

MEETING MINUTES of the AUTISM COUNCIL

Date: November 19, 2007

Location: Madison, Wisconsin

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

Members Absent: Rose Helms, Michael Williams

Department Staff: Sandy Blakeney, Beth Wroblewski

Facilitator: Kris Freundlich

The meeting was called to order at 10:05 a.m.

PUBLIC COMMENT

Six individuals registered to speak.

Jeff Crisco (Pediatric Psychology Associates): He expressed concern regarding the growing wait list for intensive services. He stated that effectiveness of any new therapies must be shown through studies controlled in a scientific manner and evaluated by qualified professionals. He noted that he was concerned about putting “too much” in the hands of parents; in his experience as a provider, he is concerned that parents will not be consistent or reliable in providing treatment. He also raised concern about how waiver funds are spent. He suggested a review process of non-therapeutic services being funded by the ongoing (“post-intensive”) phase of waiver services and that if money is going for non-therapeutic services, it should be withdrawn and made available for the intensive in-home services.

Tamra Kasper (Center for Autism Intervention): As a speech language therapist and Applied Behavioral Analysis (ABA) clinician, she focuses primarily on natural settings. Her agency has a parent-directed model which helps parents learn to teach their children. They see a significant need for this and also see that it is cost-effective. She is concerned that the proposal for other treatment models is not sufficiently researched. She is concerned that this is about cost savings vs. effective treatment.

Marisa McKee: (Center for Autism Intervention): She noted that some parents are doing a parent-directed approach of working with their child while waiting for services through the waiver. At least one parent has indicated to her that they would prefer to wait longer to be assured of an effective therapy. She believes that Governor Doyle considered ABA to be most effective treatment approach. She supports using research and literature to guide intervention techniques.

Alisa Morrison (Center for Autism Intervention): She is concerned that parents would not be able to provide the repeated therapies required by an ABA approach, that ABA is not a “natural” approach and parents already overwhelmed would not be able to provide this therapy. ABA requires consistent, reliable, repeated implementation vs. incidental exposure.

Amanda Wing (Easter Seals of Southeast Wisconsin): As a provider and as a family member of a person with Autism Spectrum Disorder (ASD), she supports the proposal to allow new effective therapies. She noted that current services work well for many, but “one size does not fit all.” In her family’s experience, they did home-based services with support of family, neighbors, community, and this was effective for her sibling. She encouraged the council to support efforts to offer families more options in treatment modalities.

Cynthia Thomas (Innovative Counseling): As a provider and a parent of a child with ASD, she is concerned about the impact of a family-directed therapy intervention model. She stated it would be challenging for a family to meet the requirements of consistency and structure while also trying to meet the other needs in the home. She is concerned this could undermine the effectiveness of the treatment.

REFRESHER ON HOW THIS COUNCIL OPERATES

Kris Freundlich reviewed the charge to this council, to advise the Department of Health and Family Services (DHFS) on supports and services for children with ASD. The shared common value (touchstone) on the Council is having good, quality supports for children and their families. The Council members are expected to operate honestly, openly, and respectfully towards the rest of the membership. Occasionally there will be productive ideological conflict or diversity of opinion, resulting in a wealth of dialog. According to the Council Bylaws, in the event that the Council does not reach agreement following dialogue and a vote, then the split decision will be shared with DHFS. Thus, it is valuable for DHFS to be aware of differences of opinion on the Council; consensus is not required.

APPROVAL OF MINUTES

The Council reviewed the draft of the August 11, 2007 Meeting Minutes.

Motion (Vivian Hazell): That the Autism Council approve the August 11, 2007 minutes.

Seconded: Milana Millan

The motion was Approved by unanimous voice vote.

The Council reviewed the draft of the October 11, 2007 Meeting Minutes.

Discussion: Members requested a few minor revisions to the minutes. There was also a brief discussion related to current DHFS policy towards providers implementing variations on the ABA model of treatment. DHFS staff noted that all the providers currently providing ABA services have implemented some new procedures and intervention strategies within the broad framework permitted by the approved children’s waiver and specifically intensive treatment services. Glen Sallows asked about what is in place currently to ensure provider accountability in this regard. Beth outlined that the current policy is that every provider, for every service delivered under Medicaid, must have full, complete documentation and reporting in order to be accountable for every service delivered. This reporting procedure is already in place for all providers. The question currently being addressed by the Autism Council is how to ensure this

requirement is met if families provide a significant portion of the direct intervention for their child versus the current approach which utilizes paid professional staff and paid line staff delivering much of the direct intervention.

Motion (Nissan Bar-Lev): That the Autism Council approve the October 11, 2007 minutes, with the changes requested.

Seconded: Glen Sallows

The motion was Approved by unanimous voice vote.

STATUS OF LEGISLATION FOR INSURANCE TO COVER AUTISM SERVICES

Katie Plona, Legislative Liaison for the Department of Health and Family Services (DHFS), reviewed Senate Bill 178. The bill was passed out of the senate committee on a 4-1 vote and referred to the Joint Committee on Finance, where it remains as of the date of this meeting. The corresponding Assembly Bill 417 has been introduced to the Assembly with no action taken to date.

Updates on the status of either of these bills can be found at the Wisconsin Legislature website at <http://www.legis.state.wi.us/index.htm>.

In the DHFS “fiscal note” that accompanied the Senate bill, it was estimated that there would be a cost to each State employee paying for health insurance since this benefit would be added to employee policies. The increase in the per-month premium would be between \$3.45 and \$4.10. This is considered a minimal increase, and the estimate is based upon the estimated costs of Children’s Long-Term Support (CLTS) Waiver services for autism-related treatment, which is approximately \$6.7 - \$8 million per year.

The fiscal note from the Office of the Commissioner of Insurance (OCI) estimated a small additional cost to regulate the requirement, but that the cost would likely be absorbed in the existing budget.

The Department of Public Instruction (DPI) did not anticipate a fiscal impact of this requirement.

Katie Plona noted that the biggest potential obstacle would be the cost associated with the bill, since it is always more difficult to pass a bill with an associated cost. She noted that “next steps” for the Council and Council members could be to contact the Joint Committee on Finance, or any member of the Senate and/or Assembly leadership who would be responsible for scheduling bills, as well as their own representatives. She clarified that the Finance Committee would be looking at the overall cost of the requirement, not simply the cost to State employees.

The bill does not specify a timeline for services, nor does it specify any certain amount of service to be provided. An important point to make, if advocating for the bill, is the potential cost savings for the CLTS Waiver program, which could potentially make more funds available for to address the waiting list for intensive treatment services through the waiver.

Nissan Bar-Lev made the point that it is difficult to garner support for the bill when there are no specifics as to how it would work. Pam Stoika further commented that without knowing how the requirement would work, it doesn’t seem possible to estimate the potential cost.

Paula Petit questioned what the Council could do to support the bill, and Katie Plona noted that the Council could choose to pass a resolution or advocate support of the bill with the Senate and Assembly.

Motion (Nissan Bar-Lev): Given that the scope of the Autism Council is to advise DHFS on how to handle the waiver, and due to the significant size of the wait list for autism services through the waiver, the Council supports SB 178 and AB 417 in order to ensure continued provision of treatment through waiver services as well as reduction of the existing wait list.

Seconded: Paula Petit

The motion was Approved by unanimous voice vote.

OTHER MODELS OF TREATMENT

This was a continuation of the dialog regarding alternative methods of treatment. The Council had asked DHFS to draft some information regarding what changes might need to be made to the waiver to allow for a consultative model of intensive treatment, plus the Council was interested in having a more in-depth presentation of what a consultative model might look like within the CLTS Waivers. Beth Wroblewski reiterated for the Council that there has been no presentation or proposal regarding a change to the waivers made to the DHFS Secretary or to the federal Centers for Medicare and Medicaid Services (CMS). In addition, Beth reminded the Council that this topic is an issue that the Council requested be considered; it is not an issue that was raised or in any way driven by DHFS.

She noted that since the State, the Council, therapy providers, parents, and other interested parties are always interested in finding the best ways to help children meet their needs, then it is likely that this will not be the last time that the Council will be discussing the possibility of alternative methods of treatment. It will be important for the Council to develop a method by which they would consider new suggestions for autism treatment approaches in the future.

Beth gave a presentation that provided an overview of the Children's Long-Term Support (CLTS) Waivers: the definition of intensive treatment services as currently written, issues to be addressed, background on options, and a look at one option, a parent-driven model of treatment, which is the primary model being requested currently in variance requests made to DHFS. Major points of the presentation follow:

Overview of the current waivers:

- Intensive In-Home Treatment Services are one component of the CLTS Waivers, available to eligible children who meet all additional authorization criteria, including a diagnosis of Autism, Pervasive Developmental Disorder or Asperger Syndrome within the Autism Spectrum Disorders.
- Current treatment model requires 20-35 hours of direct face-to-face treatment in the child's home with the treatment team.
- Current treatment team includes a lead therapist who oversees child's treatment plan, a senior therapist who implements the plan and supervises line staff, line staff who deliver most of the service, and the family, who must be involved sufficiently to be able to reinforce behavior and implement therapeutic goals as developed by the treatment team.

- The waivers clearly define the minimum qualifications required of each component of the team.
- Per-child cost estimated to be approximately \$40,000 per year. All treatment hours are paid at a combined hourly rate (i.e., rates do not vary based on who is providing the treatment).
- Current budget allows for approximately 200 new intensive treatment slots per year.
- The currently approved model includes treatment-oriented behavioral services that:
 - use behavior analytic methods to change key behaviors or skills in a meaningful way;
 - have clearly defined goals for each child with measurable standards for progress;
 - begin with precursor skills and progress to more complex tasks;
 - progress to generalizing learned skills to other settings;
 - include data collection within each treatment session; and
 - include continuous assessments of the child's response to treatment in order to adapt the approach as needed.
- Currently, decisions about approved providers and approaches are made within the framework of the approved CLTS Waivers and are outlined in the Waiver policy manual, as well as policy papers and procedural descriptions.
- Variance requests are reviewed on an individual basis with key factors including effectiveness, intensity, and safety.

Issues to be addressed:

- Variances to the waiver rules are typically approved for extenuating circumstances.
- 20-hour minimum intensity level of treatment must be met for therapy to be considered intensive.
- Some families have requested that other treatment options be available for their children, including increased access to Lead and Senior time.
- Some families have wanted to implement more of the direct intervention themselves, rather than using the Line Therapist approach.
- Children who need services are currently waiting approximately 1 1/2 years for a waiver slot.
- Early intervention is a high priority, yet the wait lengthens and the "early" component of treatment is at risk.

Background on options:

- Governor Doyle, in his letter to the Department of Health and Family Services, stated that he does not want to restrict access to other therapies.
- CMS has approved various options for autism treatment in other states.

One option: Parent consultation model:

- Professional trains and supports the family to provide direct intervention.
- Lead and/or Senior Therapist continue to be required, with same qualifications as present.
- Parents/family members are trained to implement the treatment in place of the Line staff.
- Per-child cost estimated to be \$5000 - \$10,000 per year.
- Some existing waiver policies would be revised, including development of the Individual Service Plan, tracking hours of service received, responsibilities of parents as providers.
- Would require consideration of several issues, including:

- how this model would balance with the current option
- how would families receive unbiased information to make a true choice
- determine a process to evaluate other approaches that may be proposed
- assure that the cost of a new model is not higher than the current model
- assure that the number of children served does not decrease

Next steps:

Does the Council wish to make a recommendation to DHFS regarding consideration of an alternative model of intensive treatment?

Discussion:

Paula and Milana both raised questions about the current wait list for slots and how/if that wait might be impacted by implementation of a consultative model. Beth explained that there would be some complexity in this. Basically, there is a sum-certain amount of available funding in the budget. If we assume that a child receiving the current model of treatment will use about \$40,000 per year, then for every family that chooses treatment that would require less than \$40,000 per year, there would be savings. When there is sufficient savings, an additional slot would be made available. One challenge to this scenario would be to ensure that families are not pressured to choose a treatment model based on saving funds. DHFS would have to decide ‘when’ the money has been saved sufficiently to make a new slot available. There may need to be a ‘lock-in’ period where a family could not change their choice of treatment option. Beth clarified that families choosing the alternative option of treatment would not “jump” the waiting list.

Kris Freundlich asked the Council to consider the question of whether or not they would recommend that DHFS consider an alternative method of intensive treatment. Council members made the following points and/or raised the following concerns:

- Is the Council able to discuss this, or will it just be different providers advocating for their own approach?
- This Council is not qualified to determine what is an “effective” treatment.
- The Governor’s Task Force on Autism (precursor to this Council) also debated this issue. Governor Doyle supported ensuring that parents have choices in terms of therapy.
- The Council is passionate about making sure that children have what is best.
- There is fear that the services will be diluted by offering alternatives.
- Discussing an alternative model is not to the exclusion of the current model.
- Why would parents choose this alternative option?
- The approved waiver requires that all treatment be research-based.
- Council should *only* discuss alternatives that are shown to be effective.
- There is wide variety among the available research; different journals have different philosophical perspectives.
- Perhaps would be useful to have an agreed-upon “expert” resource (e.g., the Waisman Center?) to assist the Council in its dialog.
- DHFS would determine if and how a treatment would meet the requirements of the waiver.
- Providers of the current model base their treatment on current research. We cannot know that every provider is providing the exact kind of treatment now.
- Important to offer families choices – must eliminate the “fear” that families are not able to make appropriate informed choices.

- Families are more commonly asking for professional time to help them learn how to help their own children, rather than simply stepping aside and letting the “expert” work with their child.
- Council’ role is to advise DHFS, but DHFS is responsible for writing all the policies and procedures and ensuring that safeguards are in place and standards are met.
- The dialog is valuable, regardless of whether or not a consensus is reached, or a recommendation is developed. DHFS will have access to the discussion through the minutes. Wisconsin has a strong interest in stakeholder opinion.

Motion (Vivian Hazell): That the Council further pursue dialog and evaluation of a consultative model as a possibility for developing a recommendation to the Department from the Council.

Seconded: Glen Sallows

The motion was Approved by unanimous voice vote.

Linda Tuchman, representing the Waisman Center, indicated that the Waisman Center would be open to discussing the idea of coming in as an “expert” resource for the Council in this discussion.

Pam Stoika suggested that if members of the Council knew of parents who would be willing to share their reasons for wanting an alternative treatment model, they should invite those parents to present those reasons in writing or in person.

Information for Families/Others

Transitions Document: Beth summarized the process so far in terms of developing a Transition Checklist for families. A draft was presented two meetings ago and the Council felt it needed revision. Sandy Blakeney has drafted a revision and it will be shared with the full council electronically. The workgroup will discuss it once more and bring a final version to the Council in February, 2008.

Ideas for Information for Families on Waiting List: There are already advocacy groups and providers who offer information to families for ideas of what they can do to help their children while waiting for a waiver slot. DHFS is not in a position to do this and needs to be cautious about appearing to offer clinical advice. Council might want to consider doing their own checklist of information. Viv Hazell reminded the Council that the Autism Society of Wisconsin sends an e-newsletter to all counties to share with families on the wait list. Glen Sallows said that WEAP has no problem with suggesting recommendations for families. Pam Stoika felt that there is already a great deal of effort in Wisconsin for this and would not want the Council to duplicate that effort. Paula indicated that families need to know what is available to them.

Pam Stoika and Glen Sallows volunteered to work on finding out what is already available, identify any gaps, and possibly put something together for the Council to review.

AUTISM CORE TRAINING

The Waisman Center at the UW-Madison is a partner in the National Professional Development Center on Autism Spectrum Disorders. Linda Tuchman, Leonard Abbeduto and Lanette Collette Klingenberg were on hand to discuss this program, its mission, the role of the Waisman Center in

the program, and how it could interface with the Council's interest in making core training in Autism Spectrum Disorders available to stakeholders in Wisconsin.

The project is funded by the US Department of Education, Office of Special Education Programs. It is a 5-year, multi-university program that began on July 1, 2007. The mission of the project is to promote the use of evidence-based practice (EBP) for children and adolescents with autism spectrum disorders.

The project will focus on four areas: content development, professional development, technical assistance, and evaluation.

Linda Tuchman presented a slideshow presentation regarding the project, and discussed the possibilities for coordination with the issues currently under discussion by the Autism Council. For example, an outcome of this project will be a set of *strategies* that will have been researched and developed by which various methods of interventions can be reviewed to determine whether they would be considered effective. The result of the project will not be recommendations of best practices but rather, a strategic approach for evaluating modalities as they are developed.

One product of this project will be an Evidence-Based Practices Module of an online course, such as an "Autism 101" course of providers and other interested parties.

A hope is that this project will motivate researchers to look for more approaches for addressing the needs of young people with ASD.

The project hopes to assemble a Planning Group to work on developing a core training module. Looking for representation from the Autism Council on that group.

Discussion

- The first 5-day training would be in the summer of 2008, so the Planning Group will be convening in early 2008.
- Nissan Bar-Lev suggested that DPI would strongly support this, and recommended including autism consultants from the CESA's around the state.
- The goal after 5 years would be to have created a wealth of materials and capacity for continuing, as well as applying to be re-funded to continue the project.
- With new line staff constantly being hired to work as paraprofessionals, the Council would have a major interest in an "Autism 101" training. It's important to have representation from the Council on this planning committee, as there is a potential overlap between this project and the Council's interest in core training.
- The three main topics of the Council's "core training" initiative would be (1) basic information about ASP and treatment approaches; (2) basic professional conduct; (3) information specific to the Wisconsin CLTS Waivers, including ensuring health and safety of the waiver participant. This third topic is an area where the Council and DHFS could create the materials.
- The goal following the initial training of 25 people would be that some of those people would develop trainings – a "train the trainer" approach. The project would remain available to provide consultation over the next two years.
- The theme is "collaboration," including researchers, providers, and other stakeholders. The more partners, the better the project.

- Viv Hazell suggested doing a parent training module at the same time, as parents are overwhelmed with trying to understand their child's needs.
- Linda Tuchman reiterated how this project coincides with the Council's earlier discussion regarding treatment modalities and evidence-based effectiveness. The knowledge they are gathering now is what they would have to offer and is a continuous "work in progress," since new research is always being done. However, at this time this is the only project looking at all aspects of the issue across the age span and across treatment approaches.
- When done, the project will be able to identify which approaches are shown to be effective, although it will not be able to say which approaches are "best."
- Len outlined the process: they use a matrix of communication, play, age ranges, etc. They set criteria against which they measure a study. If the study meets the requirements, they will then put it through the matrix. The committee and all interested parties would be able to plug their results into the matrix. The hope is to have this tool done in early 2008.
- One hoped-for result is that this will spur more research on intervention methods.

The Planning Committee hopes to meet in early January 2008.

Motion (Michael Williams): That the Council nominate Pam Stoika and Milana Millan to represent the Council on the planning committee.

Seconded: Viv Hazell

The motion was Approved by unanimous voice vote.

Update on Council vacancies. DHFS assumes that with the biennial budget finalized, activity in the Governor's Office on Council membership will resume. Beth reminded Council members that if they had anyone to recommend who could broaden the diversity of the membership (racial, ethnic, geographical, etc.), they should let Beth or Sandy know. When the Governor's Office reviewed applicants previously, there were no applications from people who matched the Council's wish for parents with children currently receiving intensive services through the waiver, or on the wait list, etc.

The meeting was adjourned at 3:00 PM.

Minutes Respectfully Submitted by
Sandy Blakeney
February 18, 2008