

Autism Council Meeting  
May 16, 2011

Council Members: Nissan Bar-Lev, Vivian Hazel, Rose Helms, Glen Sallows, Pam Stoika, Brad Thompson

Facilitator: Kris Freundlich

DHS Staff: Tracey Brent, Julie Bryda, Sue Larsen, Bill Murray

**I. Welcome—Kris Freundlich**

**II. Introductions of Council Members**

**III. Diagnostics Workgroup Presentation—Rachel Fenning, Ph.D., UW Madison Waisman Center, MCH LEND Program; Gail Chodron, UW Waisman Center**

Rachel Fenning and Gail Chodron gave an informative presentation regarding diagnostic workgroups and the progress they have made. Rachel and Gail talked about some of the instruments typically used in diagnosing a child with autism and spoke to the degree of their effectiveness and efficiency. They also raised the issue of whether testing should be standardized or defined so that diagnosis are accurate and have state-wide consistency.

The presenters also talked about outreach attempts that have been made to pediatricians, family doctors, and childcare sites to train them on how to screen a child and when it is appropriate to make a referral. A Council suggestion was to consider the role schools can play in assessment.

**IV. Bureau Updates—Sue Larsen**

Sue Larsen has been appointed as the interim Children's Long-Term Support (CLTS) Section Chief, and Beth Wroblewski has been promoted to the Deputy Administrator position. In addition, the Department has named Pris Boroniec as the head of the Division of Long-Term Care.

The Children Service's Section is working on a number of initiatives at this time. The Third Party Administrator (TPA) project continues to roll-out statewide, with a mandatory implementation date of December 31, 2011. Compass Wisconsin: Threshold will now be expanding into Kenosha and Waukesha counties as well as already being implemented in Racine and Walworth starting June 6<sup>th</sup>. The section is also working on creating a new, user-friendly website that will highlight all of the children's programs.

The Children's Section, on behalf of the Department has hosted several listening sessions for families which both Secretary Smith and Deputy Secretary Rhoades have attended.

**V. Approval of Minutes**

- a. Nissan Bar-Lev made a motion to approve the minutes
- b. Vivian Hazel seconded the motion
- c. All approved

**LUNCH**

**VI. Outcomes Dialogue**

The Council discussed what can be done to ensure that good outcomes are achieved for each child. Parents want good outcomes for their child, but also must define goals for them as well. Parents want their child to be able to adapt in the community and with peers; and they want their child to acquire self-advocacy and basic daily living skills. Each child's outcomes are individualized, as their capacity is varied. This in turn makes measuring successful outcomes difficult in the program.

Desired developmental outcomes also evolve over time and as a child ages the needs of that child change. At younger ages, parents should help teach their child and as they age parents should have more of a supportive role in their development. It is important to note that goal setting should not only be determined by the child, but by the family as well. A suggestion from the Council is for DHS to consider partnering more closely with schools within existing funding streams to help mirror desired outcomes for children.

Council members also spoke to the importance of having the child's family/caretaker attend trainings and conferences to be educated on how to be most effectively supportive of their child. They also noted that conferences are often held at inconvenient times (during the middle of the week, during normal work hours), and can be quite costly for families.

**VII. Dialogue: Talking points for future meeting with Secretary Smith**

The Department will work with Secretary Smith's staff to schedule a time for him to meet with the Council. The Council has four areas of concern they'd like to address with Secretary Smith.

- a. Wisconsin's commitment to autism  
Wisconsin has a unique commitment to autism and has created a legacy. Wisconsin has proven to be a good steward of the public dollar and offer families a choice. It's important to note that autism doesn't just affect the individual, but the whole family as well.

- b. Funding  
Funding for the waiver should not be cut because these programs and services are essential to helping these children function and reach their

capacity to be as independent and capable as possible. The number of children with autism is growing; the number of providers is not.

c. Circle of support

Treatment for autism should be a collaborative effort between all relevant parties (e.g., families, schools, community partners.).

d. Scope of the Council

The scope of this council has changed, whereas it started by discussing waiver issues, it has now evolved into broader lifespan issues. Membership of this council is a concern. Many seats are vacant, and require appointment by the Governor. The Council would like to know Secretary Smith's thoughts on the Council, and possibly whether moving this to a Department Council would be more efficient and logical.

**VIII. Updates**

The next work group meeting will be held on May 25<sup>th</sup> in Madison.

As of 5/16/11 the date breaks down as follows:

- There are 5,283 children on the waiver
- 918 of these children are in the intensive program
- 1,492 of these children are in the ongoing program

**IX. Adjourned 2:45**