con’s of the ideas, as well as how to approach the concerns about budget, best practice, effectiveness of treatment, family choice. The Council decided that they would like to form a small work group to continue gathering information and developing recommendations on this topic.

Volunteers for the work group are: Vivian Hazell, Milana Millan, Pam Stoika, and Glen Sallows. They will meet with Beth via telephone on January 19, 2006, from 2:00 PM to 4:00 PM. No later than January 18, 2006, work group members need to send Sandy the phone number where they can be reached at the meeting time as well as any additional thoughts/concerns/suggestions (“yeah-but’s”) concerning the ideas put forward already.

SUFFICIENCY OF STAFFING

Council members received a handout that contained Recommendations 10 through 19 of the Governor’s Task Force on Autism, related to “Building A Qualified Workforce.” Beth reviewed the challenges that providers face in terms of having a full team ready when a child has received a waiver slot and they are ready to begin services. First, there is consistent turnover of line staff. These are often college students, so as their schedules change, they will become unavailable. Turnover of staff can also be a budget drain, since providers invest time and money in training staff who often do not stay very long. In addition, this is a challenging and emotionally-demanding job; when they could make the same wage doing a less difficult job, many do make that choice. With less line staff available, providers need to find ways to work more efficiently and to use their staff more efficiently.

Viv Hazell discussed the added problem of billing. Providers must ensure that their staff are trained, but they are not allowed to bill for training time when the training does not involve direct child contact. They consider it a double cost in that they need to pay for the training and pay their

staff to attend the training, but it cannot be billed to the waiver. She wondered if there could be a way to allow providers to bill some training time against a child's authorized hours. There was discussion about how to balance a family's desire to maximize their authorized hours in treatment AND to have well-qualified staff providing that treatment.

Members discussed what providers are doing now to train their staff. There are a variety of methods being used including some center-based training, some in-home training where new staff shadow senior therapists, and some use of study guides. Each provider has their own process for training their staff.

The major issues were:

- Availability of **new** employees to hire
- Turnover of staff - expense of training staff who do not stay
- Availability of staff in rural areas
- Providers requiring staff to work **ONLY** for one agency.

SMALL GROUP RECOMMENDATIONS

The small groups met separately and then each group reported on their discussion and ultimate suggestions/recommendations for addressing the issue sufficiency of staffing. The following ideas were presented:

Have one or more of the CESA's (Cooperative Educational Service Agencies) around the state offer a free training for line staff. The group thought this was a good idea because this would be a familiar setting, a well-known provider of training opportunities, at low to no cost. Perhaps the benefit would carry over to the schools in that some schools want to have therapists on staff but require them to have the necessary training. Issues with this idea included: CESA would control the training; there are DHFS rules regarding staff training that would need to be met; schools decide individually whether or not they will allow non staff in the school setting and under what circumstances. Nissan suggested that there could be an effort to develop an interagency agreement between DHFS and DPI for this kind of training.

Have coursework available at colleges, technical schools, universities, CESA's, etc., which could count towards the required 30 hours of training. This would require two things: the development of a standard, agreed-upon curriculum and the development of criteria for which coursework would count.

Allow some therapy hours to be center-based. Advantages for the providers would be that this could address travel and supervision issues, and it could reduce the drain on the available provider pool by being able to serve multiple children in the same setting. The Council discussed a further idea of allowing all therapy hours to be provided in a center (or school). Deb Mandarino stated that the research does not show that all the therapy must be in-home to be effective. Pam Stoika pointed out that the "spirit" of the children's waiver is that intensive services would be provided in-home. Paula Pettit suggested that there may be times when extenuating circumstances could justify center-based intensive therapy. Deb and Milana Millan felt that the

state rules are too inflexible and requiring services to be in-home is difficult especially for children who already have very long bus rides to and from school each day.

Beth Wroblewski pointed out that there is a firm restriction on how much treatment can be provided in the schools, because intensive treatment may not in any way supplant school services. However, the waivers do allow for up to 25% of services to be provided out of the home. A center-based option is possible under the flexibility already included in the waiver. Providers might look at the “workshop” method of providing treatment. Beth noted that people don’t tend to go with this option, choosing to stay more with the “known quantity” of in-home treatment. Deb said there are many center-based programs in other states.

Other Ideas of the Small Groups:

Count therapy hours provided by the family toward the weekly intensive hours.

Allow families the choice of approving the use of some treatment hours for staff training.

Council members were concerned about the importance of families giving **informed consent** for this use of treatment hours. There would need to be some commitment for the family that the hours they approve for staff training would eventually benefit the family in terms of availability of trained staff, etc. Families would need to make an informed choice to accept the risk of it not directly benefitting their child.

Web-based training and data analysis. RELATE NOW is a new project being developed that relates to this idea. The Council is interested in learning more about this; perhaps a presentation could be arranged for the next meeting.

The Council decided that they would like to form a small work group to continue gathering information and developing recommendations on this topic. Volunteers for the work group are: Nissan Bar-Lev, Pam Stoika, Terri Enters, and Glen Sallows. They will meet with Beth via telephone on January 26, 2006, from 2:00 PM to 4:00 PM. No later than January 18, 2006, work group members need to send Sandy the phone number where they can be reached at the meeting time as well as any additional thoughts/concerns/suggestions (“yeah-but’s”) concerning the ideas put forward already.

EFFECTIVE TRANSITIONS

This topic was tabled until the next meeting.

COUNCIL BYLAWS

The Council Bylaws had been distributed twice to members in the past for review. At this time there was a **Motion to Approve, Seconded, and All were in Favor.**

PRIORITIES/NEXT STEPS

Kris discussed the Prioritization Tool and asked Council members to complete and submit it to her within the next two days. Kris would follow up with absent members to be sure they have the opportunity to submit their listings.

Beth addressed the issue of the list of priorities that this Council has been developing as well as the priorities of the Governor's Task Force on Autism. DHFS cannot dictate rules for other departments, such as the Department of Public Instruction (DPI). For example, DHFS cannot define the requirements for who attends an IEP meeting for a child. However, if there are issues that are priorities to this Council, such as inconsistencies among counties in how they apply DHFS rules or guidelines, DHFS could take steps to ensure standardization. The Council can take a look at their areas of concern and then make recommendations to DHFS as to areas that may need changes, and the Council may make suggestions as to those changes.

UPDATE ON PARENTAL FEE

Paula Petit asked how compliance was going with the implementation of the CLTS Parental Fee. It appears that compliance has been good so far, although it will be one to one-and-one-half years before DHFS can have sufficient data to know. DHFS has issued clarification that the Parental Fee applies to *all* long-term support programs. The Department is also looking at making the Birth to 3 Program cost share consistent with the Parental Fee. While Birth to 3 is not in fact a long-term support program, the DHFS Birth to 3 Workgroup is looking at making this change.

The first complete data set we will have related to the Parental Fee will be in May, 2007. DHFS has stated that the funds collected through the Parental Fee will be set aside for long-term supports. It will take at least three years of revenue data before DHFS has enough information in order to begin to make long-term programmatic commitments for the revenue from the Parental Fee. However, in the meantime, as soon as there is revenue available from the Parental Fee, it will be used to authorize special one-time requests.

Milana Millan wondered if there were significant "hidden costs" associated with the Parental Fee. Beth clarified that the Department very specifically kept the Parental Fee system simple, with very low overhead and minimal costs associated.

Next Meeting The next Council meeting is scheduled for February 20, 2006 in room 630 of the 1 W. Wilson St. Office Building.

Minutes Respectfully Submitted by
Sandy Blakeney
February 20, 2006