Autism Council Meeting
November 16, 2009
**FINAL MINUTES**

Council Members: Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Milana Millan, Glen Sallows, Pam Stoika

Facilitator: Kristine Freundlich

DHS Staff: Julie Bryda, Bill Murray, Katie Sepnieski

I. Public Comment
   a. Peggy Helm-Quest from the Division of Public Health discussed the Autism Society of Wisconsin (ASW) meeting held on November 14, 2009. ASW and the Division of Public Health (DPH) are applying for a National Grant and needs data from the Department of Public Instruction (DPI). However, DPI can not share data due to FERPA (Federal Education Regulation of Protection Authority). DPH would like to work with the Council to make a recommendation for DPI to release the data for planning reasons. DPH has ideas how the data could be gathered without violating FERPA.
      i. DHS will follow up with ASW to discuss this issue.

II. Introductions of Council members
   a. Discussed the issue of members responding regarding their attendance for each meeting due to the possibility of not meeting quorum.

III. Approval of Minutes-All
   a. Vivian made a motion to approve minutes with changes outlined by Council members.
   b. Milana seconded motion
   c. All approved

IV. Quality Assurance Discussion-How do you know that the treatment services provided through the CLTS Waivers are producing good outcomes for the child?
   a. The Department of Health Services is developing evidence for the Centers of Medicare and Medicaid Services (CMS) for the CLTS Waivers renewal. The evidence needs to be submitted to CMS early 2010. The evidence needs to include quality issues. Some Council members shared how their agencies review progress in their program.
   b. As progress is made with the child, the family may choose to transition early or after the completion of the 3-years of treatment. The family may choose to continue with treatment within the ongoing phase of Waiver services. Providers keep track of why a transition may occur early or the

reasons the parent may want to continue with treatment services for their child.

i. Reasons to transition early-
    1. Child has gained many skills and treatment is no longer necessary.
    2. Child is school age and it is difficult to have treatment at an intensive level of 20 to 35 hours per week.
    3. Family and/or the child can no longer tolerate the intensive hours.
ii. DHS will work with providers to develop a transition/discharge form for both early transition and at the end of the 3-years in order to track why a child transitions.
iii. DHS is considering if a standardized way to gather data is necessary, with input from the Council to meet the expectations of CMS.
iv. DHS is considering working with all providers to review the trends for transition and determine how to review the outcomes.
v. The provider members use different tools to determine progress:
    1. Assessment tools are being used (Vineland, Outcomes on the ISP, The ABLLS, Personality Inventory for Children, Social Response Survey)
    2. Discussions with the families regarding what will work for them are occurring.
    3. A narrative regarding the goals and outcomes outlines the progress that is being made
    4. Collecting data on five main competencies:
        a. daily living, social skills, self-regulate, communication and learning
        b. Data is collected for each child which addresses the competencies
    5. Hire psychologists to complete testing for children involved in the intensive in-home treatment services
vi. What is occurring with the older children that have ongoing treatment needs? Families are unsure what can be done.
    1. DHS is working with counties to remind them that intensive service providers can offer services to families which focus on behavioral interventions and treatment.
    2. When children transition the provider's focus may change to supporting the family in order to meet the child's outcomes.
    3. Many times the outcomes are written for the child but the family needs to be included in how the treatment will be implemented.
    4. Vivian offered to share the video "Something to Contribute"

c. The goals of the family change, which in turn changes the treatment. It may be difficult for families to understand the regression of the child when they had a "typical" child at one point. The importance of educating the parents on the diagnosis, the treatment interventions, and services available is vital.
    i. Families are able to verbalize what has changed in the child's life and within the family. Where were the deficits and how did they change?
    ii. Families are able to use the skills they were taught in the intensive in-home treatment as the child grows and the needs change.
    iii.

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V. Quality Assurance-How do you know that the non-treatment services provided through the waiver are producing good outcomes for the child?
a. DHS works with Counties to review the needs of the families.
    i. DHS follows trends to determine if the needs of families are being met.
    ii. DHS may offer more technical assistance to the county service coordinators to determine what else can be offered.
b. Services can assist with keeping the family intact.
    i. Respite can give the siblings time away from caring for the child with the disability. It can also bring the parents together in order to do other things. Respite can also give a break to the child from the family.
    ii. Finding a way to have the child included in family activities is important but an assistant or additional support may be necessary. The cost of these services may need to be covered in order to meet the family's need.
    iii. Life skills training is important, to teach autonomy and independence. There are situations that the parent cannot care for the child such as a mother taking her teenage son into a public restroom.
    iv. Social skill groups can be beneficial. As the child gets older it is more difficult to find a friend network.
    v. Other devices can be useful such as a trampoline, bicycle or other ways to assist with sensory issues and with extra energy.
c. Finding a provider for services can be very difficult.
    i. Even if respite is on a plan it doesn't mean it is being used.
d. Education for parents is very important. It may be necessary for the family to take courses regarding the disability and how it will impact their lives.
    i. CESA trainings have been beneficial as well as conferences.
    ii. Having the children included in the conferences can be helpful. The families are aware of the issues and how to navigate systems.

VI. Quality Assurance-Reasonable and effective ratio of lead therapists to children served, and the frequency of qualified therapist interaction with children receiving waiver services.

a. WEAP has a range of 60-120 kids being seeing by one Lead. They prefer 60 kids.
    i. Within intensive in-home treatment services, the lead will see the child every two months. This is for an hour at a time.
    ii. Clinic supervisors see the children on the opposite month that the Lead therapist sees the child.
b. Within post intensive, Lead Therapist visit ranges depending on the county. Some counties require every 3 months, other counties require every six months. However this requires the senior therapist to be highly educated. There are also weekly staff meetings to discuss specific children.
c. BBA sees 40 kids per month. This is in the child's home so travel is involved.
    i. There is not any line therapists involved in ongoing services.
    ii. The Lead therapist sees the child every three months or more often if needed.
d. In the parent directed model families hire the staff. The provider consults with the family and then the family trains the staff they hired.
e. Consultation model is when the family comes into the office for assistance.
f. Intensive providers are losing line therapists because families are hiring them that a higher rate through a fiscal intermediary. Intensive providers may be interested in creating other services such as respite.

VII. Updates

a. Autism Insurance Mandate
    i. DHS continues to work on policies regarding the impact of the mandate on the CLTS Waivers. Families should contact the Office of the Commissioner of Insurance (OCI) if they are not getting the information from their insurance companies (800-236-8517).
    ii. DHS will coordinate with OCI to develop a FAQ document for families, county agencies, and providers.
b. Variance requests for treatment outside the home
    i. DHS continues to review variance requests for most counties. Several counties are reviewing the requests without oversight of DHS.
c. DHS has been contacted by several staff from intensive provider agencies that plans to start their own agencies. These staff needs to understand that if a variance was granted for a Lead staff position it was within the current agency and is not automatic that they will be recognized as a Lead in a new agency.

d. Rethink Autism is a new program that is located in New York. This is a web-based tool for families to view and complete modules to implement the treatment. DHS has obtained 10 pilot slots to use for children currently enrolled in the CLTS Waivers. DHS will work with the counties to evaluate how the program is working.
    i. www.rethinkautism.com

VIII. The next Autism Council meeting will be in February 2010.