

**Division of Long Term Care
Treatment Intervention Advisory Committee (TIAC)
Autism and Other Developmental Disabilities**

MEETING MINUTES

May 3, 2013
10:00 AM to 12:00 PM
Department of Health Services (DHS)
1 W. Wilson Street, Room B139
Madison, WI 53707

Committee Members Present: Jennifer Asmus, Michael Axelrod (via Adobe Connect), Roger Bass, Maribeth Gettinger, Lana Collet- Klingenberg, Christine Peterson (via Adobe Connect), Linda Tuchman-Ginsberg

Committee Members Absent: None

DHS Staff Present: Julie Bryda, Sue Larsen, Meghan Mitchell, Bill Murray

Members of the Public: Shirin Cabraal, Mitchell Hagopian, Richelle Kroening, Nancy Dexter-Schabow

Welcome

TIAC committee members were welcomed by DHS staff and the agenda for the day was reviewed.

Public Testimony

- Mitchell Hagopian, Attorney from Disability Rights Wisconsin (DRW) provided the committee with a list of 16 questions regarding the TIAC's processes, determinations, and composition.
- He also suggested that comments from the public may be more beneficial at the end of the TIAC meeting, because all those in attendance have then heard the discussion and determinations regarding the treatments in review.
- DRW appreciates the annual review of treatments previously assessed and hopes to see a transparent process between the TIAC, the Department's final decisions, and those affected by determinations.
- Mr. Hagopian suggested the historical goal of the waiver has been to provide an array of non-medical services and treatments based on the needs of individual participants. Because of this historical premise, he believes the committee should not be bogged down in empirical nuances when the treatment is reported to be working for other children outside of the literature.
- There were no other public comments.

Approval of Meeting Minutes:

The minutes of the February 8, 2013, TIAC meeting were reviewed. On page 4, a suggestion was made to add a clarification for the review of Multisystemic Therapy. The one study that involved a sample of children was a grant prospectus and there is no publication from the grant. TIAC members have not been successful in communicating with the primary investigator regarding this study. The minutes will be edited by placing in parentheses "grant prospectus" following the term "publication." It was also

suggested to use “children with autism” as opposed to “autistic children.” Jenny made a motion to approve the minutes, Maribeth seconded the motion and the motion carried.

TIAC Focus and DHS 107 Language

- The committee members and the Department discussed the focus of the TIAC and how that focus has changed over time. Initially the committee was formed to evaluate the effectiveness of behavioral treatments for children with autism spectrum disorders and other developmental disabilities. As the committee has continued their reviews, it is evident that while any one treatment may not be effective for a specific target population, there sometimes is evidence that the treatment is effective for other target populations.
- Though the committee currently focuses on research specific to children with autism spectrum disorders, they do document and report on findings regarding other target populations.
- Additionally, many research articles do not focus on a “disorder,” rather they focus on specific behaviors that could encompass multiple types of disabilities; therefore, having a specific focus is vital to the efficiency of the TIAC.
- DHS 107.035(2)(d) language states that the TIAC (as a pro bono committee established by the Department to perform health care services review) is one of the four decision making steps in determining whether or not a treatment is experimental. The TIAC makes an advisory determination on the evidence supporting any particular treatment and shares this with the Department.
- Some members of the public have confused the TIAC’s role with the final decision that rests with DHS, and the committee suggests using a more appropriate term for their role so there is less confusion regarding responsibilities.

The TIAC Review and Advisory Determination Flow Chart was reviewed and discussed by the committee members and Department staff. This chart details how the TIAC’s advisory determination is made. The determination outcomes consist of Levels 1 through 5:

- Level 1: strong evidence: proven and effective
- Level 2: moderate evidence: proven and effective
- Level 3: emerging evidence: promising practice
- Level 4: insufficient evidence to establish efficacy
- Level 5: untested (no evidence or potential harm)

The DHS Decision Process Flow Chart was reviewed and discussed by the committee members and Department staff. This flow chart contains a number of questions the Department will consider relative to any proposed treatment. All treatments that are brought to the Department for review will be required to process through this flow chart. These questions include:

- Are there claims the treatment will cure or produce positive medical outcomes, or is there interest in documenting efficacy?
- Are there health and safety concerns?
- Is the intervention intended to meet non-treatment outcomes?
- Is the provider operating under professional credentialing standards?

Depending on the outcome of each question the TIAC would be used to review and make an advisory decision, otherwise the Bureau of Long Term Support (BLTS) Director would review the decision for

treatment and funding purposes. Currently the Department's review of an intervention is an internal decision that does not have formal protocol at this time. The Department's overall intent is to edit this flow chart into a formal process that captures areas of concern outside of empirical evidence, such as desired outcomes. To complete this task, the Department is reviewing this process with Bureau management, Division management, and the DHS Secretary's Office to determine an effective process.

- The committee suggested a TIAC referral should not be made if an intervention has claims of curing or producing positive medical outcomes. Determining medical efficacy is outside of the TIAC's initial charge and current expertise.
- The committee suggested moving question two regarding health and safety concerns to the first question on the flow chart. If a provider does not meet health and safety standards the TIAC believes they should not review that treatment for efficacy.
- The committee is unsure of their involvement and would prefer not to review a treatment when a provider does not meet credentialing standards. If the Department determines a provider does not have the proper credentials, the TIAC should not review that treatment since they are not familiar with DHS standards.
- The committee is concerned about the question that suggests an intervention is intended to meet non-treatment outcomes. This appears to be a paradox because there are differences between "side effects" and "treatment effects" in the literature. If a variable is measured, it is considered an outcome; if the researchers did not measure the variable, it is then considered anecdotal.
- The committee is concerned about the proposed work flow between the Department review process and the TIAC review process if the Department is referring non-treatment outcomes to the committee which in turn are filtered back to the Department for approval.
- The committee also noted that empirical literature relies on statistical methods to prove effectiveness. There could be treatments that in general are not supported by the literature but for a specific child with specific characteristics, they may be beneficial. Evaluating the micro-level effects (or outcomes) of treatment is different than looking at the collective effectiveness of a treatment.
- The committee believes having boundaries regarding the evaluation and determination of a treatment helps to remove any generality. Because of this, it is important that they evaluate the literature based on the measured outcomes (not unrelated outcomes or side effects) so the determination is reliable.

The Department is beginning to search for additional committee members with varying backgrounds, which could potentially include someone with a medical background. Despite a member's area of expertise, being able to research a treatment therapy involves skills that do not vary by discipline, and that is why the TIAC members are able to find consensus with various educational backgrounds.

The committee acknowledges Linda Tuchman-Ginsberg's pending retirement and appreciates her involvement in the TIAC.

Meeting adjournment

Lana Collet-Klingenberg made a motion to adjourn the meeting, Jenny Asmus seconded the motion. All approved and the meeting was adjourned at 11:54 A.M.