Governor's Autism Council Meeting Minutes
Thursday, April 11, 2013
10:00 AM to 3:00 PM

Council Members: Nissan Bar-Lev, Wendy Coomer, Vivian Hazell, Rose Helms, Milana Millan, Glen Sallows, Pam Stoika
Facilitator: Kris Freundlich
DHS Staff: Julie Bryda, Susan Larsen, Meghan Mitchell, Bill Murray
Guests: Daniel Parker (Wisconsin Department of Public Instruction); Ellie Hartman, Sarah Nelson, and Jessica Thompson (Wisconsin Department of Health Services)

The meeting started late (10:40 AM) due to an unanticipated last minute change of location.

Public comments: There were no members of the public present.

1. **Welcome and Introductions**
   Council Member Updates
   A new member was appointed by the Governor's Office: Wendy Coomer. Wendy introduced herself and shared a bit about her background as a parent and her current role in the Wisconsin Department of Administration.

2. **Approval of November 19, 2012 Council Meeting Minutes**
   Nissan Bar-Lev asked that the wording "at a recent meeting with the Department of Public Instruction" be removed to accurately reflect his comments. Milana made a motion to approve the minutes with the aforementioned change. Nissan seconded the motion and the minutes were approved.

3. **Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)**
   The new manual eliminates the separate classifications of Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Asperger's and Autism, which will be combined into a new diagnosis of "Autism Spectrum Disorder."

   Currently it is envisioned that eligible children with an existing DSM-IV diagnosis will remain funded through the Children's Long-Term Support (CLTS) Waivers. After the manual update, it is envisioned the waiver will fund children with an Autism Spectrum Disorder.

   Rett's Disorder is being moved to a genetic diagnosis in the DSM-5 and it is envisioned that this will remain a disqualifying diagnosis, as will Childhood Disintegrative Disorder (though where this latter diagnosis falls in the new DSM is currently unknown).

4. **Waitlist Proposal Update**
   The Autism Council's letter regarding a revised wait list procedure was shared with Secretary Smith and Kitty Rhodes.

   The proposal was reviewed but there is no wish to pursue this at this time by DHS Administration, who is concerned with how this policy may impact other DHS wait list policies. Additionally, the Department was concerned that the Centers for Medicaid and Medicare Services (CMS) approval for our autism wait list procedure as "first come, first served."

For non-autism funding related programs, specific criteria have to be met in order for a child to bypass the wait list and receive priority services. These factors include crisis needs, the absence of integral family members, and other extenuating circumstances.

It was noted that the Family Support Program may allow a child to bypass the wait list based on a child's developmental needs. For example, if a child is in an optimal developmental period for acquiring speech and was unable to obtain services, the wait list can be bypassed so that he/she can receive services.

It was recommended that any potential variance process have specific criteria for wait list changes. Potential variance processes could include additional testing, provider involvement, and parental involvement.

Council members wished for it to be noted that for autism treatment to be most effective, children have critical "windows of time" when acquiring certain skills is necessary for proper brain functioning and development. For children with autism, bypassing the wait list should refer to this window of learning opportunity.

Council members expressed an interest in rewriting their proposal.

5. **Line Staff Core Curriculum Update**
   Dr. Nan Huai previously gave a presentation to the Council focused on recommendations for revising part of the content of the forty hours of training required for new autism provider staff prior to being waiver-qualified. This includes a focus on ethical requirements, mandatory reporting laws, seclusion and restraint, the basics of evidence-based treatment, and a general "Autism 101" overview.

   At the autism treatment provider meeting on Monday, April 15, the Department would like to share the new requirements with the providers.

   It may be beneficial to ask providers to share their training and development process regarding the five areas mentioned above. The Department is considering establishing a deadline for when providers are expected to have this curriculum implemented and may provide feedback regarding the training curriculum.

Break for lunch at 12:04 pm

6. **Autism Treatment: Home and School Issues**
   Nissan Bar-Lev and Daniel Parker (DPI) led this discussion related to concerns over school-age children who are eligible for autism treatment funded by the CLTS waivers. Relevant topics included:

   - In Wisconsin, compulsory attendance requires any child age six and over to attend a full day of school. District policy on attendance provides options for children under this age. Many families ask to shorten the school day for children with developmental issues. A shortened school day is only allowed for specific reasons approved by the Individualized Education Program (IEP) team. Challenges exist when trying to coordinate public education and autism treatment.

- DPI is in the process of drafting guidance related to the coordination of public education and treatment. This will be shared with DHS for input on the CLTS waiver coordination side of this issue.

- DPI continues to develop additional resources for teachers that specialize in services for children with autism. The various Cooperative Educational Service Agencies (CESAs) across Wisconsin will also provide training and provide professional development to their trainers using a coaching module.

Rose Helms commented that the important area of social skills training is often provided by autism treatment providers whereas education is designed to teach academic skills. For some children, social skills (provided through the autism treatment provider) are very important and families may value the importance of social skills over educational skills.

Vivian Hazell noted that some school districts restrict the access of autism providers to school settings. This is a topic that needs additional discussion.

Pam Stoika inquired how an intensive treatment model can realistically be utilized for children who attend a full day of school. DPI has been and will continue to evaluate state and federal laws on treatment within school settings as it is believed some states may allow for this.

7. Transition presentation

Jessica Thompson, Sarah Nelson, and Ellie Hartman (DHS) presented to the Council on the topic of transition issues for children with disabilities, with an emphasis on issues related to children with autism. DHS has an interest in facilitating smooth transitions to adult long-term care and increasing integrated employment options for all children with disabilities, including autism diagnoses. The group presented on the following broad topics:

- The CLTS Waiver program is working on contract language which would require a transition-focused meeting between county waiver agency children's services staff and adult services staff. For "legacy waiver" counties that do not yet have in place managed care organizations (MCOs) or IRIS (Include, Respect, I Self Direct, the DHS self-directed services model for adults), it is very important they thoroughly evaluate potential jobs and natural supports when children are still involved in the CLTS Waivers.

- A DHS Youth in Transition web site is being created with transition resources so that CLTS service coordinators can identify other programs they can potentially collaborate with, including the CLTS Mentoring service and the national Community of Practice on Transition and their transition toolkit for children with autism diagnoses. Jessica Thompson will share the link for the toolkit when it is available.

- Wisconsin recently became a National Core Indicator state and has started collecting data regarding employment for people with disabilities. This data is only collected in counties with MCOs and IRIS participants.

Approximately 14% of people with developmental disabilities (DD) have a community paid job. This percentage is typical regardless of the economy. From 2010-2011 the statistics show

approximately 15% of the DD population was employed in the community which equates to roughly 10,000 people.

The total number of individuals with a DD level of care on their functional screen is 17,500. Of this number, 8,900 have some type of employment (56%), and 2,400 have community-based employment (14%). “Home employment” is either classified as working through a company or self-employed.

Employment statistics are smaller for individuals who are classified with a physical disability (PD) level of care and no co-occurring developmental disabilities, mental illness, or traumatic brain injury.

For adults with an autism diagnosis in the long-term care system, community employment is very similar to adults without autism. However for ages 18-24, employment within the community is lower than the national average at 11%.

“Work-centered” employment is within a facility that only employs people with disabilities, and “group centered” employment work is when a group of individuals work together with a job coach for a certain job.

For people with a developmental disability in the adult long-term care system, approximately 33% are receiving pre-vocational services, whereas approximately 16% receive supported employment services.

Individuals with a physical disability have much lower rates of employment. These individuals cite multiple barriers to employment, one of them being health conditions.

For the first time last year the DHS started to evaluate the types of employment participants have:

Of those who are working: 26% worked in integrated employment, 5% worked in enclaves (work crews), and 77% worked in a facility. Wages vary depending on the type of employment from $8.01 per hour (integrated employment) to $2.33 per hour (facility work).

Transition planning for children with autism should utilize evidence-based practices and include training for relevant individuals.

Keys for successful transition include having a proper job match in addition to other factors.

The Council suggests this topic be considered for inclusion in a future autism provider meeting.

As the Council’s roles and responsibilities change and mold, it is important to think ahead for services that children with autism will need in future years. The design of the Council’s scope may need to be re-identified for the aging autism population and their transitional needs.

8. DLTC/BLTS Updates

Sue Larsen provided the following Division and Bureau updates: Kitty Rhodes was approved by the Legislature to be the Secretary of the Department of Health Services, and Pris Boroniec has left her position with the Department as DLTC Administrator.

Adobe Connect can be a beneficial tool for Council members to attend and participate in meetings when they are not able to travel to the Madison area.

The Department is evaluating issues related to coordination of benefits with fiscal management staff and Wisconsin Physicians Service (WPS) to provide more reliable data through the data warehouse.

The Governor's budget did not reduce any funding for the Children's Long-Term Support Waivers; however, an additional 30 million dollars was included for services for children with mental health concerns.

This committee may want to formulate some suggestions for the development of new mental health programs.

The U.S. Department of Education/Office of Special Education Programs has issued notice to the Department for a 5 percent budget cut to the Birth to 3 Program Part C funding (approximately $450,000.) The Department is looking for strategies to absorb these costs without affecting the services to children participating in the program.

9. Additional Information

The committee members are interested in having another meeting before the next scheduled committee meeting to discuss the waitlist proposal and school/waiver issues.

Adjourned: 2:57 PM