

## **MEETING MINUTES of the AUTISM COUNCIL**

**Date:** October 11, 2007

**Location:** Madison, Wisconsin

**Members Present:** Nissan Bar-Lev, Terri Enters, Vivian Hazell, Joan Ketterman, Milana Millan, Glen Sallows, Pam Stoika,

**Members Absent:** Rose Helms, Paula Petit, Paul Reuteman, Michael Williams

**Department Staff:** Jacqueline Moss, Beth Wroblewski

**Facilitator:** Kris Freundlich

The meeting was called to order at 10:10 a.m. with introductions of Council members present and public guests.

Beth Wroblewski opened the meeting with a summary of the Council's decision at their last meeting to call this special session for the sole purpose of discussing whether or not the Council would recommend that DHFS consider expanding the allowable treatment models for intensive in-home services under the CLTS Waivers. At the August 2007 meeting the Council created a subcommittee to review existing treatment methods and to create a framework by which the Council could discuss and evaluate those models (see the August 20, 2007 minutes for a detailed discussion of this issue).

Beth reviewed the criteria that must be met for treatment to be allowable under the federal rules regulating Medicaid Home and Community-Based Waivers. For example, a treatment may not be aversive or experimental, and a treatment must be proven to be *effective*. Discussion of level of proof, and how to measure effectiveness, are some of the issues the Council faces in addressing this topic.

The subcommittee volunteers were Terri Enters, Vivian Hazell, Milana Millan, Pam Stoika, and Mike Williams. Prior to this meeting, the committee prepared materials which were distributed to the Council members, and met with State staff to review the current waiver language regarding treatment modalities. Each member from the subcommittee (excluding Mike Williams, who was unable to attend) made a short presentation to the Council.

**Vivian Hazell:** As a "spectrum" disorder, autism requires a "spectrum" response. The Autism Task Force (precursor to the Autism Council) had recommended that DHFS allow for flexibility in treatment modalities. Governor Doyle acknowledged that it is important to fund interventions that are proven, and that it is also important to have the ability to give parents choices in treatment methods.

**Pam Stoika:** The ability to offer alternative treatment methods could address the lengthening wait for funding. The opportunity for “early” intervention could be lost due to the long wait for a waiver slot. Parents are able to be very effective in promoting their child’s development without regard to the funding source, but they may need ideas and support to be equipped to take the lead in their child’s treatment. Line staff are often college students working temporarily with no long-term investment in the child. In addition to wait-list issues, alternative methods could address the staff-sufficiency issue as well as the problems some families incur with having multiple line staff in their homes.

Pam noted that any treatment method must address the specific deficits associated with Autism Spectrum Disorders, must assure continuing State oversight of high quality, must be fiscally possible for providers and, finally, must be implemented quickly enough to have an impact.

**Milana Millan:** There are difficulties specific to rural areas of the state. Providers have to travel very long distances. Children often are receiving just the bare minimum of 20 hours per week. Pediatric specialists are not available locally. Standards of quality must also assure that any type of system must have minimum standards of contact to ensure frequent and reliable contact with the child.

**Terri Enters:** It is critical to address the capacity of the family over the long term.

To establish a framework for the discussion, Beth reviewed the issues. Expanding treatment choices for parents means that parents would make informed decisions about the model that would best meet their individual child’s needs. Determining “effectiveness” includes trying to anticipate a child’s and family’s needs, the strengths and needs of a specific child, and equipping a family with what they need to be able to help their child meet their goals. There can be multiple approaches to an effective treatment. There was a wealth of information available for the subcommittee to review, and they distilled it down into a document that the Council could use as a tool for discussing the myriad programs and services that exist, classifying the models of treatment, and considering whether and how other models might be incorporated into the existing CLTS Waivers. Beth pointed out that while the different models have a variety of names, they are mostly the same idea of providing consultative services to parents who could implement treatment approaches with their own children. It’s important to look at the substance of each of the different models against the criteria for waiver-allowable services.

Glen Sallows raised the question as to how “effective” was being defined. Beth provided an overview of the basic rules concerning Medicaid fee-for-service as well as Medicaid waiver services. Section 1915(a) of the Social Security Act (SSA) defines the parameters of eligibility as well as criteria for allowable services. While states have some latitude regarding services, their decisions must be consistent with Federal rules. The description currently used was approved by CMS, but this in no way constitutes this as the sole treatment approach that would be permitted by CMS.

To be approved by CMS as a waiver service, any treatment modality must meet specific criteria, including: it must be non-aversive; effectiveness must be measurable; must have clearly specified limitations (e.g., “intensive” must be 20-35 hours of face-to-face service per week); must clearly specify who is qualified to provide the service. The CLTS Waivers were renewed in November 2006 and are renewed on a 5-year cycle. Waivers can be amended within the 5-year period.

In reviewing services to be considered allowable, the State and CMS look for trends. How much technical assistance is needed for training providers to be in compliance? Use random and/or targeted reviews to measure effectiveness of the intervention. Providers are occasionally audited to assure cost-effectiveness of interventions. Effective treatment must drive our choices, but how to define “effective?” Do we look at the overall effectiveness of an approach, or do we look at the individual impact of an intervention with a specific child?

Kris Freundlich provided a summary of the discussion so far and offered a framework for the next phase of the discussion. She posed the following question: “Does the Council want to consider the advisability of broadening the autism service delivery system to include a more consultative model, where parents would receive support and training to provide interventions directly with their child?” The Council needs to define what they mean when they consider “effectiveness.”

There was discussion regarding accountability and effectiveness, with the following points made:

- The Council needs to consider if they are looking at effectiveness of approach or effectiveness for specific child.
- Need to review the different approaches; e.g., parent consultative model, behavioral approach, learning social skills, etc.
- What is DHFS’s role in determining whether or not to expand the treatment service? Analyze the different approaches; determine if they are established or experimental; and determine if a treatment model meets all the criteria to be an allowable waiver service.
- What needs to be changed or expanded? Who would provide this different service? How would it relate to the current requirement of 20 hours of face-to-face service? Parents cannot be paid, but they can document services they provide and take direction from service providers.
- Any change would broaden choices – nothing would be eliminated.

Kris posed the question to the Council: Does the group want to advance the possibility of broadening the autism service delivery system/model? Has enough information been provided?  
Discussion:

### **Need Options**

- pre-waiver test of experimental soundness
- current CMS approved waiver goes beyond the test (shift happened several years into fee-for-service)

### **Need Caveats**

- Should have a “track record”
- Evidence of benefit of treatment
- An impartial body should review the research
- Per Governor Doyle letter to the Council, don’t want to limit solely to clinical trials or single-subject design experiments
- Effective treatment must be the driver of our choices, but how to define “effective” (individual vs. cohort)

### **Qualified Providers**

- Providers must meet all qualifications and be willing to meet all service specifications

### **Accountability**

- A system is already in place that requires every provider to have complete documentation showing that services billed were delivered. This in and of itself would not shift with any new treatment approach.
- May need to develop a system for family-provided services.

### **How Do We Give Families Options?**

- Families need to know the impact of their decisions and agree to trading “sweat equity” for a consultative model.
- Existing model already covers a broad spectrum of practices with tracking mechanisms in place.
- Currently a very specified/prescriptive model:
  - Lead = specific # of hours and role (e.g., develop treatment plan)
  - Senior = more direct and ongoing role with plan implementation
  - Line = implement plan (is a paraprofessional)
- Could these resources and professionals be used in a different manner?
  - define new roles (variance within current waiver)
  - define a different rate structure (variance within current waiver)
  - make changes to payment structure (more complicated due to current CMS approval of blended rate)
- Refinements could address wait-list issues.
- Any plan needs to show effectiveness and cost savings.
- Changes could = family choice/empowerment.

### **Ideas about Potential Next Steps**

- Proceed on a “pilot” basis within set parameters?
- Get DHFS clarification of what would need to happen to include an alternative treatment model.
- What does the Council want to do as a next step?

**Motion (Terri Enters):** Move to charge DHFS to amend the CLTS waivers to include in-home parent consulting as an allowable service.

### **Discussion:**

- Need to better define the parameters of the recommendation before presenting to DHFS.
- Concerns regarding the impetus for this change – are there members who have a conflict and should not vote?
- Need to respect the work of the subcommittee. This is a recommendation only, and Council member can express their concerns.
- Any treatment model should be research-based.
- Is the 15-page document that the committee developed clear enough to present as a recommendation?
- DHFS staff should create a framework for reviewing this recommendation before the November 19, 2007 meeting.
- The Council does not make the final decision – they do make recommendations.
- Would like to be able to take a vote on November 19, 2007

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October 11, 2007

**The motion was suspended until the next meeting.**

The meeting was adjourned at 2:50 p.m.

**Proposed 2008 Meeting Schedule (to be finalized at 11/19/07 meeting)**

February 18, 2008

May 19, 2008

August 18, 2008

November 17, 2008

Minutes Respectfully Submitted by  
Sandy Blakeney  
November 19, 2007