Autism Council Meeting
August 17, 2009
Approved Minutes

Council Members: Julie Bryda, Vivian Hazell, Rose Helms, Joan Ketterman, Milana Millan, Glen Sallows, Pam Stoika, Brad Thompson, Michael Williams

Facilitator: Kristine Freundlich

DHS Staff: Bill Murray, Katie Sepnieski, Reed Bonner

I. Public Comment- No public comment

II. Introductions of Council Members

III. Introduction of new Children's Services Section staff member. Julie Bryda introduced Reed Bonner, the newest member of the Children's Services Section. Reed is working on the Children's Long-Term Support (CLTS) Waivers renewals. He is developing the evidence that needs to be submitted to the Federal Centers for Medicaid and Medicare Services (CMS) for their review. He has been working on the county record review reports, and the family surveys that are sent out each year. He is reviewing the six quality areas that are required by CMS. The areas are: Administrative Authority, Level of Care, Plan of Care, Qualified Providers, Health Safety and Welfare, and Financial Accountability. He will be collecting the data to ensure CMS that the CLTS Waivers are meeting all requirements.

IV. Approval of Minutes
   a. Glen made motion to approve
   b. Brad 2nd the motion
   c. All approved

V. Quality Assurance-Julie Bryda
   a. The Department of Health Services (DHS) is reviewing the services being provided by providers for families with children with an autism spectrum disorder (ASD). This is for both the intensive and ongoing phases of the CLTS Waivers.

b. A survey was given to providers at statewide meetings in June. The survey asked for a list of lead and senior therapists and the therapy model being provided by each provider of intensive in-home treatment services within the CLTS Waivers. Each agency sent the information in to the DHS for review. A total of 15 out of 16 surveys were returned. DHS is determining if the therapy models are evidence-based research. This is a piece of the quality assurance requirements by CMS. DHS will be working with an independent agency in reviewing the therapy models to determine if there is evidence-based research.
c. Many of the providers in the ongoing part of the CLTS Waiver may not meet the qualifications of Counseling and Therapeutic Services which is a service code in the CLTS Waivers.
d. It is difficult for families to know who is qualified to provide services within the CLTS Waivers. Is there a way for families to be educated on the appropriate treatment for children with ASD?
    i. There may be confusion by providers and families regarding what services are allowable since families are given a choice of providers and services.
    ii. It would be helpful for providers and families to be provided information regarding what are considered to be evidence-based models. Without this information it is difficult for providers to know what they should being doing in order to appropriately implement treatment that is CLTS Waiver allowable.
    iii. DHS needs to assure that evidence-based treatment models are funded under the CLTS Waivers. This is a federal requirement and also the direction provided by the Governor.
    iv. DHS is working with counties to determine how to proceed with what service is being delivered to each individual. It is not the intent of DHS to disallow funding to counties and providers based on past concerns.
    v. The best way to reach families is through conferences such as the Autism Society of Wisconsin (ASW) and Circles of Life. Also the training could be videotaped and then provided to families that are beginning services. It could be a DVD. The training could focus on:
        1. What choices do families have within the CLTS Waivers?
        2. How to choice a treatment that meets the needs of the family?
        3. What are the acronyms for the programs?
        4. How should the family be involved in all aspects of the program?
        5. What do families do when things go wrong, who should be called?
        6. How do families plan for their child when in the CLTS Waivers ongoing phase and transitioning to adult services?

7. What services are covered? Parents need to understand what is funded and what isn't. Parents attend conferences and hear about services that are not CLTS Waiver allowable.

vi. The Autism Council will develop a workgroup focusing on what services are appropriate for families. This could impact children that are waiting for services, are not eligible for the CLTS Waivers, have transitioned to ongoing, etc.

1. Volunteers-Pam, Michael, Vivian, Rose

vii. ASW is also getting many questions from parents regarding how to meet their needs through the CLTS Waivers including both evidence and non-evidence based services..

viii. ASW is redesigning their website to answer these questions. It would include a flowchart of how to get through the process. ASW conference is March 2010. Jane Pribek from ASW sent out a call for proposals.

e. What is the quality assurance process? Is there a way for DHS to develop a process that will assure ongoing quality and have it reviewed at a certain point each year (quarterly, annually)?

i. DHS has begun the process to review quality assurance in all aspects of the CLTS Waivers. Ongoing training with providers, county staff, and families is being scheduled for 2010.

VI. Coordination of services between school and CLTS Waivers-Brian Johnson, Department of Public Instruction (DPI)

a. Brian shared information about the National Professional Development (NPD) grant. They finished their first year and are now expanding the work to as many different venues as possible. The information will focus on evidence-based practice (EBP) within the school system.

b. There are modules online that provide information about the evidence-based practices.

c. Through CESA regions, the NPD grant will be presenting to all the regions, and there will be four webinars. It will include the EBP and additional information that school staff have asked for. The webinars will be live and will be pre-recorded and saved on the DPI website. Anyone will be able to watch the webinars.

i. Brian will forward the information to Bill Murray and then disseminate to the Autism Council.

ii. The first webinar is October 13, 2009.

d. DPI is also focusing on the social and functional piece of autism spectrum disorders. The two pieces are important for teachers to learn about. The concern is if it is not an academic requirement it is will not be funded by the school district. By middle school these issues are no longer the focus; the child does not get the support needed.

i. This appears to be a trend for all children with autism across systems. The main focus is for younger children to receive the

treatment and then it was not necessary to follow through all grades.

ii. There is a state-wide conference on transition and how to implement successful strategies across the age ranges. DPI does want to begin focusing on this, including post-secondary education and the workforce. The targeted attendees are special education teachers, parents and post-secondary educational staff.

e. Council members shared additional suggestions regarding the importance of training across age ranges.

f. Collaboration between the schools and the CLTS Waivers is an ongoing discussion with school staff. Both programs are doing positive treatment for children but there needs to be a way for collaboration at all times. This could include having monthly meetings with ideas shared. This helps the different entities figure out what is working. Typically there is only collaboration when there is a crisis.

   i. It is helpful to have a Birth to 3 transition team involving the school staff. This allows for a smoother transition into school.

   ii. Also to ensure that all parties understand the rules and regulations for both DPI and CLTS Waivers. It can make it difficult for collaboration when staff is unsure of what is allowed.

g. Brian was invited back if there is information he would like to share.

h. Brian handed out information regarding DPI's directive for the Appropriate Use of Seclusion and Physical Restraint in Special Education Programs.

LUNCH

VII. Transitioning into Adult Services-Julie Bryda

a. DHS has been working on issues surrounding the transition from children enrolled in the CLTS Waivers into the adult long-term support managed care programs such as FamilyCare. DHS has discovered that several children were terminated from the CLTS Waivers prior to being fully enrolled in FamilyCare and receiving services.

   i. A Frequently Asked Questions document is being created for counties and families to assist with a smooth transition.

b. Families currently enrolled in the CLTS Waivers are unaware of what the adult system offers for their child. FamilyCare is participant focused instead of family focused. Many families have questions about FamilyCare, e.g.

   i. What is FamilyCare?

   ii. Who is responsible for what?

   iii. What is a Disability Specialist?

   iv. What is the criteria for the level of care for adults?

   v. What is the transition process and the age planning should begin?

   vi. What does CMS require in FamilyCare?

vii. If a child is not in the CLTS Waivers what is the process for enrolling in the adult long-term support programs?
    1. For a new applicant it can take 18 months for a Disablity Determination to be made.

c. There is confusion regarding what funding is available and how to manage their budgets and resources. An example would be an adult receiving SSI and how it should be managed. Young adults are not educated on how to navigate the long-term support system and knowing the requirements of each program. Council members had a few suggestions to assist families and Disability Specialists:
    i. There should be information for the legal guardians. The information should be provided a few years prior to the transition plan.
    ii. Having a strong service coordinator that is knowledgeable about the system can be beneficial for a family. The parent can then determine where to go and what agency should be contacted to ensure all systems are in place before the child becomes an adult.

d. The Aging and Disability Resource Centers (ADRC) did not receive funding in the 2009-2011 budget for transition planning. It became optional for ADRCs. This means that the Disability Specialist may not be able to attend Individual Education Plan (IEP) meetings, or other relevant meetings.

e. A person enrolling into FamilyCare needs an adult Disability Determination from Social Security Administration prior to receiving services.

f. WI FACETS had a transition list for parents regarding what services they needed to think about for their kids. It was broken-down by age.

VIII. State Implementation Grant for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities- Sharon Fleischfresser and Amy Whitehead Division of Public Health

a. Sharon gave an overview of the Children and Youth with Special Healthcare Needs Regional Centers.

b. The Grant is completing its first year of a three year cycle. There are four focus areas: Training, Research, State Demonstration, Evaluation

c. Connections Statewide Goals:
    i. Strengthen statewide infrastructure
        1. Community of Practice on ASD and other Developmental Disabilities
        2. Statewide outreach campaign
        3. Electronic repository
    ii. Strengthen regional and local partnerships
        1. Identify resources and gaps
        2. Regional training for key partners
    iii. Resource Mapping

1. Asset-based process to identify what exists for families and providers
2. Emphasize strengths and cross-community collaborations
3. Outcome is identify ASD resources and recommend ways that information can be shared
4. Coordinated with First Step and Repository

d. Plans for Year Two of the Grant
   i. Community of Practice on ASD/DD
   ii. Resource Mapping
   iii. Regional Community Training
   iv. Provider Training-Webcasts on early identification, diagnosis, and coordination of services; technical assistance calls in collaboration with LEND

e. November 30th, 2009 is the next date for the Community of Practice on Autism Spectrum Disorders and other Developmental Disabilities

f. The grant is focused on making connections within the community, with schools, and other services that are provided to children with ASD.

g. There are ongoing trainings for early detection and screening for pediatricians. Prior to the grant, there was a survey sent to primary physicians and less than 50% were using standardized/validated testing.

h. There can be incorrect information being provided and there is an emphasis on developing a framework of questions.

i. With the autism insurance mandate it would be important for primary physicians to be aware of the appropriate testing that needs to be done in order for the child to get appropriate treatment.

j. It may be difficult for families to get the information:
   i. Not internet savvy
   ii. Cannot attend conferences/trainings
   iii. Child is not involved in the CLTS Waivers or part of a different system

k. Each region has developed a regional core team
   i. The teams review what information is being disseminated and what needs to be changed or improved upon
   ii. The goal is to develop partnerships with public health departments, local entities

IX. Data Update-Katie Sepnieski

a. 286 new slots have been assigned to children for Intensive In-Home Treatment Services

b. 172 new children in the last year have been added to the wait list for Intensive In-Home Treatment Services

c. Starting on August 1, 2009, DHS began releasing 4 slots per week. This is a change from 11 slots per week. In late fall, DHS will have a determination of how many slots will be released starting in January 2010. DHS will notify county administrative agencies and providers of the slot releases prior to 2010.

X. Updates-DHS Staff

a. Insurance Mandate issues-Julie Bryda
    i. DHS is collecting questions from families and counties regarding how the insurance mandate will impact children receiving services. DHS will develop a Frequently Asked Questions document that will be disseminated to counties and families.
    ii. DHS is reviewing how children currently receiving only intensive in-home treatment through the waiver will transition to private insurance. CLTS Waivers are the funding of last resort. Children with private insurance will be required to go through their private insurance for services.
    iii. DHS is working in collaboration with the Office of the Commissioner of Insurance (OCI) on the transition of families to the private insurance. OCI has created a stakeholder's group to determine the process in rolling out the mandate.
    iv. OCI has discussed that each insurance network may develop their own providers.
    v. There will continue to be the struggle of finding qualified staff for providers.
    vi. DHS may have WisLines for the Autism Council, County Administrative Agencies, and providers to discuss the implementation of the insurance.
    vii. Counties will need to determine if the family does have the private insurance benefit. DHS will work with counties to develop a process or policy regarding this issue.

b. Variance Request Forms-Bill Murray
    i. DHS developed a form for community outings variance requests. The form is uniform in order to maintain consistency. Each request is currently being reviewed by DHS with the intent of the county service coordinators approving the requests in the future.
    ii. The form is being presented at regional meetings with counties in August.

c. Status of provider meetings-Julie
    i. The feedback from providers was positive. It helped for the providers to meet staff from DHS. The information shared at the meetings was useful for providers.
    ii. In the future it would be helpful to have counties involved in the meetings.

d. National Autism Council-Brad Thompson
    i. There continues to be a push towards having an ATAA. Currently there are not any state representatives that are interested in participating or finding out what their position is. Brad has contacted both Senator Feingold and Senator Kohl regarding their position on ATAA. He has not gotten a response from either Senator.

ii. WI is the 14th state that passed legislation for insurance for autism reform. There are only 5 states that don't have this issue pending.
iii. It would be helpful for others to contact the Senators regarding the two bills. Brad will send a link regarding this issue.

XI. Final Remarks-Council Members

a. The Council members did not have any additional comments