

**MEETING MINUTES
of the
AUTISM COUNCIL**

- Date:** June 4, 2008
- Location:** Madison, Wisconsin
- Members Present:** Nissan Bar-Lev, Terri Enters, Vivian Hazell, Joan Ketterman, Pam Stoika, Glen Sallows, Brad Thompson, Michael Williams
- Members Absent:** Rose Helms, Milana Millan, Paul Reuteman
- Department Staff:** Sandy Blakeney, Julie Bryda
- Facilitator:** Kris Freundlich

The meeting was called to order at 10:15 a.m. The Council welcomed a newly appointed Council member, Bradley Thompson, and full introductions were made. Brad is the parent of two teenage sons, one of whom has autism. Brad and his family have had extensive experience with various types of autism treatment services over the years in multiple states. He is an advocate of using many types of service approaches, and he has interest in issues related to the transition from teenage to adult for individuals with autism.

PUBLIC COMMENT

Two individuals registered to speak to the Council, and a third individual sent comments via e-mail which were distributed to the Council.

Jackie Moen is the mother of two children with autism who participated in intensive in-home treatment. Though they made progress, they continued to have needs that Jackie thought could not be met by services provided exclusively in the home and commented that a “social disorder” like autism should not be addressed by isolating the children within their home. Jackie created a nonprofit organization to provide services to children with autism in a more social setting. The organization is officially a “mental health clinic” in terms of how the organization is regulated, and they have a mental health aspect especially in terms of providing therapy services for family members of children with autism. The children who participate in this program are age 2 1/2 to school age. They participate in classrooms with three therapists and a maximum of seven children. The therapists’ backgrounds vary (Early Childhood Education, Special Education, Speech/Language, Occupational Therapy, etc.), but all of the therapists would qualify for the “senior therapist” level defined by the CLTS Waivers service code (SPC 512). Each child has a treatment plan based upon goals set by the child’s treatment team. The center is a natural setting with the child’s peers, therapists facilitate interactions based upon individual children’s goals. The center first began with a pilot program in the summer of 2007 and opened for business on October 1, 2007. They were unprepared for the large response, and they currently serve over 90 children. Some children attend a couple times a week, some are there almost full time (about 38

hours per week). The fee is less than \$25,000 per year, which would be significantly less than the cost of traditional in-home ABA therapy.

Matt Wisse is a parent of a child currently participating in the CLTS Waivers intensive in-home treatment phase of the program. Matt described his son, his needs and his abilities, and explained that he believes his son would benefit greatly from community outings as part of his treatment, but that their requests to have therapies provided outside of the home have thus far been denied by the county and DHFS. He understands that there are regulations inherent in the CLTS Waivers that require the intensive phase of services to be provided in the home, but that exceptions are granted for requests that meet waiver requirements. He and his son's provider are working to develop an appropriate request (including a specific goal with a specific outcome for a specific period of time, and details for how progress toward the outcome would be measured). Julie Bryda (a Children's Services Specialist with DHFS) explained that county waiver agencies review variance requests like this and that DHFS staff consult with the counties. She assured Matt that DHFS would examine his request. She also explained that the in-home requirement is also relaxed somewhat during the last six months of intensive treatment, as a child begins to transition toward ongoing services, so if a family is wanting therapies that are more like the services available during the ongoing phase of the waiver program, they can transition early from intensive to ongoing if they meet all the necessary requirements to be eligible to transition. Matt ended by saying he hopes to be part of the solution to this problem, and would like to see the existing CLTS waiver rules changed.

Kirby Lenz submitted written comments to the Council. Kirby is a member of Senator Kapanke's Task Force on Autism in the LaCrosse area, and he is employed as president of Chileda, a residential and day treatment program for children with Autism Spectrum Disorders. Kirby's comments were in support of changes to the current CLTS Waivers and he asked the Council to consider making a recommendation that the DHFS develop greater flexibility in the intensive phase of the waiver program to include a "managed care" model.

Discussion Following Public Comment

- The Council discussed the importance of counties and providers having the same information and using consistent interpretations of the state waiver regulations. DHFS holds meetings in each state region three times each year, providing updates and clarifications to the county waiver agencies. The waiver agencies are responsible for ensuring that they understand the regulations and communicate them accurately to service providers.
- DHFS staff will compile a description about how information is disseminated currently to share with the Council at an upcoming meeting.

APPROVAL OF MINUTES

The Council reviewed the draft of the April 2, 2008 Meeting Minutes.

Motion (Viv Hazell): That the Autism Council approve the April 2, 2008 minutes.

Seconded: Pam Stoika

The motion was Approved by unanimous voice vote.

DATA REGARDING TRANSITIONS TO ONGOING SERVICES

The council was given the policy regarding eligibility to transition from intensive to ongoing services. Sandy Blakeney presented data showing a comparison over several years reflecting children transitioning from intensive to ongoing services. The Council was interested in seeing whether or not *more* children are transitioning as soon as the minimum requirement of one year of services has been met. The Council has heard anecdotal information that families are moving out of the intensive phase earlier because the requirement to have up to 35 hours of line staff in their homes every week is too difficult for families. Data indicates that there has been an increase in the rate of children transitioning earlier than three years:

Percent of approved transitions after just 1 to 1 1/2 years of intensive in-home treatment:

2005: 1.1 % of transitions

2006: 2.6 % of transitions

2007: 5.1 % of transitions

2008: 4.2 % of transitions (to date)

Discussion of early transitions:

- Families are tired, or they want other services, or their child's progress has leveled off.
- County waiver agencies work with families to avoid inappropriate or premature decisions to transition early, since families do not have the option to return to intensive services after making that decision. This is their one "shot" at the intensive in-home treatment services.
- It is expected that the rate of early transitions increase since the wait for intensive slots has grown and children are starting intensive services at an older age, closer to school age.
- Some children would benefit from a lower level of intensive services (e.g., 10-12 hours per week), but this is not allowed at the intensive level, and at the ongoing level of services, that many hours of intensive services would be too costly.
- Changes in the rate of transition to ongoing is challenging for providers; more difficult to project their budgets into the future if children are starting later (in age) and leaving the intensive phase earlier.
- Intensive services have documented positive outcomes – if children are not receiving those intensive level services at an intensive level, they are at risk for problems that can impact their long term development, families, school success, and, their community.

FLEXIBILITY IN TREATMENT

At the last Council meeting, the Council asked DHFS to "draft guidelines allowing parent 'line hours' to count toward treatment hours during the period that the child has waiver funding, while addressing waiver safeguards." Sandy Blakeney and Julie Bryda presented the Council with an overview of the Council discussions so far on this topic plus a short review of the current applicable CLTS Waiver policies that affect this issue. It was also reiterated that the Department would not consider changes that would require amending the current waivers, so any changes would need to be both cost neutral and in compliance with the waivers as they are currently written.

The primary reasons for the interest in this kind of change is to address the challenges families have expressed in having the intensive level of therapy provided in their home. A possible byproduct of this change could be that some funding becomes available to decrease the wait time for waiver slots.

The presentation laid out potential changes to policies in order to allow members of a child's family or household to provide unpaid line therapy hours that are counted toward the required treatment hours. Ideas presented as possible policy changes included:

- require a Variance Request before implementing unpaid therapy hours
- cap the maximum allowable unpaid therapy hours
- identify who would be approved to provide unpaid therapy hours
- expectation of parents to meet original waiver team responsibilities without counting the time as treatment hours
- safeguards to ensure that parents make an informed choice regarding unpaid line therapy
- increased training and supervision requirements
- responsibilities of parents to maximum

Implications of the changes discussed included:

- Possible need to revise the system of provider reimbursement.
 - Currently a “bundled rate:” providers charge a single hourly rate for all therapists (line, senior and lead) for direct service, travel, and staffing hours.
 - Unpaid therapy hours would replace some of the hours of providers’ lower-paid staff (line staff); this may impact their ability to pay the senior and lead therapist rates.
 - Might need to “unbundle” the reimbursement rate if utilizing unpaid therapy hours
- DHFS staff would need to revise existing procedures in order to implement the changes and develop new materials for waiver agencies and providers to inform them of the changes.
- DHFS staff would need to update existing resources (forms, documents, etc.)
 - Electronic Individual Service Invoice (ISI) revised
 - Variance request form
 - Parent/Legal Guardian signed agreement to participate
 - Tracking data and costs

Discussion of implications regarding establishing this change:

- Informing families and providers: will need to think about how this will be done, who will do this, and what informational materials would need to be developed.
- May be challenging for providers to make the assessment that a family would not be qualified to do this service, or is not following through and should discontinue.
- Parameters: will there be a “cap” on the maximum hours that can be provided by family members? Will family line hours be counted toward the required 80 per month?
- Documentation: providers will need to document verification that hours were provided, that the service was delivered according to the established service plan for the child, etc.
- This would not affect the existing policies regarding allowable location of service provision (e.g., services are delivered in-home, except when an appropriate variance request has been approved). However, this could help some families with school-aged children who struggle finding the hours to have line therapists coming into their home.
- Must be sure that parents/family members who provide the service are sufficiently trained in the service techniques and the required documentation.

- Provider reimbursement: with the current flat hourly rate (“bundled rate”), providers would not have [monetary] incentive to increase senior/lead time and decrease line therapist time. Would a new reimbursement structure need to be developed?
- Would this kind of change affect the existing policy regarding 2:1 service? E.g., currently policy requires prior approval for a provider to bill for two therapists providing direct service to a child at the same time, and would only occur when it has been determined to be necessary in order to assure the health and safety of the child. It is highly unlikely that a child who would be approved for 2:1 services would be a good candidate for having the family provide a portion of the intensive services.
- Would this kind of change affect the “overlap” policy, in which two or more line therapists who are providing treatment sessions in succession to a child may overlap with each other during the transition from one session to the other. Providers may bill for only one of the therapists’ time during that overlap period. This does not apply to Senior time, as that would be considered training and not direct service. A change that would allow families to provide line therapy would not affect this policy.

The Council discussion generated a number of issues that DHFS staff will continue to address and bring back to the Council for further consideration. Next steps identified were to get Legal Counsel approval for making this change, continue investigating how to manage the provider reimbursement rate structure, continue drafting policy changes, and develop an estimated timeline of when a change like this could be implemented.

MATERIALS FOR FAMILIES ON WAIT LIST

Council members determined that this issue has been addressed in the past and that each provider is ensuring that families they work with, who are waiting for waiver funding, are receiving informative materials during that time. Glen Sallows brought a handout showing results that WEAP found after training some parents to provide limited intensity treatment to their child while waiting for funding.

GETTING THE HOUSE IN ORDER: CREATING MEDICAL HOME SOLUTIONS FOR CHILDREN WITH AUTISM

Joan Ketterman and Julie Bryda reported on a conference they attended in Chicago in December 2007. Many midwest states participated in brainstorming, reviewing current practices, unmet needs, and presented plans for moving forward. There were school representatives, caregivers, medical providers, public policy-makers, as well as state, county, university, and legislative representatives. The discussion was energetic, the participants were high-level professionals who struggle with coordinating medical with school programs. A striking point was that Wisconsin was one of the best-funded programs; participants from other states described creative things they have done with their funding, including more collaboration across provider and funding agencies. The Wisconsin contingent’s plan included improved collaboration, early identification screening, and development of best-practice model (the Waisman Center project).

UPDATES/REPORTS

- **Waisman Center Projects**

Julie Bryda informed the Council that the Waisman Center is applying for a new grant in order to look at autism diagnoses. The grant was due in June 2008. DHFS staff have been assisting with gathering data for the application. This project could provide DHFS with much needed guidance on the issues of autism diagnosing.

The National Professional Development Center on Autism Spectrum Disorders, in which the Waisman Center is a partner, has been outlined in details in minutes from Council Meetings on November 19, 2007 and April 2, 2008. Joan Ketterman provided the Council with an update on the progress toward developing a training curriculum. They have a very tight timeline for providing initial trainings. At this point, they have identified school districts that will be included, but dates and locations were not in place yet.

- **Council Membership**

The Governor appointed Brad Thompson to fill the position vacated by Deb Mandarino. Sandy Blakeney has been in regular contact with the Governor's Appointments office.

- **Current Issues with Travel Expenses**

There was discussion about the rising cost of gas and its impact on agencies providing in-home treatment. There may need to be consideration of treatment models (center based, parents as line, distance training) that are more cost-effective. Julie noted that the waivers currently allow for variances to allow "conference call" supervision as well as other alternatives to the standard model. Suggestions from Council members included setting up a toll-free number to get input from families, offering more online training opportunities, and developing regional trainings for families.

UPDATE ON TRANSITION TO NEW DEPARTMENTS

Diane Waller and Jennifer Jones, members of the DHFS transition team coordinating the establishment of the new Department of Children and Families (DCF), provided the Council with a presentation on the new departmental structure and the current status of the transition:

- First cabinet agency devoted exclusively to helping children and their families
- DCF mission "To promote the economic and social well-being of Wisconsin's children and families."
- Achieve goals by streamlining government, integrating program approaches, emphasize performance and outcomes, improve quality, include consumers in decision-making.
- New department starts 7/1/08 with all administrators in place, relocation of staff will take more time.

Council comments and input:

- Important for child care agencies to refer children and families to autism providers.
- How will parents know about changes? Some parents have limited access to Internet.
- Medical doctors are a common referral point for autism services. With no insurance coverage for autism services, doctors do not refer.
- Council can share info and input with DCF by emailing dcf@wisconsin.gov

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- For many families, autism becomes the “sole” focus, but many struggle with other issues (e.g., child care). Important to continue collaboration of services regardless of which Department oversees those services.
- There was no additional funding available in the Governor’s budget for creating this new department.
- Good communication between the two departments will be crucial.
- County agencies are dealing with issues such as if or how funding streams will be split as a result of this department restructuring.

Meeting was adjourned at 3:00 pm.

Minutes Respectfully Submitted by
Sandy Blakeney
August 18, 2008