Autism Council Meeting
May 18, 2009
Final Minutes

Council Members: Nissan Bar-Lev, Julie Bryda, Teri Enters, Vivian Hazell, Rose Helms, Pam Stoika, Brad Thompson, Glen Sallows

Facilitator: Kristine Freundlich

DHS Staff: Sandy Blakeney, Bill Murray, Katie Sepnieski

I. Public Comment
   a. Two parents spoke about issues regarding their children and participation in the Children's Long-Term Support (CLTS) Waivers.

II. Introductions and Announcements of Council Members
   a. Vivian has been invited to work with a regional group to focus on autism needs and services in the area. Vivian will be sharing issues addressed at the Council and will also help develop some resource materials.
   b. Nissan announced that CESA 2 has received $3.5 million of recovery funds to spend over the next two years for special educations services.

III. Quality Assurance Presentation-Julie Bryda
   a. The Federal Centers for Medicare and Medicaid Services (CMS) reviewed the adult home and community based waivers for renewal and has established the quality framework for Wisconsin to implement. The CLTS Waivers will begin implementing many of the quality pieces that CMS is requiring in the adult waivers.
   b. The State is reviewing the CLTS Waivers with counties to assure compliance with all the requirements for all children participating in the CLTS Waivers. This is done several ways:
      i. Single State audit guide, outlines the requirements
      ii. Random record reviews by State Children's Service Specialists
      iii. Recertification assurance report
      iv. Participant/Guardians Survey
   c. The State has developed a database to assure that all quality pieces are being met. If quality pieces are not being met then Corrective Action Plans are required for counties that do not meet requirements. Counties are required to complete the corrective action plan within a set timeline.

d. The Department of Health Services (DHS) Children's Services Section (CSS) is reviewing all restrictive measures being used by participants in the CLTS Waivers. Any restrictive measures being used by a Waiver participant requires prior approval from DHS in order for a provider to implement the practice. The Bureau of Long-Term Supports has centralized the restrictive measures applications reviews in order to have consistency across programs.
e. The Department is reviewing all quality pieces in order to maintain the integrity of the program and continue to meet federal requirements.
f. Counties are being trained on the quality issues, by ongoing WisLines, regional meetings, trainings, and county technical assistance meetings.

IV. National Autism Council Update-Brad Thompson

a. Senate Bill 819 also called the "Autism Treatment Acceleration Act of 2009 "(ATAA) was introduced in the Senate in April 2009, and the house version (H.R. 2413) was introduced in the House in May 2009. This is the first national bill related to autism. The bill includes 12 different sections, each outlining a separate autism program. One section provides for federal reform of autism insurance coverage. If passed, this will require all insurance companies across the country to provide coverage for evidence-based, medically-necessary autism treatments and therapies. Another section creates an "Interdepartmental Autism Coordinating Committee" which will monitor governmental and non-governmental activities related to autism health services; make recommendations to Health and Human Services, among other things. The Council will be comprised of HHS department heads, other federal agencies designed to treat individuals with autism, at least one member with autism, at least one parent/guardian of a child with autism, and two-fifths of the council will be members of the public. Brad reported that the advocates had hoped that President Obama would create a separate specific council, but it was added to this bill instead.
b. Brad will send a copy of the bill to forward to the entire Council.
c. Autismvotes.com allows you to find appropriate legislative person to contact regarding the bill.

V. Autism Insurance Mandate-Nissan Bar-Lev

a. The rally for the insurance mandate was canceled.
b. Governor Doyle attended the Annual ASW Conference, spoke to the group for 45 minutes and received a standing ovation. Even with the state's current budget woes, the Governor did not downplay the importance of addressing the needs of individuals with autism.
c. There has been discussion with legislators that the bills would become part of the Governor's proposed biennial budget.
d. The Assembly insurance committee has additional concerns about the legislation and has not voted on the bill.

e. The Office of the Insurance Commissioner will have meetings with stakeholders to determine what needs to be included in the insurance coverage, once the legislation is passed.

VI. The National Professional Development Center (NPDC) on Autism Spectrum Disorder/ Waisman Center Update-Linda Tuchman, Lana Collett-Klingenberg, Ellen Franzone

a. The Federal government did provide funding for university students specific to autism treatment training. Applications are open for both students and parents.
b. The project started in 2007 and presented at the Autism Council at the November 2007 meeting. Since then the center has made great strides in Wisconsin to provide resources, professional development, and technical assistance that will increase the number of highly qualified personnel serving children and youth with ASD.
c. The Center received a grant to improve educational services for children with autism spectrum disorders. The goals of the center were very specific:
    i. Promote optimal development and learning of infants, children and youth with ASD and provide support to families through the use of evidence-based practices.
    ii. Increase the number of highly qualified personnel serving children with ASD through sustainable technical assistance and professional development
    iii. Technical assistance to 12 state partners (4 at each regional center over 5 year period)
    iv. Professional development for 12 state partners through:
        1. Online introductory course on ASD
        2. Intensive five day hands-on training for state autism training team at one of the three regional centers (UNC-Chapel Hill, University of WI-Madison, UC-Davis) during first year of partnership with state
        3. Technical assistance for implementing an intensive hands-on state training within the partner state during second year of partnership
    v. Increase the capacity of states to implement evidence-based practices for early identification, intervention, education, professional development, and technical assistance.
d. Wisconsin was the first to be accepted to be involved in this project. The Center has completed its first year and is now working on the second year to complete criteria.
e. The Center worked on designing modules with criteria for what is evidence-based treatment and research.
f. Modules are available online via the AIM website: http://www.autisminternetmodules.org

g. There are briefs done which directs families and others as to why the module is being used for a specific child. The module components have:
    i. Pre-tests/post tests
    ii. Contextual Information
    iii. Step by Step instructions
    iv. Case Examples
    v. Video Examples
    vi. Implementation Checklist
    vii. Evidence-Base
    viii. Resources
h. The information is practical and free of charge. The briefs include information from the researcher that did the work in order to make sure the information is correct.
i. The NPDC hosts a week-long Summer Institute during a state's first year of involvement with the center. Participants include model site teams and training/technical assistance providers from around the state. During the second year of involvement, state partners take the lead in the planning and presentation of the Summer Institute.
j. Each year, each university site partners with a state. This partnership includes strategic planning with an interagency autism planning group, planning and hosting of a Summer Institute, facilitation of a community of practice, development of model school sites, and information dissemination. The overall goal of these partnerships is to promote the use of Evidence Based Practices to fidelity and to put in place a model of sustainable training and technical assistance for educational providers to learners with ASD.
    i. Model Sites
        1. Identify and recruit student/parent
        2. Participate in NPDC online course
        3. Work with NPDC staff to implement evaluation tools
        4. Attend Summer Institutes
k. Lessons learned and next steps for sustainability
    i. Team involvement critical for implementing evidence-based practices
    ii. Involvement and training for paraprofessionals
    iii. Development of training and technical assistance network
    iv. Coordination and collaboration across partners
    v. The Center is working with the Department of Public Instruction (DPI) to expand on the work being done. Having DPI engaged in the transition of training teachers and paraprofessionals would assist
l. For additional information visit the NCDP website: http://www.waisman.wisc.edu/cedd/autismpdc/

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VII. The National Autism Policy Collaboration Request-Katie Sepnieski

a. The National Autism Policy Collaborative (NAPC) works in collaboration with State agencies serving people with an Autism Spectrum Disorder (ASD). The NAPC was given the opportunity to submit a report to the Executive Branch and legislators on Capitol Hill showing each State's commitment to autism policy development and the issues most pertinent to each agency.

b. DHS submitted a letter to NAPC listing the priorities which are outlined below:

    i. Ensuring state-of-the-art diagnostic processes are used to appropriately identify children with an ASD, including improved early detection and intervention in order to deliver necessary supports and services.

    ii. Eliminating the state waiting list for children with an ASD to receive waiver services.

    iii. Partnering with state and nationally recognized entities to promote quality training for providers of services to individuals with autism spectrum disorders, both within the public school system as well as in family homes and other community settings.

    iv. Encouraging the passage of legislation that would require insurance companies to cover the cost of treatment for children with ASD.

VIII. Education Updates-Bill Murray

a. Lakeland College staff contacted Julie and Bill to discuss the potential for the college to develop a certification program for paraprofessionals to be trained to be line therapists for the intensive in-home treatment services for children with ASD. It would meet 20 of the 30 hours of required hours.

    i. It is a 2-day training, 10 hours per day, the topics include:

        1. Overview of treatment
        2. Boundaries and Ethics
        3. Specific behavior interventions
        4. Creation of a learning portfolio

b. UW-Eau Claire Master's Program for Applied Behavioral Analysis

    i. Students that complete the program are capable of taking the National Board Exam.

    ii. UW-Eau Claire graduates 20-25 students each year in the undergraduate program. All the graduates move out of State since their degree is not recognized in WI to do programming. The students met with legislators to discuss this issue. There will continue to be discussion as to the need to have the ABA graduates be licensed or certificated in the State of Wisconsin.

IX. Experimental Treatment-Bill Murray

a. CMS requires the CLTS Waiver to have strict rules regarding the use of experimental treatments by participants. The use of experimental treatment can not be funded by the CLTS Waiver program.
b. Definition of independent peer-reviewed research.
    i. Independent - The research authors and protocols have not been subject to control by others. They are not affiliated with a larger controlling unit that provides guidance in how the research is conducted. The published research and protocols must be free of any affiliation with the creator and/or originator of the treatment method or product.
    ii. Peer-Reviewed - The process of subjecting an author's scholarly work, research, or ideas to the scrutiny of others who are experts in the same field. This encourages authors to meet the accepted standards of their discipline and prevents the dissemination of irrelevant findings, unwarranted claims, unacceptable interpretations, and personal views. Publications that have not undergone peer review are likely to be regarded with suspicion by scholars and professionals.
c. DHS is requiring practitioners receiving funding for treatment services through the CLTS Waivers and the Family Support Program to use evidence-based treatment methods. It reduces harm, conserves valuable resources, and results in better outcomes for children.

X. Variance Request for Community Outings-Bill Murray

a. A form was created for requesting community outings for children receiving the intensive in-home treatment services through the CLTS Waivers. DHS shared the form with four counties, a few providers, and the Autism Council to review and offer suggestions in order to capture the most useful information.
b. The purpose of the universal form is to have consistency across the State in regards to what needs to be submitted for a variance.
c. The variance requests will need to have specific goals, timelines, and data collection in order to determine if the goals are being met. Skills need to be generalized across environments in order to maintain the skill.
d. The requests are being reviewed by the State Autism Team, to ensure consistency and assist counties in understanding what needs to be submitted.

XI. Review of Draft Minutes from February Meeting-All

a. Error on the 2nd to last page- VII e, children that transition to ongoing have met the criteria to transition but have not been terminated
b. Vivian 1st to accept minutes with change
c. Teri 2nd minutes
d. All approved

XII. Data Update-Sandy Blakeney

a. Summary of services for children participating in the CLTS Waivers for intensive and ongoing services
    i. 837 children participating in the intensive services
    ii. 1301 children participating in the ongoing services
    iii. 236 children on the waiting list for intensive services
    iv. 118 children have transitioned from intensive to ongoing services for 2009.

XIII. Final Remarks-All

a. 3500 children are waiting on county wait lists for services that do not meet the qualifications for the intensive in-home treatment services and transition to ongoing services. Some of these children have an ASD. The Governor's budget includes an additional 1000 slots to serve children waiting on a county wait list.
b. There is a need for services for older children and across the lifespan, and education for parents to learn the resources available.
c. The next Autism Council meeting is August 17, 2009.