

Association for Behavioral Health and Wellness

Advancing benefits and services in mental health, substance use and behavior change.

February 11, 2014

Scientific Resource Center Portland VA Research Foundation 3170 SW U.S. Veterans Hospital Road Mail code: R&D 71 Portland, Oregon 97239

To Whom It May Concern:

The Association for Behavioral Health and Wellness (ABHW) is writing to comment on the draft report titled *Therapies for Children with Autism Spectrum Disorder—Behavioral Interventions Update*.

ABHW is an association of the nation's leading behavioral health and wellness companies. These companies provide an array of services related to mental health, substance use, employee assistance, disease management, and other health and wellness programs to approximately 125 million people in both the public and private sectors. ABHW and its member companies use their behavioral health expertise to improve health care outcomes for individuals and families across the health care spectrum.

Assuring the delivery of effective behavioral health services to the autism spectrum population has been a challenge with the rapid enactment of autism legislation pushing the issue before there is clear research and evidence that addresses matters that are critical to the management of treatment. ABHW believes that the research community needs to address some of these critical research issues to help guide the field in an effective manner.

The following are a set of research questions on behavior therapies for Autism Spectrum Disorders (ASD) compiled by ABHW and its member companies. The questions are focused on what we collectively see as the current gaps in knowledge; answers to these questions are important to assure effective delivery of services in the provider community.

- What treatments for ASD are likely to be effective for what subpopulations (i.e. age, gender, IQ)? Are there subpopulations with differential responses to interventions?
- What plans are there for definitive, transparent and broad communication around knowledge of safety concerns (particular around unsafe therapies like chelation and secret in therapy)?
- Are there any identifiable changes early in the treatment phase that predict treatment outcomes?
- What is the evidence that effects measured at the end of the treatment phase predict long-term functional outcomes?
- What evidence supports specific components of treatment as driving outcomes, either within a single treatment or across treatments?

- What are the modifiers of outcome for different treatments or approaches?
- Intensive behavioral therapy appears to work for some children; will we ever know with reasonable certainty if treatment approaches should be viewed as a "one size fits all" model?
- In general, is there a threshold IQ for which Applied Behavioral Analysis (ABA) is effective? What is the expected trajectory of change for ABA? How do you define the outcome?
- Is there an ideal age at which to begin ABA?
- What is the effect of ABA and how long will the gains last? What is needed to sustain the gains?
- In general, is there a threshold IQ for which the Denver Model (and any other evidence based intensive behavioral therapies) is effective? What is the expected trajectory of change for the Denver Model (and any other evidence based intensive behavioral therapies)? How do you define the outcome?
- Is there an ideal age at which to begin the Denver Model (and any other evidence based intensive behavioral therapies)?
- What is the effect of Denver Model (and any other evidence based intensive behavioral therapies) and how long will the gains last? What is needed to sustain the gains?
- For what characteristics is ABA, the Denver Model, and other evidence based treatments not effective?
- Is there any evidence or tool that helps define the level of intensity of treatment needed?
- Are there tools that you recommend to measure the effectiveness of treatment?

Other Research Needs

• Given the status of autism behavioral treatment research and the barriers to research in this population, what other research types, other than randomized control trials and matched group cohort studies, would AHRQ consider valid to test and demonstrate treatment effectiveness (e.g. single case studies, large multi-site observational studies)?

We appreciate the opportunity to comment and bring the perspective of the practical application of science to service delivery to guide future research. If you have any questions or would like to discuss any of these issues with ABHW, please contact Pamela Greenberg, MPP, President and CEO, at (202) 449-7660 or greenberg@abhw.org.

Sincerely,

Pamela Dreenberge

Pamela Greenberg, MPP President and CEO

Cc:

Thomas Insel, M.D., Director of the National Institute of Mental Health and Chair of the IACC