

MEETING MINUTES of the AUTISM COUNCIL

- Date:** April 2, 2008
- Location:** Madison, Wisconsin
- Members Present:** Nissan Bar-Lev, Terri Enters, Vivian Hazell, Rose Helms, Milana Millan, Pam Stoika, Glen Sallows, Michael Williams
- Members Absent:** Joan Ketterman, Paula Petit, Paul Reuteman
- Department Staff:** Sandy Blakeney, Beth Wroblewski, Katie Sepnieski
- Facilitator:** Kris Freundlich

The meeting was called to order at 10:15 a.m. with introductions all around.

PUBLIC COMMENT

Jennifer Savino's 3-year-old was diagnosed four months ago. The "world" of autism is new to her. Finds the rules and regulations confusing. Insurance will cover massage, but not speech therapy. Wants waiver services, for her child, and the requirement of *in-home services* means she has had to quit her job, and cash out her 401K's and her equity. She believes that the waiver rules should recognize preschool as a "natural setting" for a 3-year-old and relax the in-home requirement. She asks the Council to work to help make the wait list shorter.

APPROVAL OF MINUTES

The Council reviewed the draft of the November 19, 2007 Meeting Minutes.

Motion (Milana Millan): That the Autism Council approve the November 19, 2007 minutes.

Seconded: Vivian Hazell

The motion was Approved by unanimous voice vote.

UPDATE ON WAISMAN CENTER GRANT

A full discussion of this project was included in the November 19, 2007 meeting minutes. Pam Stoika provided the Council with a brief overview of the project and the activities to date.

- Project goals include identifying "best practices" in autism treatment methods and developing training content designed for public schools.

- For the Autism Council, most relevant is the “best practices” question. The project will look at specific strategies and not entire treatment programs. Looking for what strategies are most effective in helping children make gains.
- Per a one-page handout provided by Pam, the project team has identified the basic requirements in order to be considered an effective evidence-based intervention (listed below). Pam noted that if an intervention meets the basic criteria, the team does not continue to review that intervention; i.e., they are not doing comparative reviews. Minimum criteria include *at least one* of the following three:
 1. Two high-quality experimental or quasi-experimental group design studies; *or*
 2. Three different investigators or research groups must have conducted five high-quality single-subject design studies; *or*
 3. One high-quality randomized or quasi-experimental group design and three high-quality single-subject design studies conducted by at least three different investigators or research groups
- The project is looking at individual strategies rather than complete programs. To date, strategies that have been identified as “best practice” include:
 - Computer aided instruction & communication
 - Early identification, screening, & diagnosis
 - Differential reinforcement techniques
 - Discrete trial training (DTT)
 - Functional behavioral assessment (FBA)
 - Functional communication training (FCT)
 - Independent work systems
 - Naturalistic language training
 - Naturalistic play-based instruction
 - Peer-mediated intervention (PMI)
 - Picture Exchange Communication System (PECS)
 - Pivotal Response Training (PRT)
 - Positive Behavioral Support (PBS)
 - Response intervention and redirection
 - Social Stories
 - Stimulus control/environmental arrangement
 - Video modeling
 - Visual supports

Discussion

Viv noted that many programs use a variety of different strategies – does this mean that a provider could use the specific individual strategies that are within an established program? Pam indicated that yes, the purpose of the project is to create training modules for the public school system. Nissan Bar Lev (also a member of the project’s Planning Group) noted that the list of strategies is not finite, many more are being considered and added to the list. Also the project has a very short timeline, with the first 5-day training scheduled for the last week of June 2008. Pam

remarked that this process is important to the Council as they proceed with their work of looking at potential alternative methods of treatment that the State of Wisconsin might be willing to fund.

OTHER MODELS OF TREATMENT

Beth Wroblewski provided a summary of the work done on this subject to date, as reflected in the minutes of earlier Council meetings.

- The Council has completed a series of meetings considering whether or not to look at other models.
- There is the possibility of counting parent hours toward intensive treatment hours – this is a policy-change issue.
- The Council decided they would continue the dialog and consider making recommendations to DHFS.
- DHFS is interested in hearing from families about this issue. The Department wants to stay open to all new possibilities in order to stay current with the available opportunities that arise over time; we do not want Wisconsin to remain ‘frozen in time’ with regards to treatment opportunities.

Two parents volunteered to present their experiences to the Council.

Tracy Swink is a pediatric neurologist, originally affiliated with the Marshfield Clinic, now co-founder and director of the Bridge Center, a non-profit organization that supports children with ASD and their families. Dr. Swink has two children with ASD. Dr. Swink’s professional background includes studying and working directly with Stanley Greenspan in Washington D.C., who developed the DIR (Direct, Individual-Difference, Relationship-Based)/Floortime model of intervention. Dr. Swink’s son was diagnosed with autism and began treatment at age 2. The treatment was not effective for him and she watched him “slip away.” Overcoming her grief at not being able to help her child, Dr. Swink began to research the options available to help her child. She had heard Dr. Greenspan when she was doing her residency at Johns Hopkins University, and she returned to D.C. to study and work with Greenspan’s team for a few years.

The DIR/Floortime model resonated with her and she returned to Wisconsin and pulled together a team of people to work with her child using this method. Using the DIR/Floortime model, she let her son “take the lead” in that the team responded and adjusted their approaches to his specific developmental level at any given time, as well as to the things to which he specifically was drawn (e.g., Batman, the Civil War). Dr. Swink said that her son is in the third grade now, works with a paraprofessional, and he talks about “life’s important things,” such as good friends, books he love, playing the piano or a game of chess.

Dr. Swink told the Council that the DIR/Floortime approach is all about those relationships, all the people who joined her family in following her son’s lead, and joining him on his journey.

Beth asked Dr. Swink if she found that the CLTS Waiver program limits the effectiveness of the DIR/Floortime model. Dr. Swink said that it does add some constraints to the model, but that the essence of DIR is flexibility, so the team learns to maneuver around obstacles in order to make it work. It is mostly difficult to get all the required hours of treatment in.

Vicki Martin is a Registered Nurse who has three children, two of whom have autism spectrum disorders. They are a 12-year-old daughter and a 13-year-old son. They were both diagnosed very young and at the time, living in Illinois, they had access to full insurance coverage for Applied Behavioral Analysis (ABA) treatment for their children. Vicki's son responded extremely well to the therapy and, at age 13, Vicki considers him to be recovered from autism. Vicki's daughter, Julia, on the other hand, did not respond as well to ABA. She had a much more serious communication delay, which made many of the existing models of treatment less effective. While doing ABA, they brought in consultants to train the treatment team on the use of PECS (Picture Exchange Communication System – a system designed to help with initiation of expressive communication, can be used in conjunction with ABA and speech-language therapy for teaching functional communication). After about 1 1/2 years with little success and no generalization of skills, they stopped ABA.

The family then travelled to D.C. to see Dr. Greenspan and did the DIR/Floortime model for the next 2 years. They did have some success with this technique. During this time, they also had speech and OT with DIR-trained therapists, plus they complemented the DIR model with a method called Theraplay (a structured play therapy for children and their parents, the goal of which is to enhance attachment, self-esteem, trust in others and joyful engagement).

Julia did progress, but at 5 years old she still had few essential skills and no real improvement in communication. The family moved to Wisconsin in 2001 and began intensive in-home therapy, and she began school in a special-ed class with some kindergarten inclusion. They also learned about and invested in RDI (Relationship Development Intervention). She continued to gain some skills, but it was slow going.

Vicki heard about Soma Mukhopadhyay, who developed a technique called the Rapid Prompting Method (RPM) when teaching and raising her son with autism. Vicki brought Julia to Soma's HALO clinic in Austin, TX, where Soma assessed Julia and provided Vicki with information about the RPM plan. At that time, Julia's family decided to stop doing ABA and focus on the RPM method. This included multiple trips to Texas, plus Vicki organized workshops to bring Soma to the midwest to work with Julia and other children.

Vicki provided the Council with many written testimonials from teachers and therapists who work directly with Julia discussing the progress they have seen in Julia's ability to communicate and relate to others. She also shared many pages of Julia's own creative writing samples. She reports that Julia has been able to tap into her logic and reasoning abilities and is able to express her thoughts, wants, and needs better and better all the time. Vicki also provided the Council with specific information about the SOMA/RPM technique and examples of the difference between this technique and the more controversial technique of "facilitated communication." Most importantly, SOMA/RPM does not include any physical assistance for the child to spell or choose answers.

In concluding her comments, Vicki asked the Council and DHFS to continue to look at the possibilities of including more choice in treatment methods, for the children who simply do not respond to ABA treatment. She also echoed concerns about the need for *early* intervention and reduction of waiting lists. Vicki supported the idea of offering center-based treatment options as a way to have more choices in treatment, options for families who cannot do the intensive in-home program, more highly trained therapists and more supervision and accountability.

Council Discussion

Kris Freundlich reminded the Council that they had asked to hear from families as to their experiences with treatment options for their children, and she opened it up to discussion, to see if the Council wants to recommend future considerations to DHFS.

- Importance of having flexibility and varying approaches. Viv Hazell: for a “spectrum disorder,” we need a spectrum of support. Identifying specific individual therapies does not respect the different needs or changing needs of each individual child. Pam Stoika: providers cannot be “one-trick ponies.” We need providers to be able to evaluate a child’s progress and have more tools in their toolkit. It is a problem when a therapist is trained in one thing very well, but then they never shift from that one technique.
- DHFS has been looking at the existing regulations to see (1) how a treatment model fits, if it fits, within the current system and (2) how to open Wisconsin to what we have learned in the last 10 years and not just stay with what we knew 10 years ago.
- Nissan Bar Lev said the Council needs to focus on what part(s) of the waiver regulations block or hinder the necessity for flexibility within the program. For example, the requirement of intensive *in-home* treatment can exclude families with single working parents.
- Glen Sallows suggested the solution is for the waiver to allow intensive treatment in daycare and pre-school settings.
- The parents who spoke today are “power houses” who would do anything and everything for their children, regardless of the CLTS Waiver program.

Rose Helms expressed how important it is to hear from parents, and to hear many different points of view. Disturbing to hear about the possibility of the waiver “discriminating” against certain families; this was certainly never the intent of the waiver program. Rose also mentioned the concerns about the long wait for a waiver slot, and said that the Autism Society of Wisconsin (ASW) is working hard to share resources with parents for ideas of what to do while waiting. The issue cannot be completely about the wait list – parents are and need to be diligent in looking for resources for their child. She also supported the idea of having choices of therapy models, but to err on the side of caution (e.g., parents who will do “anything and everything” for their child might give up on a specific treatment too soon, not give it a chance to work). She would have liked a program that included “a little ABA, a little RDI, and little sensory integration.”

Rose suggested perhaps there should be a “neutral” source (an independent consultant?) available while families wait for waiver slots where their child can be assessed to determine the best treatment model for their unique needs. There was discussion on this suggestion:

- Doubt that there could a “neutral” or independent consultant who could help families evaluate ALL their choices. But the county support and service coordinator should be an important tool for families to use. Parents are overwhelmed and often cannot do this alone – need support.

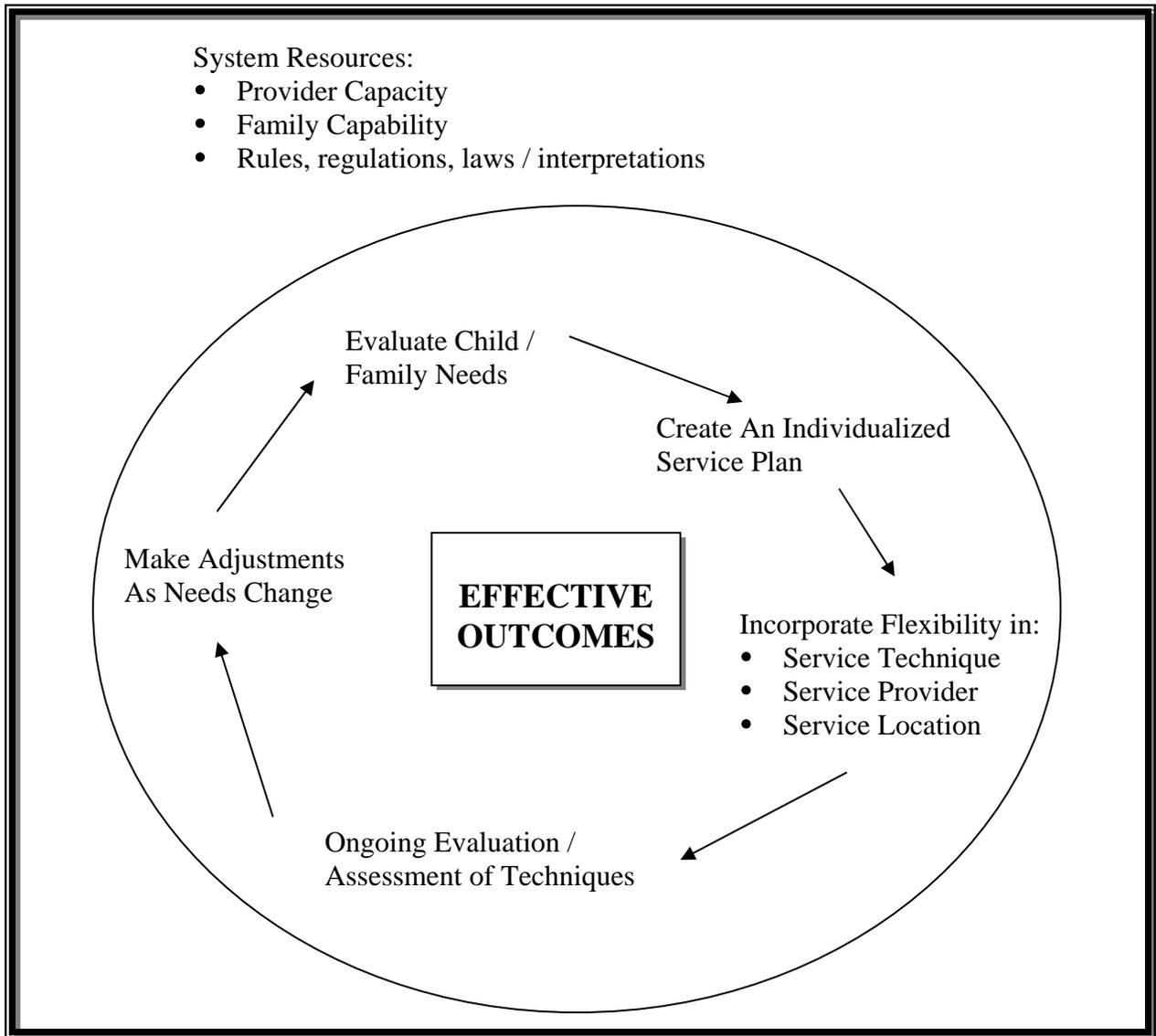
- Milana Millan suggested the Waisman project is an important resource. Parents need to be able to see and learn about different strategies. Right now, parents are confined to the required hours. Day care providers are not trained. Parents need support for how to tap into different interventions (e.g., how to *get* an additional therapy, such as OT).
- Nissan said that the Waisman project will primarily be providing a database that suggests effective strategies to schools and providers. Getting the best treatment is still a “smart consumer’s field.” Perhaps the CLTS Waiver program needs to provide families with information resources in order to be smart consumers.
- Mike Williams said that parents are under so much pressure at the time that their child is diagnosed that they can’t be “smart consumers” at that moment. A screening tool, or a consultant (as Rose suggested) would be a good idea, but cumbersome. The ideal thing would be a sophisticated assessment tool for each child to assess the effectiveness of a therapy method for each individual child.
- A CD with video of an actual session, showing what different kinds of treatment models look like, could be a valuable resource for families.

Kris offered a summary of the discussion, and suggested that the core of the discussion was the importance of **effective outcomes for each individual child.**

The Council also brought up several points related to incorporating flexibility in treatment options:

- Need to look at the barriers to flexibility in treatment options.
- Important to evaluate the needs of the child and the entire family – effectiveness varied from one family to the next.
- All other Children’s Services programs run by DHFS look at the needs of the individual family and child. Requiring a single model of treatment (ABA) does not fit the value of “family first.”
For some families, “flexibility” would mean continuing longer than the 3 years of intensive. But it also can mean flexibility in location of services and type of services. Could count the community hours as part of the treatment (generalization of social skills).
- Counties interpret the waiver regulations inconsistently – this is difficult for providers.
- Should be able to count those “golden opportunities” while in the home or community as part of the therapy hours.

The Council came up with a graphic representation of their discussion:



Following the discussion, the Council passed this motion:

Motion (Pam Stoika): That DHFS consider and develop options retaining current waiver accountability standards and focus on effective outcomes while increasing flexibility, intervention techniques, provider services, and locations in which services can be provided.

Seconded: Milana Millan

The motion was Approved by unanimous voice vote.

Glen Sallows offered up two separate statements as motions to follow the motion just passed. Discussion involved concern that the statements would potentially limit DHFS in attempting to address flexibility as defined in the previous motion. After additional refinement, the next two motions were passed:

Motion (Glen Sallows): The Council recommends that DHFS draft guidelines allowing parent “line hours” to count toward treatment hours during the period that the child has waiver funding, while addressing waiver safeguards.

Seconded: Nissan Bar Lev

The motion was Approved on voice vote with 6 In Favor, 1 Against (Milana Millan), and 1 Abstaining (Rose Helms)

Motion (Glen Sallows): That DHFS consider altering the current policy to approve treatment in other natural environments such as day care, preschool, and community settings.

Seconded: Nissan Bar Lev

The motion was Approved on voice vote with 6 In Favor, 1 Against (Milana Millan), and 1 Abstaining (Rose Helms)

TRANSITION DOCUMENT

Sandy Blakeney presented a final draft of the brochure/checklist that the subcommittee has developed for families. The Council discussed the fact that the brochure outlines a process where a family knows about an upcoming transition (i.e., from intensive to ongoing services) enough in advance to follow the guidelines. The brochure is not designed necessarily to address the issues when there is a transition due to, for example, a termination of services due to a child no longer meeting eligibility requirements. While those families do not have six months to transition to other services, the checklist can still provide some guidance as to planning for changes. The Council was happy with the brochure. DHFS will complete the formatting and have it published and distributed.

MEDICAL HOME

This discussion was tabled until the next meeting, since neither Joan nor Julie were able to attend this meeting.

UPDATES

- Katie Sepnieski of the Children’s Services Section distributed copies of the letter that was sent by the Council to members of the Wisconsin Senate and Assembly encouraging passage of SB 178 and AB 417 regarding insurance coverage for children with autism.
- Katie updated the Council on the progress of the updated rule regarding the Parental Payment Limits system (formerly known as the Parental Fee system). The parental fee system has been in place since 2006, but was included within an interim rule that is expiring with the fiscal year ending June 30, 2008. Katie is shepherding through the necessary changes to HFS 1, which will incorporate the Parental Payment Limits system, to be in place by July 1, 2008. There are no changes to the existing system as it relates to the CLTS Waivers. The new rule will roll in the Family Support Program. The same system will eventually apply as well to the Birth to 3 Program, although that will be included in a different rule that will be completed later in the year. Public Hearings on the changes to HFS 1 were held around the

state on March 26, 2008. No members of the public attended and no public comments were submitted.

- Handling family concerns received by Council members. Sandy discussed the issue of Council members receiving emails from families with concerns about the CLTS waivers and the services their children are or are not receiving. Members have requested that the emails be forwarded to the full Council, and this raised some concerns among staff regarding family confidentiality. Sandy clarified that DHFS will investigate and respond to every family who expresses concern or describes problems related to any program administered by the Department, but we will not forward an email you received from a family if it includes any protected health information or could reasonably be expected to divulge protected information. Therefore it is important, first, to be sure that the family *wants you to share their email with DHFS*, since they will be contacted by the Department in order to follow up on the concern. If there is any doubt, you should check with the family prior to sharing with DHFS.
- Katie distributed the handout entitled “Information on Outcomes: A tool for families, caregivers, and providers.” This document was developed by the DHFS Children’s Long Term Supports Council for distribution to parents and other interested parties.
- Reminder that the Circles of Life Conference would be held on April 24-25, 2008. Registration is closed, but people are not being turned away.
- The Long-Term Care Conference is coming up on April 14-16, 2008. Registration is closed and the conference is full. This year, there is a Children’s track, and many county support and service coordinators are expected to attend.
- Dispute Resolution Options: Beth explained that DHFS continues to have a contract with Marquette University for provision of mediation services. To date, there have been no family requests for dispute resolution. The pilot program was not widely publicized in an effort to be able to see how the system would work, but since there were no requests, DHFS has now made it more widely known. Discussion:
 - Viv Hazell asked when would this form of dispute resolution be used with regards to the Children’s Waivers. This system is for issues that are not eligible for the fair-hearing process, so it would not be used for decisions regarding eligibility, reduction of services, etc. This is more appropriate for issues such as a family wants a different type of approach for their child and they are told they cannot have it.
 - The Children’s Services Specialists (CSS) around the state are very involved with solving issues with families. It can be faster to work with a CSS to resolve a problem than to go through the dispute resolution process.
 - Nissan noted that the special education dispute resolution system is quite different from the waivers, since so many waiver issues go to fair hearing. In the special education system, the process requires that the people involved can commit resources for resolution, and Nissan wondered who is at the table for waiver disputes. Beth noted that with the waivers, the State has essentially already “written the check.”

- Rose mentioned the idea in the past of having an ombudsperson as a neutral party to help resolve issues. Beth said that DHFS did not go with this option because an ombudsperson would have no authority to compel any agreement that was reached.
- Sandy distributed a data report for the first half of fiscal year 2008 (7/1/07 – 12/31/07).
- Katie gave the Council an overview of the Autism Task Force created by Senator Dan Kapanke. This taskforce meets in LaCrosse occasionally, with the last meeting being March 25, 2008. Their primary focus appears to be wait lists, insurance coverage, and alternative treatment models. They are also trying to put together an informational brochure for families in the western part of the state. Glen Sallows is a member of the taskforce. Beth mentioned that Julie Bryda attends the meetings on a regular basis in order to be able to answer questions or respond to issues related to children's services through DHFS. It is a slight draw on staff resources, but important for DHFS staff to be available.
- Kris distributed a summary of the Council's accomplishments to date. The Council was glad to receive this.
- Update on Council vacancies – there are two vacancies. Sandy has been in touch with the Governor's office. We expect the Governor's office to have a chance to work on appointments in the near future. The Council continues to hope to increase the diversity of the Council membership, and to have a member who is a parent of a child receiving intensive in-home services through the waivers.

The meeting was adjourned at 3:00 PM.

Minutes Respectfully Submitted by
Sandy Blakeney
June 4, 2008