

MEETING MINUTES of the AUTISM COUNCIL

- Date:** August 18, 2008
- Location:** Madison, Wisconsin
- Members Present:** Terri Enters, Vivian Hazell, Joan Ketterman, Paul Reuteman, Pam Stoika, Glen Sallows, Brad Thompson, Michael Williams
- Members Absent:** Nissan Bar-Lev, Rose Helms, Milana Millan
- Department Staff:** Sandy Blakeney, Julie Bryda, Beth Wroblewski
- Facilitator:** Kris Freundlich

The meeting was called to order with introductions all around at 10:10 a.m. There was no public comment.

STAFF UPDATES

Beth Wroblewski announced that Julie Bryda has been hired as the Manager of the Children's Services Section (CSS) in the Bureau of Long-Term Support (BLTS). This position had been held by Beth's until she was hired to be the Director of BLTS. Julie will continue to attend and provide support and input to the Council. The Bureau will fill Julie's position as the Lead staff for the CLTS Waivers team, working directly with counties and families on issues related to administration of the CLTS Waivers.

BUDGET

The Children's Section has been asked to submit proposals to DHS Secretary Karen Timberlake for children's long-term support services, including children with autism. Staff in the Bureau have been gathering data, developing cost models, and expect to have an excellent proposal to put forward. While there is no guarantee that they will make it into the Governor's final budget proposal, children's services are a priority of Secretary Timberlake; the Secretary has stated she wants to "raise children up" in DHS.

In the process of developing a proposal, the Children's Section looked at the current rate of release of new slots for intensive services (4 slots per week, 200 new slots per year). With finalized expenditure data from 2007, we have found that we can increase the rate of slot release to 11 per week, at least through the end of the 2008 calendar year, if not longer. Staff continue to work with Fiscal Services staff to plan for future funding and slot release.

Children's Section staff have been informing county waiver staff at regional meetings about the increase in slot release.

INSURANCE – OTHER STATES' ACTIVITIES

Julie Bryda gave a synopsis of activities among other states regarding legislative efforts to require private insurance companies to cover autism services. Louisiana, Arizona, Florida, and Pennsylvania recently passed insurance legislation. All contained some similarities: maximum benefit ranging from \$36,000 to \$40,000 per year for Applied Behavioral Analysis treatment. All include a lifetime cap. Senator Kapanke's Autism Task Force has also been looking at these efforts, and they have been invited to attend a Council meeting to discuss approaches.

Discussion

- Council members discussed whether or not they wanted to make a statement of support for legislation.
- Concern about legislation limiting benefits to ABA treatment only; if this Council makes a statement, would be focused on evidence-based therapy, not locked into a specific treatment modality.
- How would waivers and insurance be coordinated? By federal rule, waiver funding cannot supplant insurance coverage.
- Created a subgroup to discuss all related issues, including the Autism Task Force proposal, and decide if the Council wishes to write a statement in response, addressed to DHS, not as a budget item but including key points the Council want to be sure are addressed. Members: Brad Thompson (lead), Pam Stoika, Paul Reuteman, Nissan Bar-Lev (will be invited to participate).

APPROVAL OF MINUTES

The Council reviewed the draft of the June 4, 2008 Meeting Minutes.

Motion (Glen Sallows): That the Autism Council approve the June 4, 2008 minutes.

Seconded: Joan Ketterman

The motion was Approved by unanimous voice vote.

FLEXIBILITY IN TREATMENT

Sandy Blakeney and Julie Bryda reviewed the discussion to date regarding the issues surrounding the idea of allowing parents to provide some "line therapist" hours for their child participating in in-home intensive services.

In an effort to understand what is happening now, under the current model, DHS staff looked at a sample of provider invoices submitted for payment for intensive services delivered in June and July 2008. The sample was comprised of 147 invoices from 9 counties and from 5 different service providers. Sandy and Julie presented the data and members discussed the results.

- Children received an average of about 21.9 hours of direct face-to-face treatment per week. Prior to the CLTS waivers, children were receiving an average of 26.5 hours per week under MA fee-for-service.
- 16% of the children received less than the minimum 20 hours per week.
- Providers billed for about 90% of the hours authorized.
- Of the hours billed, 66% were for direct face-to-face treatment, 25% were for travel related to direct services, and 9% were for staffing.

- Reported staffing hours raised many questions about how “staffing” and “supervision” are being defined and reported.
- Counties and providers have requested more training on how to define and report “training” hours.
- The age of a child affects availability for treatment; it is difficult for older children to get the required hours in order to be eligible to transition to ongoing services.
- Many questions and concerns were raised by this sample, but it is unclear as to whether it is simply a bookkeeping issue, or are there broader problems that need to be addressed by the Department? Are the current requirements of the waivers being met? If not, why not?
- DHS will continue to study and evaluate.

The proposal to include parent line hours would have financial implications.

- The current “bundled” reimbursement rate assumes providers have a cost “savings” for line staff that helps them reimburse professional staff at a higher rate. If parents provide unpaid line staff hours, the hourly rate would need to be broken out and a different rate structure would need to be put in place for those families who choose to do this alternative treatment model.
- Providers would need to determine if the family needed increased support from the senior/lead therapist.
- Choice to use the alternative model would be available to all families, not just those in rural/remote areas where transportation is an issue.

The discussion raises several crucial questions that apply to waiver services delivered under the current model as well as under any future approved alternative model.

- Must monitor effectiveness of any treatment.
- Treatment must meet child and parent needs.
- Waiver safeguards must be met.
- Must assure that providers meet all provider requirements.
- Must assure that parents receive all required training and supervision.
- Having parents as line staff can never be a model “by default.” Must be the parents’ choice. The current model must always be available.
- Not all families will be appropriate for this alternative model.
- Counties and parents should be involved in the development of a new treatment model. Input could be gathered through speakers, surveys, teleconferences, etc.
- Parent concerns include parents “stepping out” of their role as parents in order to provide line treatment as determined by the provider.
- Created a subgroup to discuss all items listed above. Members: Vivian Hazell, Terri Enters, Glen Sallows, Joan Ketterman, Milana Millan, Nissan Bar-Lev (Milana and Nissan will be invited to participate).
- DHS will establish an internal subgroup to look at fiscal issues and possibility of “unbundling” the reimbursement rate.

REPORTS/UPDATES

The family concern raised at the June meeting has been resolved, although the family continues to be dissatisfied. Staff from the county and from DHS have discussed and responded to the issues raised. This family essentially wanted approval for a “shadow” for their child in school; this is not a waiver-allowable service. DHS and the county have discussed with this family the strategies available to them through the CLTS waivers.

Julie reiterated that the waivers require intensive services to be provided in the home. Providers may submit a request for specific treatment goals that include treatment in a community setting. Many requests for community services are actually “daily living skills” and are not allowable during the intensive phase of services. If a child has met the requirements for transitioning to ongoing services, and the child would benefit from community services, the child should be transitioned to ongoing services.

A committee of 5 CSS staff review all requests for out-of-home services. No single staff person makes the decision. The rules regarding out-of-home services have been in place since the waivers began, but some families feel they are new because providers were improperly providing services in the community or school.

In-school services are limited by the rules of the Individuals with Disabilities Education Act (IDEA).

Providers continue to struggle to keep enough line staff. Need to be able to demonstrate that an effort is being made to find and retain staff.

Cost of travel continues to increase for providers.

Suggestion that providers set up a way to communicate with each other to work collaboratively to resolve problems, share solutions to common issues. Perhaps a list serv.

Meeting was adjourned at 3:00 pm.

Minutes Respectfully Submitted by
Sandy Blakeney
November 17, 2008