

MINUTES

Evidence-based Guidelines Subcommittee

Meridian Park Room
Community Health Education Center, Room 117 B&C
19300 SW 65th Avenue, Tualatin, OR 97062
November 7, 2013
2:00pm - 5:00pm

Members Present: Wiley Chan, MD, Chair; Steve Marks, MD, Vice-Chair; Beth Westbrook, PsyD; John Sattenspiel, MD; MPH; Bob Joondeph, JD; Eric Stecker, MD.

Members Absent: Leda Garside, RN, Vern Saboe, DC; Som Saha, MD.

Staff Present: Darren Coffman; Cat Livingston, MD, MPH; Jason Gingerich.

Also Attending: Alison Little, MD and Shannon Vandegriff (CEBP); Denise Taray (DMAP); Keith Cheng (Trillium Family Services); Shanna Beatty (MedImmune); Paul Terdal (Autism Speaks); Geri Auerback (Kaiser Permanente); Christie and Eric Riehl; Chris Gray (Lund Report); Brian Niebuurt (OHA); Brenna Legard; Jenny Fischer (ORABA); Scott Fournier; Eric Larsson (Lovaas Institute, HERC ad hoc expert); Katharine Zuckerman, MD (OHSU, HERC ad hoc expert); Anna Dvortcsak, private practice speech therapist

Roll Call/Minutes Approval/Staff Report

The meeting was called to order at 2:00 pm and roll was called. Minutes from the September 12 EbGS meeting were reviewed and approved. **Motion approved 6-0.**

Livingston reported on the October 10 VbBS and HERC meetings. VbBS reviewed the ADHD coverage guidance and associated guideline in October, as the guideline had been inadvertently omitted from the packet in August. The VbBS also reviewed the prenatal genetic testing guidance and approved a corresponding guideline for the Prioritized List after brief discussion. Both of these coverage guidances will now be reviewed by HERC.

ACTION: HERC staff will post the approved September minutes on the website as soon as possible.

➤ **Topic: Evidence Evaluation: Applied Behavior Analysis for Autism Spectrum Disorder**

Discussion: Livingston explained some updates to the evidence evaluation that have been made or are recommended. Staff will update the evidence summary so that new evidence from Maglione 2012 is included in the summary conclusion, stating that there is some evidence for Early Intensive Behavioral Interventions (EIBI) and other types of interventions. In addition, she drew the subcommittee's attention to a table Dr. Little added to the evidence evaluation, summarizing the key components of the studies from the Warren report.

Chan then introduced Drs. Larsson and Zuckerman, who are serving as the HERC's appointed ad hoc experts for this topic. Dr. Eric Fombonne has also been appointed as an ad hoc expert but could not attend the meeting.

Dr. Larsson provided a general overview of ABA and autism spectrum disorder. He noted that EIBI are aimed at actually allowing a child to regain normal developmental function. Other more focused interventions are used when EIBI has failed or is not appropriate, with the goal of addressing a social or communications deficit, or eliminating problematic behaviors like self-harm. This latter group includes older children for whom focused ABA may reduce the need for residential care. He also emphasized the need for a periodic assessment. He recommended a focused assessment every six months using a standardized tool, and that children not benefiting from treatment after six months be provided other care options. He said that the assessment needs to be reimbursed. Without reimbursement he said that evaluation may be skipped and could lead to continuation of costly treatment which does not benefit the child. Multiple standardized tools are available.

Dr. Zuckerman introduced herself as a general pediatrician who does research on health disparities related to autism care. She said that the condition can be diagnosed before age 2 but the average age of diagnosis in the United States is 5, and is over 7 years old for children of African-American or Hispanic backgrounds. Minority children tend to receive less treatment focused on core symptoms and fewer hours per week of treatment. She said most parents who are informed will seek ABA treatment, which makes conducting a randomized controlled trial very difficult. She also noted that the Oregon Health Authority is already investing in early diagnosis for autism spectrum disorder by including developmental screening (which includes screening for autism) as a core CCO metric. More children will be diagnosed early, but unless coverage changes there will be no additional access to ABA services.

The subcommittee then began discussion of a number of questions submitted to staff by email since the September meeting. The first discussed parent vs. provider-based training. Chan summarized the discussion, saying that it appears that parent involvement is important and that the ability of the parents to participate in treatment varies widely. Group therapy was deemed appropriate for some patients (but not all).

In discussing the subcommittee question regarding which outcomes are most important, Chan referred the committee to Dr. Larsson's and Dr. Fombonne written answers from the meeting packet. The subcommittee concluded that most of the outcomes are intermediate, but that looking at intermediate outcomes is common in the medical literature as well.

The subcommittee discussed the appropriate level of detail for the recommended duration and intensity of treatment. There was no clear limits elucidated by the evidence and parameters could be provided as the result of this committee or by the Value-based Benefits Subcommittee or other implementers.

Public Testimony:

Chan then opened the floor for public comments.

Keith Chang introduced himself as the Chief Medical Officer of Trillium Family Services. He also provides direct care to patients with autism in his work at OHSU and is also the parent of a child with autism spectrum disorder. Trillium was approached by a private insurer to develop an autism program. He provided an overview of a program provided by a Trillium partner organization with experience in Southern California. The program included varying levels of service based on a child's needs and reported high rates of success in reducing problem behaviors and increasing skills. He said that if you intervene early you hopefully won't have to spend so much on residential care later on in the person's life.

Christie Riehl provided some written testimony about her daughter's ABA treatment, which was provided to reduce severe self-injurious behavior starting at the age of 14. She showed video footage of her child before and after treatment and said that the treatment benefited her child and reduced the amount of care required. She asked the subcommittee to consider that older children can benefit from ABA if they have moderate to severe autism.

Paul Terdal testified, representing Autism Speaks. He said has two children with autism. He addressed the issues of operationalization, directing the subcommittee to the standards outlined in Senate Bill 365, Section 2. He asked the subcommittee to consider a strong recommendation based on the HERC Coverage Guidance Development Framework. In addition he asked that coverage be extended for older children. Very few older patients will need intensive ABA, but there will be some, such as Riehl's daughter. He argued that a clinical study is reasonable if failure to treat will not result in death or serious disability. He said that the failure to treat that child could have resulted in death and certainly resulted in disability. Rather than going forward with the current draft, he suggested asking the ad hoc experts to write a new draft.

Anna Dvortcsak testified that she is a speech/language pathologist who works with children with autism and trains professionals on ABA interventions. She said

ABA is a continuum of interventions. She recommended the subcommittee review a report from the National Professional Developmental Center as well as the National Standards Report. These include an intensive review, including recommendations on intensity of treatment. She cited a study saying that care for the average child with autism has a cost of about \$3.2 million over a lifetime, and that with early intervention we can reduce those costs by 65 percent. She is aware of limitations in the research. She said that it's not reasonable to have a control group which doesn't receive intervention because of ethical concerns. In addition, a control when the child is in the community is not possible because parents seek this treatment on their own even though they are in the control arm of a study.

Coffman invited the members of the public who testified to provide additional comments in writing during the public comment period.

Summary Recommendations:

The subcommittee then discussed several points regarding the summary recommendations. For children aged 12 and under, despite weak evidence, the subcommittee voted 5-1 to change the recommendation to strong, with Marks opposed. Staff will edit the first paragraph at subcommittee request, leaving in the statement that the evidence is weak but making a strong recommendation for coverage.

Stecker asked why the GRADE table shows preferences as moderately variable when a state law has been passed to mandate coverage. After discussion and testimony from Zuckerman, the subcommittee voted 6-0 to change it to low variability.

Sattenspiel asked about the limiting of coverage to that initiated before a certain age, but no specific cutoff was identified in the evidence. After discussion, the subcommittee removed the language requiring initiation of therapy at a certain age from the draft.

Discussion turned to coverage for children over the age of 12. Zuckerman noted that due to disparities in age at diagnosis, such a limit might prevent some children from receiving treatment, but acknowledged that the gap is narrowing as the Oregon Health Plan has made screening a priority. Larsson said that the more intensive interventions are not studied in this age group because the field of ABA does not recommend them. He said there is evidence for effectiveness of more focused treatment in this population. After discussion, the subcommittee voted 5-1 (Joondeph opposed) not to change the staff recommendations, but some members expressed openness to reviewing evidence that would support focused ABA for this population.

The subcommittee agreed to keep the suggested language describing the range of intensity and duration described in the evidence without making a specific coverage recommendation, and left in the strong recommendation that parent and caregiver involvement and training be included.

Livingston asked about the language regarding an evaluation every six months. After discussion the subcommittee voted 5-1 (Marks opposed) to keep the recommendation on evaluation as presented and to make it a strong recommendation.

The subcommittee voted 6-0 to post the evaluation of evidence for a 30-day public comment. The summary recommendation will be posted as modified during the meeting and is shown in Appendix A.

Next meeting: The next meeting is scheduled for Thursday, February 6, 2014 at 2:00 p.m. The meeting was adjourned at 5:00 p.m.

Appendix A: Summary conclusions to be posted for public comment

Applied behavior analysis (ABA), including early intensive behavioral intervention (EIBI), is recommended for coverage¹ for treatment of autism spectrum disorder² in children ages 2-12 (*strong recommendation*).

Rationale: This strength of recommendation was based on sufficient (but low quality) evidence and expert input, including testimony on parent/caregiver values and preferences.

Parent/caregiver involvement and training is recommended to be a component of treatment (*strong recommendation*).

Rationale: Evidence and expert input indicated that parental involvement in ABA is a key part of effective treatment.

Initial coverage should be provided for up to six months. Ongoing coverage should be based on demonstrated progress towards meaningful objectives using a standardized, multimodal assessment, no more frequently than every six months (*strong recommendation*).

Rationale: Ensuring that patients are making meaningful progress is important to ensure quality outcomes and effective use of resources. The six month assessment was chosen based on expert input to allow for sufficient time for progress while not being burdensome to providers and plans.

In studies showing benefit, interventions ranged from less than two to 40 hours per week and had a duration of 10 weeks to three years. No specific minimum duration or intensity has been determined to be required for efficacy.

ABA is not recommended for coverage for treatment of autism spectrum disorder in persons over the age of 12 (*weak recommendation*).

Rationale: The evidence suggests that ABA is most effective when administered at younger ages, and there is insufficient evidence to support ABA treatment at older ages.

Note: The evidence for the treatment of conditions comorbid with autism spectrum disorder is beyond the scope of this evidence summary.

¹ These conclusions apply to the Oregon Health Plan as governed by the Prioritized List of Health Services and to no other health plan.

² Autism spectrum disorder should be diagnosed by a qualified health care professional according to DSM-5 criteria.