

Governor's Autism Council

Wednesday, July 24, 2013
10:00 AM to 3:00 PM
Department of Administration
Room 122 (Yahara Room)
Madison, WI 53707

MEETING MINUTES

Council Members: Nissan Bar-Lev, Vivian Hazell, Nan Huai (for Glen Sallows), Milana Millan, Pam Stoika
Facilitator: Kris Freundlich
DHS Staff: Julie Bryda, Bill Murray, Alyssa Zirk
Guests: Peggy Helm-Quest, Joanna Juhnke

The meeting started at 10:07 AM.

Public comments: There were three members of the public in attendance but no comments.

1. Welcome and Introductions

Members of the Council, DHS staff and members of the public introduced themselves.

2. Council Autism Wait List Discussion

- The Council has previously discussed the status of the increasing number of children on the Autism Wait List and the science/evidence behind prioritizing serving the youngest children. It was pointed out that children who do not begin intervention at a very early age will likely not learn to speak.
- Recent legislation has been introduced to eliminate the wait list.
- The Council was reminded that the Autism Society of WI (ASW), who recently sent a letter to the Department of Health Services (DHS) stating they are not in favor of fast-tracking services for the youngest children, as they represent all families who have children with autism and cannot favor any one part of the larger population.
- The Council discussed concerns that children both within the inner city and rural areas, for a number of reasons, frequently do not receive a diagnosis until they are in school, which is a longstanding concern. Some members questioned whether the Council is prepared to ignore the research related to the long term benefits for the youngest children.
- The Council suggested that DHS might wish to consider a cutoff age of 6 years (as many other states do) to shorten the wait list and reflect the realities of the research. This was not a recommendation, merely a suggested option.
- The Council discussed rewording their previous letter to DHS Secretary Smith and sending it to Governor Walker, stressing the need for early intervention (children 3 years and under) and the realities of what it means for children and families to wait approximately two years for autism treatment services.
- The possibility of a two-tiered approach was mentioned, first dealing with the current wait list now and then revamping the existing wait list procedures.

- The Council discussed scheduling a meeting with the ASW Board, ASSEW (Autism Society of SE Wisconsin) Board and ASSCW (Autism Society of South Central WI) Board to discuss these issues.
- The Council suggested taking into consideration all perspectives on the wait list issue but make a decision, proceed and get feedback.
- Agreed upon next steps involve Pam rewriting the letter and sending it to Governor Walker after receiving input from the Council. Nissan suggested waiting until after the ASW, ASSEW and ASSCW Boards can meet with the Council, targeted for August 2013, and DHS to be invited to attend. The Council will extend an offer to others, and Milana and Pam will be spearheading this effort.
- The Council is concerned all groups need to know and understand more about the issues to ensure everyone makes an informed decision.

3. Revision of the Autism Council By-Laws

- Council members received copies of the updated By-laws and will be reviewing them for discussion and approval at a future meeting.

4. Requests for Waiver Funded Items and Services

- DHS discussed the critical need for collaboration among providers, families, and county waiver agencies to ensure recommendations for CLTS Waiver funded items are framed within the context of waiver allowable services based on the assessed needs of the child and effective outcome.
- DHS is planning future discussions with counties to assist them to focus families with discussions regarding the assessed need of their child.
- The Council noted that most requests of providers come from county waiver agency conversations with families and the process of identifying needs, then requesting provider input by writing a supporting letter.

5. Division of Long Term Care (DLTC)/Children's Services Section Updates

- The Centers for Medicare and Medicaid Services (CMS) has accepted the Children's Long-Term Support (CLTS) Waivers annual data and quality report. The Department's Third Party Administration claims process has increased the ability to improve tracking and trending of the service data.
- The Department's joint efforts with the Department of Workforce Development (DWD) and the Department of Public Instruction (DPI) surrounding Youth in Transition improvements and the *Lets Get to Work* Grant both continue.
- "Heart of the Matter" listening sessions with county waiver agency staff, families and other stakeholders led by the Department are being held around the state. Providers will be invited to attend the next round of listening sessions. The hope is to update the Council at an upcoming meeting with preliminary reports from the organizers.
- The DHS Information Technology (IT) system infrastructure continues to be developed and is being enhanced in several areas, including:
 - Children's Wait List
 - Incident Reporting
 - Wisconsin Provider Index
- Current waiver participant enrollment data was shared with the Council.

6. Compulsory Education Laws & Timeline for Autism Treatment

- Marge Resan and Daniel Parker from the Wisconsin Department of Public Instruction (DPI) provided an overview on compulsory education laws.
- DPI is developing a document to share with DHS and establish a joint statement on this issue. School districts set their own policies within state and federal law, DPI does not have authority to force compliance.
- Question: *Can the Individualized Education Program (IEP) team shorten a school day so a child can receive treatment?*
 - Answer: Shortening a school day is restrictive in the larger context of the child's needs, and is only acceptable for the child's unique disability-related needs. If the sole purpose is to obtain therapy, schools cannot shorten the school day. State statutes address compulsory attendance, requiring full days until a child is 18 years old. Five year old kindergarten is optional, but if a family enrolls their child, the child is obligated to attend.
 - Compulsory school attendance applies to all children, regardless of any disability status. Shortening school days for any reason is discrimination. State and federal regulations mandate schools adhere to Free and Appropriate Public Education (FAPE) requirements. All students must be educated in the least restrictive environment with their peers unless the IEP team can justify different actions based on child specific data.
- Question: *What if a parent consents to shorten a school day for their child in order to get treatment?*
 - Answer: Compulsory attendance requirements overrule parent's consent for the shortened school day. IEP teams make placement decisions, and parents are equal participants in the team. The IEP team can make a decision to shorten a school day, but it must have a plan to increase the time spent back in school.
- Question: *Can home-based autism therapists provide services to children in public schools?*
 - Answer: Federal rules require schools to be the sole provider of FAPE services. Direct services must be provided by school staff, as this is part of access to FAPE.
 - Non-instructional times are less clear and are guided by district visitor policies, insurance and liability requirements, confidentiality issues, etc.
- Question: *How do medical issues play into this decision?*
- Answer: School personnel must make educational decisions based on state and federal law, while physicians must make medical decisions.
- There is a need to balance all of this information as some providers tell parents their child will not receive services from the provider unless they remove their child from school.

7. Meeting Adjournment

- The meeting was adjourned at 2:27 PM.