

**MINUTES  
of the  
Autism Council**

**DATE:** February 20, 2006

**LOCATION:** Madison, Wisconsin

**MEMBERS PRESENT:** Nissan Bar-Lev, Heather Boyd, Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Milana Millan, Paula Petit, Paul Reuteman, Glen Sallows, Pam Stoika, Michael Williams

**ABSENT:** Debra Mandarino

**FACILITATOR:** Kris Freundlich

**STAFF PRESENT:** Sandy Blakeney, Beth Wroblewski

The meeting came to order at 10:05 AM.

No public comment was received.

Prior to commencing with the established agenda, the Council discussed the suggestion that the Council request that the Governor recognize April as "Autism Awareness Month." Vivian Hazell had contacted the Council's Support Committee with the proposal and the members of that committee agreed that it could be brought to the Council at this meeting for further discussion. In the interim, Kris gathered samples of other Governor proclamations in order to facilitate the development of a proposal for the Governor and shared those with the interested members. A draft proposal was distributed to the Council for their review. Nissan Bar-Lev would coordinate the continued effort to finalize this proposed proclamation for submission to the Governor's Office.

**Approval of Minutes:** The Council reviewed the draft of the January 9, 2006 Meeting Minutes.

There was a **Motion to Approve** the minutes which was **Seconded**, and **All were in Favor**.

**EXCEPTIONS POLICY WORK GROUP REPORT**

Volunteers for the work group were Vivian Hazell, Milana Millan, Pam Stoika, and Glen Sallows (Dr. Eric Lund represented Dr. Sallows). They met, along with Beth Wroblewski, via telephone on January 19, 2006, from 2:00 PM to 4:00 PM. Pam and Vivian presented a report from the workgroup meeting. It was pointed out that there was no consensus within the workgroup on a specific recommendation - they struggled with the various issues raised by the

idea of individualized budgets of hours for children. Vivian reviewed the general thought process that went into their report, which included: ensuring that clinical decisions be included in treatment decisions; understanding that, if individual budgets are to be used, they must be capitated; the importance of flexibility in decision-making by treatment teams. Beth reviewed again that in order for a child to have a full four years of intensive in-home autism treatment services, that child would need to consistently average 28.5 hours of treatment per week. Children who receive services at the maximum of 35 hours per week would reach the end of their budgeted hours after about 2.5 years. As was mentioned in earlier meetings, we will not have accurate data regarding actual hours of treatment used in 2005 until well after March of 2006. Data for 2004 doesn't give an accurate picture since that was the first year of the waiver.

Viv wondered if changing the program to the individual budget strategy would affect the availability of new slots each year (250 per fiscal year) and Beth explained that it would not. Viv does feel that this would have an impact on providers, with the goal being to "put the clinical process back in the hands of providers."

Pam Stoika said that the workgroup did discuss the fact that in no scenario is there an assumption of a child receiving four years of treatment. In fact, for the most flexibility, it is necessary that hours be averaged across the entire population of children receiving services, so that those who receive less than 35 hours of treatment are, in effect, "subsidizing" those who are receiving the full maximum of 35 hours per week. This raised the question of whether or not the Exceptions Policy may be sufficient as it stands. Milana suggested that, instead of developing an entirely new policy, perhaps the Council would want to look again at the existing policy to see if it just needs some minor "tweaking."

Nissan pointed out that despite the appeal of having an individual budget for each child, any recommendation the Council makes is still limited by the requirement of remaining budget neutral. He stated that the Wisconsin Legislature's *intent* was for eligible children to receive 3 years of treatment. Individual budgets remove the ability to average the overall budget across all the children in the program.

The group agreed that there could be many "unintended consequences" of moving to an individualized budget system. Milana encouraged the Council to focus on the needs of the child. She worried that the child currently authorized for the maximum number of hours per week has a high need for treatment, but receiving treatment at the highest level would shorten the overall amount of time in which treatment could be received.

Nissan suggested that DHFS develop a plan for distributing unexpended funds after each annual cycle to fill needs of children. Beth responded that we won't know in the short run whether or not there are unexpended funds. Over the first few years, a pattern will begin to emerge and allow DHFS to start making some predictions and planning based upon unexpended funds at the end of each budget cycle.

Rose Helms wondered how much administrative time would be involved in managing an individualized budget system vs. administrative time used in submitting requests now for extensions beyond the three years. Rose suggested that we may be able to avoid most problems

having to do with the end of intensive services by making sure that treatment teams and families are doing a good job of getting transition plans in place.

Kris asked the Council what they wanted to achieve with this discussion. Paul Reuteman responded that the goal is to get “ideal” care for all children who need it. Milana suggested that there perhaps is no consensus on what is “ideal.” Nissan said the Council needs an agreement on what would be an appropriate exception to the 3 years. He wondered if more treatment is always better than less. Glen Sallows stated that in his estimation, for a child receiving 35 hours a week, more is not necessarily better. However, he said that it was his opinion that a child receiving 20 hours a week is not getting effective treatment.

Heather Boyd wondered if the reasons for looking at this topic were the following: 1) to review and make suggestions regarding the existing exceptions policy; 2) to increase flexibility of treatment for individual children; 3) to show children’s progress? Beth clarified that there was no intent to measure progress. The issue is more one of what clinical experts agree constitutes sufficient progress. DHFS expects that families and providers are more able to make that assessment for individual children.

Terri Enters pointed out that with individual budgets, there would be no exceptions policy. She said in her experience families are requesting extensions due to their child still having goals to meet.

Paula Petit said the Governor’s Task Force on Autism recommended that children be awarded a total number of hours; for example, the total hours available to a child approved for 35 hours of intensive in-home autism treatment services per week for 3 years would be 5460 hours. Further, the child would have the ability to use that total of hours over the course of four years instead of only 3 years.

Rose said that in her experience the main reasons families want extensions are: 1) they want to continue intensive services over the summer before school starts; 2) they have had lapses in service due to staffing problems; 3) the child is just hitting his/her peak of progress. Beth pointed out that the current policy is neutral on the reason for requesting extensions. DHFS does not have independent staff available to evaluate reasons for extension requests. That is why the policy is completely based upon a numeric formula. Plus, DHFS depends upon providers to assess whether or not an extension would be useful. The benchmark lapse of 12 weeks of services was determined based upon feedback from clinicians that anything less than 3 months would make it very difficult to make a quality treatment plan.

Rose responded to the question of what is “ideal” for children. Her definition of “ideal” would be that a child gets a waiver slot and then receives the full 35 hours of treatment per week. Children would not be penalized for not receiving 35 hours per week due to staffing problems. Also, there should be a transition plan developed and in place.

Pam’s definition of an “ideal” outcome is that families feel confident that they are competent to support their child’s needs. It is important to look at the whole family as the child’s support system, and also do transition planning, advocacy, and working with schools.

Nissan said that the issue is one of equity. For children who receive less than 35 hours per week due to provider staffing issues or rural location, are they entitled to exhaust the full number of allowable hours? And if so, there needs to be identified policy exceptions that allow that to happen. Budgeting hours for individual children would ensure it, but would be a burden for the Department. And what about situations where the issue is not staff sufficiency, but family availability - or perhaps just that less hours are more beneficial for certain children.

Beth suggested that perhaps the Council should look at new models. The issue of staff sufficiency was on the agenda for later in the meeting. Perhaps there is the possibility of a “hybrid” version of best practice - a way to use approved hours differently.

Viv said that it is also important for providers to help parents learn to support their children. For her, although there is no consensus on what is “ideal,” it would involve flexibility, as well as putting clinical decisions back in the hands of clinical teams. Viv’s perspective is that the issue of 4 years of service is less important than flexibility, clinical teams, and supporting the needs of diverse families.

Milana agreed with Rose that transitions are a big issue, as well as access to school services. She sees schools as an important means by which parents can get training opportunities (planning, advocating for, supporting their children). Schools can help families find opportunities. Milana suggests that perhaps the exceptions policy is “not so broken.”

Michael Williams returned to the idea that children who receive the full 35 hours of service per week depend upon those children receiving fewer hours to “subsidize” that higher level of treatment. Beth pointed out that when children begin on the waiver, providers across the board recommend 35 hours per week and DHFS authorizes that. DHFS does not judge whether or not it is appropriate or even possible. Experience shows that families are not using the full 35 hours. We assume a certain number of families will not utilize the full 35 hours.

Milana pointed out that this is a good example of flexibility in the system.

Nissan said that the issue continues to be equity/justice for families who cannot or do not receive the 35 hours of treatment per week. Is it more fair to have a budget to draw from or to use the current policy?

Pam said that some families don’t want the full 35 hours per week. To her, “equity” would be the opportunity to have a realistic fit for the family and not a simple dollar amount for treatment.

Joan Ketterman agreed that equity is not measured simply in dollars. Counties struggle to balance the different needs of families in order to get that realistic fit.

Kris asked the Council to give a show of hands as to whether or not the existing policy is “broken.” The result was that most members feel that the policy needs improvement, but there was no one who felt that changing to an individualize budget (within budgetary constraints)

would be preferable. The Council agreed that the workgroup should continue to look at the policy. Volunteers were Milana, Pam, Glen and Terri.

Pam said the Council needs to develop a statement on why they are not recommending a significant change to the existing policy (e.g., budget neutrality, definition of best practice).

It was agreed that the workgroup would meet, develop recommendations that could possibly be sent out before the next meeting so that the Council could make decisions on the recommendations at that meeting. Rose stressed that the public and the Governor want to know what the Council is going to do with this.

Beth pointed out that the Council is trying to balance the various pressures upon them and that it is preferable to take a longer time resolving this issue than to do it in a hurry simply because they had said it was one of the first things they would look at. Better to have thoughtful discussions leading to a better decision.

Paul Reuteman made a **Motion to maintain the current extension policy as is with future revisions based upon Council review and recommendations.** The **Motion was Seconded,** and **All in were Favor.**

During their lunch break, Bret Shaw and Kelly Gatzke presented information to the Council members about their project, Relate Now. This project provides web-based technology that could potentially help with access to training and providers for families in rural or remote areas. The members appreciated Mr. Shaw taking the time to come in and had several questions for him regarding accessibility of the program to families.

## **SUFFICIENCY OF STAFFING WORK GROUP REPORT**

The first meeting was a good first look at the issue. Now the work group hopes to start looking at what strategies the Council might look at as recommendations.

The Council reviewed the section of the Autism Task Force's recommendations to the Governor.

### **DISCUSSION:**

#### *Charge to the Council*

During this discussion, Paul and Nissan both asked for further clarification of what the Department hopes the Council can provide in terms of recommendations regarding this discussion. Beth reviewed the goals: the Governor and the Department want to know if the Council has recommendations for strategies by which all kids who would benefit from intensive in-home autism treatment services are able to access that treatment. For example, are there barriers caused by policies or model of service delivery? Are there more strategies by which providers can retain an adequate pool of staff?

#### *Model of Treatment*

One topic of discussion was the issue of the model of treatment - the number of hours and mode of delivery of intensive treatment services. Terri mentioned that counties are interested in different models because the model of up to 35 hours in the home each week does not work for some families or children. If the model does not work, does it mean that the child will not benefit from intensive treatment, or does it mean that we should look at a different model?

#### *Incentives for Getting Required Training*

Rose wondered about the specific requirements/incentives for those entering this field of work. e.g. clinical hours, pre-certification hours. Does their credit count towards a position in a new job?

Pam pointed out that the unreliability of regular work is also a discouraging factor (e.g., for college students who need to know the work will be available around their schedule).

Paula suggested that the Council look at certification requirements and the possibility of changing them in order to attract more line staff.

Viv pointed out that there are also difficulties getting and keeping professional staff, and that looking at different certification criteria might be a strategy.

#### *Availability of Training*

Pam mentioned that there are many different programs for training staff, with consultative models “popping up” around the country.

The Staff Sufficiency Work Group will continue to meet on this topic and return to the Council with further recommendations.

### **SMALL GROUP WORK: EFFECTIVE TRANSITIONS**

This topic had been tabled at the January 2006 meeting. Beth gave an overview of the issue, and the Council then split into three small groups to discuss and brainstorm possible recommendations.

#### *Overview*

This topic became a priority issue for the Council after it was raised as an issue in the course of discussing other priority topics at earlier Council meetings. The primary question is, can we do more to help families plan for an upcoming transition from intensive in-home autism treatment services to the “ongoing” phase of waiver services during which treatment is no longer covered at an intensive level, but a wider variety of services are available to best meet the child’s needs. Currently, many children are receiving treatment at an intensive level right up to the last day of the three years allowed, and then the switch to ongoing is abrupt and possibly less than effective for the child or family. An example of an alternative system is the Birth to 3 Program. In that program, federal rules require that, when a child is 2 years 6 months old, the provider and the school district need to begin planning for transition at age 3. At that time, they begin to look at what is working well for the child, what can continue after transition and how can it continue. Strategies are mapped out at that time for school, community, child care providers, etc.

One question before the Council is how “ongoing” autism services could actually help with transition. How can we help families learn skills, build supports, etc., so that they do not feel that the rug is pulled out from under them when intensive services end.

The small groups were asked to focus on: 1) how to make transitions smoother; 2) how to maintain the gains achieved during intensive services; 3) other issues or strategies.

### **SMALL GROUP RECOMMENDATIONS**

The small groups met separately and then each group reported on their discussion and ultimate suggestions/recommendations for addressing the issue of effective transitions. Each small group reported on their discussion as follows:

#### **Group A**

- 1) Within the last six months of intensive services, require that providers and county staff meet to begin planning. Questions/thoughts about this idea:
  - a) Whose burden (county or provider)?
  - b) Who attends?
  - c) Primary goal to identify community resources, and to transition to school.
  
- 2) Planning meeting:
  - Establish a timeline
  - 6 months to go
    - What to address?
    - Recommendations?
    - school calendar?
  - 3 months to go
  - 1 month to go (school involved)
  
- 3) Develop a standardized transition tool, including a checklist for parents. Viv offered that Beyond Boundaries of Autism has created a transition tool that they use, which includes:
  - Current goals for the child
  - Supports already in place for those goals
  - Focus Areas
  - An “exit summary” that is a record that goes with the child

Council members liked the idea of a checklist. Rose suggested that parents with experience be tapped to help develop a checklist. Nissan said it would help ensure that parents understand that school is not just another provider, and that the school listens to providers to learn what did or did not work for a specific child and then develop strategies for the school setting. Rose agreed that if a school is motivated to help with transition, it would be in everyone’s best interest.

Milana and Glen both suggested that the school be brought in earlier than just one month prior to transition for developing the IEP. Nissan clarified that the initial school meeting is generally about six months prior to the start of school, but that the IEP meeting is usually about one month out in order to have the most current information possible.

### **Group B**

- 1) Assuming that they do not yet know the child, have teachers, OT's, PT's, and educational assistants work in the home during the transition period.
  - Incentives could include:
    - CEUs(?)
    - Getting hands-on experience which makes staff accountable by actually using the skills they get from DPI level A-C training.
    - Staff getting to know the child improves the transition and rapport with the child.
    - Add autism treatment services to their portfolio.

Terri was concerned about the assumption that teachers and therapists would not already know the child and pointed out that school staff have often already worked with a child prior to school starting.

- 2) Require parents to work one shift per week AND attend team meetings
- 3) Transition plan written by parents, providers, school staff, county staff, and must include certain elements.
- 4) "Bank" treatment hours to use as shadow in school.

### **Group C**

- 25% of intensive services can be out of home. Increase that percentage during transition.
- Can parents use ongoing funding to "frontload" hours during transition?
- Allow collateral contact between provider and school without the child being present during transition.
- Transition time begins 4-6 months before end – rules of intensive can be modified to aid transition.
- Allow parents to leverage some of the money in the plan to get training / education so they can continue progress – be better advocate.
- Having a transition plan 4-6 months should be policy. Other options listed could be best practice guidelines
  - Conversations with schools
  - Flexible use of funding
- Better education for parents on how to use ongoing autism services.
- Offer quarterly trainings – locally (county – region) for parents for information and networking.
- Encourage providers to develop consultative follow for ongoing services.

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Paul, Paula, Joan, and Pam volunteered to continue to work on this issue as a small group between Council meetings.

**NEXT STEPS**

Work groups looking at all three current issues will meet once or twice prior to the next Council meeting and report back at that time.

**Next Meeting** The next Council meeting is scheduled for May 15, 2006 in room 630 of the 1 W. Wilson St. Office Building.

Minutes Respectfully Submitted by  
Sandy Blakeney  
May 15, 2006