

MEETING MINUTES of the AUTISM COUNCIL

- Date:** November 17, 2008
- Location:** Madison, Wisconsin
- Members Present:** Nissan Bar-Lev, Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Milana Millan, Glen Sallows, Michael Williams
- Members Absent:** Pam Stoika, Brad Thompson
- Department Staff:** Sandy Blakeney, Julie Bryda, Jacqueline Moss
- Facilitator:** Kris Freundlich

The meeting was called to order with introductions all around at 10:10 a.m.

PUBLIC COMMENT

Keith Green, grad. student at UW Madison School of Social Work: Mr. Green discussed concerns regarding adolescents with autism who are placed in emergency detention at Mendota Mental Health Institute (MMHI). These individuals have unique issues that are not conducive to the current MMHI environment: their behaviors are counterproductive for the other individuals with behavior problems; they are uniquely vulnerable to being targets of abuse or sexually inappropriate behavior because of their difficulty expressing their needs; these children generally end up in seclusion or not being treated with dignity and respect. Mr. Green does not advocate the institutionalization of children with autism, but, for those who *must* be placed out of home temporarily, he does advocate for the development of a separate unit at MMHI for children with autism, to better meet their unique needs. He asks that the Autism Council support this request and help to advocate for a change at MMHI.

Discussion:

- Council members gave several suggestions on who should be contacted in these instances including administration for the Division of Mental Health and Substance Abuse Services (DMHSAS) and Family Ties.
- DHS has funding for counties to provide services to avoid out of home placements. Placement in an institution is considered a 'last resort,' and counties must move quickly to move the child back out.
- Training is critical for facility staff, law enforcement, county workers, to better address the needs of individuals with autism.
- All places where children go will be places where children *with autism* go. The 1-in-150 children with autism will become the 1-in-150 adults with autism. Necessary to be proactive and address these issues in all settings. Must widen the emphasis beyond just children.

Mr. Green and the UW-Madison group thanked the Council for their time and discussion and the Council in turn thanked them for coming and their interest in these issues.

APPROVAL OF MINUTES

The Council received the minutes quite late and deferred review and approval until the next meeting.

MEMBERSHIP UPDATE

Paul Reuteman has resigned from the Council. This opens another position for a parent member – would like representation from a rural/remote area. Members are unclear as to how long this Council will be in existence.

STAFF UPDATE

Bill Murray and Ed Miller have joined the Children's Long-Term Support team. Both are PhD psychologists. Bill was in attendance and gave the Council a summary of his background, including a Masters degree in Applied Behavioral Analysis and extensive work with the Department as a consultant regarding evidence-based services for children with developmental disabilities and their families as well as helping build system capacity within communities.

Some of Bill's responsibilities include:

- reviewing all requests for variances within the autism programs of the CLTS Waivers, and working directly with the CLTS team in responding to variance requests
- working directly with providers to help articulate goals within variance requests
- helping to design training for providers and service coordinators in the development of variance requests to ensure they meet the policies of the CLTS Waivers and fit within the parameters of evidence-based best practice.
- working with the CLTS team to continue the process already begun, looking at flexibility within the provision of waiver services and addressing the provider billing issues that have come up in earlier meetings of the Council.
- reviewing diagnoses of children participating or applying to participate in the CLTS Waivers.

In addition to many of the same roles that Bill has, Ed Miller will also be working on a variety of quality-assurance efforts for the CLTS Waivers, designing surveys, compiling data, etc.

DPI DATA

Nissan Bar-Lev presented data from DPI regarding the prevalence of ASD in the public schools from 12/1/2000 to 12/1/2007. The trend continues to be increasing in all areas of the state.

WAISMAN PROJECTS

Twenty two evidence-based treatment models have been identified. The core training module is easy to follow and read. The project has many resources online. At this time the training module does not include certification.

MEDICAL HOME

Joan Ketterman reported on the Medical Home initiative. Wisconsin got a grant to continue until August 2011. They would like to provide a 20-minute presentation to the Council at some point to describe the efforts to create a network that will: identify children with ASD; help families

gain entry to support services; learn more about the family's experience; coordinate delivery of care systems. The goal will be go create opportunities for different ongoing projects that are related to ASD issues so that they can share information and benefit from the work of others. Next meeting is February 2009.

DHS UPDATES

- The CLTS Waivers unit lost two experienced staff (Diana Adamski and Pam Groeschl) and have gained new staff with backgrounds in children's and MA waivers.
- Becky Boyea is based in the northwest part of the state and is a Children's Services Specialist, supporting and consulting with county agencies in implementing children's programs.
- Robin Raj is based in the northeast part of the state and will work on Children's issues half-time while continuing to work with the adult waivers as well. Robin has almost 20 years experience with (adult) MA waivers.
- Theresa Walske is based in Madison; she is a policy analyst, has substantial background with Medicaid, is a speech-language pathologist, and comes to us most recently from the state Birth to 3 Program. Theresa is the Lead of the Children's Long-Term Supports team (taking Julie Bryda's place).

BUDGET UPDATE

DHS continues to release 11 new slots for intensive services per week and expects this to continue at least until June 30, 2009. Counties are reporting that this is impacting the ability of providers to start services due to capacity issues. DHS is talking with counties to try to assess the extent of the issue. The waivers continue to require that children receiving Intensive Treatment receive at least 20 hours of face-to-face treatment per week.

Discussion:

- At quarterly Regional Meetings, counties were reminded to work with their contracted providers to try to deal with staffing shortages.
- DHS is designing a method by which counties can get more advance notice of children whose names are coming up to the top of the waiting list. But counties are keeping track of the status of the children waiting in their area so that they can plan.
- Providers struggle with difficulties keeping staff in place. This is a nationwide issue.

INSURANCE LEGISLATION

Senate and Assembly bills are expected again in 2009. A bill was introduced in 2008 but did not pass. Expect more support in 2009. It is not clear yet exactly what services would be covered by insurance or exactly what the impact will be in terms of cost savings for the State.

ALTERNATIVES TO TREATMENT

Staff are continuing to look at what services are being provided to children in the intensive treatment phase of waiver services, what providers are billing for. Also studying diagnoses and assessed needs of children. The goal is to maintain the integrity of the program and look at what options are available to meet changing needs or economic realities. Staff will be returning to the Council with recommendations as the work progresses.

Discussion:

- Intensive treatment is not necessarily the only door to services for children with autism. There are other types of waiver funding that can be used to address the needs of children at a less intensive level.
- Must always stay aware of what the current research indicates is the most effective treatment.
- Some parents are asking for services that simply are not allowable by the waivers or are not appropriate for their child. Might be helpful if DHS and DPI could coordinate on some informational materials for parents.
- With provider staffing shortages, what are the alternatives? What are the fiscal implications for adding flexibility in treatment (e.g., allowing parents to be trained to provide intensive services).
- In building flexibility, DHS needs to have a thorough understanding of what exactly is being provided now and at what level these activities should be reimbursed. Will work with a subgroup to identify these terms.
- Under no circumstances can intensive services drop below the minimum of 20 hours per week.
- Concern that parents are removing children from school in order to get treatment.
- Volunteers for workgroup are: Viv Hazell, Milana Millan, Pam Stoika, along with a staff person from WEAP to be named.
- DHS is also looking at contracting with an actuarial service to help define billable services. Important to have this happening as well as the subgroup looking at actual services being delivered.

2009 Meeting Schedule

- Monday, February 23, 2009
- Monday, May 18, 2009
- Monday, August 17, 2009
- Monday, November 16, 2009

Meeting was adjourned at 2:15 pm.

Minutes Respectfully Submitted by
Sandy Blakeney
February 23, 2009