



Public Comments and Responses

Applied Behavioral Analysis and Other Behavioral Therapies for Treatment of Autism Spectrum Disorder

Washington Health Technology Assessment

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Center for Evidence-based Policy

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RESPONSE TO PUBLIC COMMENTS

The Center for Evidence-based Policy is an independent vendor contracted to produce evidence assessment reports for the WA HTA program. For transparency, all comments received during the comments process are included in this response document. Comments related to program decisions, process, or other matters not pertaining to the evidence report are acknowledged through inclusion only.

This document responds to comments from the following parties:

- Eric Brechner (Microsoft employee and parent)
- Tam Dang (affiliation/interest not declared)
- Scott Napolitan (affiliation/interest not declared)
- Maria Nardella, MA, RD, CD (Manager, Children with Special Health Care Needs Program, WA State Department of Health)
- Susan Ray (affiliation/interest not declared)
- Sara White, PhD, BCBA-D (Psychologist) and James Harle, MD (Child and Adolescent Psychiatrist) (Sendan Center)

Specific responses pertaining to each comment are included in Table 1 below. The full version of each public comment received is available in the Public Comments section, beginning on page 8.

Table 1. Response to Public Comments

Reviewer	Comment	Disposition
Eric Brechner (Microsoft employee and parent)		
	Anecdotal summary of Microsoft benefits for ABA, and the history in developing those benefits.	<i>Thank you for your comment.</i>
Tam Dang		
	“ABA therapy is very effective & helpful for Autistic children. I wish that my kid can have it but it’s not covered by our insurances.”	<i>Thank you for your comment.</i>
Scott Napolitan		
	“My 6 year old son is autistic and ABA has done wonders for him after only about a year. He was almost non-verbal when he started and now he can talk in complete sentences, can play games, participates in circle time at school and is far more connected to us. We attribute a large part of this to ABA and expect it to be the key to generalizing him, so I’d like to help if I can, even if it doesn’t affect me directly.	<i>Thank you for your comment.</i>
Maria Nardella, MA, RD, CD (Manager, Children with Special Health Care Needs Program, WA State Department of Health)		
	“On page 2 and again on page 10 the report states that “no Washington state agency covers ABA therapy”. The Department of Social & Health Services/Division of Developmental Disabilities is using ABA in the Children’s Intensive In-home Behavioral Supports (CIIBS) Program. “	<i>Currently, no Washington State agency covers ABA therapy for autism; however, other services that are commonly identified as components or alternatives to ABA are covered. In general, these services are covered if they are provided under a treatment plan of medically necessary therapies, designed and administered within the scope of practice for state licensed professionals (e.g., psychologists, speech language therapists, occupational therapists, physical therapists).</i> <i>Page 11 of the report provides a summary of the services covered by the Department of Social and Health Services (DSHS) and Uniform Medical Plan (UMP) / Public</i>
	“Page 12. ITEIP needs to be updated to Early Support for Infants & Toddlers (ESIT) now in the Department of Early Learning.”	

Reviewer	Comment	Disposition
		<i>Employee Benefit Plan (PEB).</i>
	<p>“Page 60. It states that “National coverage policies were identified.” There is no mention in this report that I could find that includes services covered by the Department of Defense (DOD) for families serving in the military. There are in fact, significant numbers of children with ASD in Washington who are able to receive ABA because of this coverage. I am surprised that in the preparation for the report that the decision making process used by DOD to add this coverage was not explored, or at least acknowledged in the report. I suggest that this be added to the final report.”</p>	<p><i>The State of Washington chose to summarize a select number of state and private payor policies. Only these policies were summarized in the HTA report. We acknowledge that there are many other policies not covered in the HTA report. The DoD coverage policies for individuals with ASD were not among the policies identified by the State of Washington for review. Please refer to pp. 58 – 60 of the HTA report for a list of policies reviewed. Appendices C and D of the report describe the select policies reviewed in more detail.</i></p>
	<p>“I understand needing to have some cut-offs for what research to consider. Is it well known among researchers that their studies need to be designed to include a minimum of 30 participants for medical studies and a minimum of 10 for allied health? I wonder what organizations are out there to fund studies of that size, particularly when no insurance reimbursement is available to supplement funding? But, I don’t know how you can address this in your report.”</p>	<p><i>Systematic reviews often exclude studies with small sample sizes because of concerns regarding validity, quality and generalizability of small studies. There were many examples of larger study samples included in the AHRQ review which can help to inform the question under review and so the exclusion of small studies was felt to improve the overall quality of the review. The AHRQ report was peer and public reviewed.</i></p>
	<p>“I think a “safety issue” to consider with ABA is the risk for children and families when something called “ABA” is provided by people without training and credentials who claim to be delivering it.”</p>	<p><i>Licensure of ABA providers is briefly discussed under policy considerations on pp. 60 of the HTA report.</i></p>
Susan Ray		
	<p>Provided: Motiwala, S.S., Gupta, S., Lilly, M.B, Ungar, W.J., & Coyte, P.C. (2006). The cost-effectiveness of expanding intensive behavioral intervention to all autistic children in Ontario. <i>Healthcare Policy</i>, 1(2), 135-151.</p>	<p><i>As outlined by the State of Washington, the AHRQ report (Warren et al 2011) was used for the systematic review of evidence. Literature not included in the AHRQ report</i></p>

Reviewer	Comment	Disposition
	Eldevik, S., Hastings, R.P., Hughes, J.C., Jahr, E., Eikeseth, S., & Cross, S. (2010). Using participant data to extend the evidence base for intensive behavioral intervention for children with autism. <i>American Association on Intellectual and Developmental Disabilities</i> , 115(5), 381-405.	<i>did not meet the HTA report inclusion criteria.</i>
Sara White, PhD, BCBA-D (Psychologist) and James Harle, MD (Child and Adolescent Psychiatrist) (Sendan Center)		
	Comments regarding the AHRQ report:	
	“Does not acknowledge that ABA is the intervention with the largest data to support it”	<i>The AHRQ report was systematic in their methods and focused on quality and validity of data as well as quantity. The authors’ conclusion was that there was a low strength of evidence for the effectiveness of UCLA/Lovaas therapy, while the evidence for all other behavioral interventions was insufficient.</i>
	“Criticisms mentioned in the report is that there has not been any research done evaluating the comparison between treatment methodologies” - “no direct studies comparing medication treatments” [...] “authors go on to endorse the use of medication with this population”	<i>There are no head to head comparisons for medication treatments but they are compared to other interventions.</i>
	“there are studies that directly address the comparison between treatment methodologies; the results show that intensive early behavioral intervention was superior to an eclectic approach in the treatment of individuals with autism”	<i>This is true for the studies listed. The authors’ conclude that there was a low strength of evidence for the effectiveness of UCLA/Lovaas therapy.</i>
	“Important to differentiate between the general field of ABA and the more specific form of intensive and comprehensive early behavioral intervention for individuals with autism” “the AHRQ report focuses on the latter but fails to acknowledge the numerous studies that demonstrate the efficacy of general behavioral principles of ABA for behavior change in a variety of populations”	<i>Focusing on the efficacy of general behavioral principles of ABA was considered outside of the scope of the AHRQ and WA HTA report.</i>
	“There are studies that address some of the concerns raised by the committee [...] however, the authors exclude them from the AHRQ report without explaining why”	<i>Lovaas 1987 did not meet inclusion criteria as described in the methods section of the AHRQ report. Sallows 2005 is included and discussed on page 36 of the HTA report and page 88 of the</i>

Reviewer	Comment	Disposition
		<i>AHRQ report.</i>
	“The AHRQ report arbitrarily holds psychosocial interventions to a much higher standard than medication”	<i>The AHRQ report assessed the quality of both psychosocial and medication interventions. If anything, the medication studies were held to a higher standard in terms of sample size.</i>
	“the author’s fail to acknowledge that [RCTs for interventional outcome studies] are extremely difficult [type of research], if not impossible, and perhaps ethically inappropriate, to implement with an intervention that is done intensively over 2 years of the individual’s life.”	<i>Thank you for your comments. The AHRQ report included studies of lower methodologic rigor for all interventions and acknowledged the difficulty of research in this area. RCTs have been conducted for some behavioral interventions (e.g., Early Start Denver Model) which would seem to indicate that this research is not impossible. Given that there is a real danger of harm with any intervention it is important that interventions be rigorously evaluated.</i>
	“ The reviewers are overly critical in the analysis of the literature [...] without taking into account the validity of the measures or diagnostic procedures used”	<i>See comment above. The AHRQ report did not include diagnosis and was considered to be outside the scope of the report.</i>
	“Criticizing the behavioral literature for ‘the duration of treatment and follow-up being relatively short’ is confusing. In the study done by Lovass in 1987 treatment took place over 2 years with a follow-up 7 years later. There have also been several other studies done that have been several year in length [...]. Given that medication studies take place over several weeks with follow-up less than six months later, again this seems like an unfair and willfully arbitrary criticism of the behavior literature.”	<i>While there are a few studies that have had longer duration and follow up times, the majority have not. The duration of follow-up was stated as a limitation for all interventions and treatments.</i>
	“Nowhere in the report does the review panel directly address that ABA is currently the treatment with the largest amount of research to back it done to date. While there are admittedly weaknesses in this body of literature, it is one of the most extensively studied interventions for individuals with autism and the results are better and more comprehensive than any other intervention.”	<i>The authors’ conclusion was that there was a low strength of evidence for the effectiveness of UCLA/Lovaas therapy, while the evidence for all other behavioral interventions was insufficient.</i>

Reviewer	Comment	Disposition
	Comments regarding the HTA report:	
	<p>Following reports omitted from the review:</p> <ol style="list-style-type: none"> 1. Maine Department of Health and Human Services & The Main Department of Education (2009) 2. New York State Department of Health (1999) 3. American Academy of Pediatrics (2007) – Management of Autism Spectrum Disorders 4. Department of Defense Report and Plan on Services to Military Dependent Children with Autism (2007) 5. US Surgeon General (1999) 6. National Institute of Mental Health 7. National Research Council (2001) 	<p><i>As directed by the State of Washington, the AHRQ report (Warren et al., 2011) was selected as the sole evidence source for the HTA report. Other reports, as suggested, did not meet inclusion criteria for the AHRQ report.</i></p> <p><i>The guideline from the American Academy of Pediatrics was included in the HTA report and a summary of the guideline can be found on pp. 54 – 56.</i></p>
	<p>“lack of information on the ratings assigned to the studies under review, rendering such ratings difficult, if not impossible, to interpret”</p>	<p><i>The ratings for individual studies were excerpted from the AHRQ report (Warren et al., 2011). For a full description of the quality rating system and methods, please refer to the AHRQ report.</i></p> <p><i>The guideline quality assessment tool used to quality assess all included guidelines was added to the HTA report and can be found in Appendix E.</i></p>
	<p>“It should be noted that within Washington State there are agencies that support the use of ABA for individuals with developmental disabilities. For example in the Children’ Intensive in-Home Behavior Support Services (CIIBS) program, the primary modality of treatment is Positive Behavioral Support Model, which is one branch of ABA. Children with autism can access these services, and thus the state is already funding ABA for children with autism at some level.”</p>	<p><i>Currently, no Washington State agency covers ABA therapy for autism; however, other services that are commonly identified as components or alternatives to ABA are covered. In general, these services are covered if they are provided under a treatment plan of medically necessary therapies,</i></p>

Reviewer	Comment	Disposition
		<p><i>designed and administered within the scope of practice for state licensed professionals (e.g., psychologists, speech language therapists, occupational therapists, physical therapists).</i></p> <p><i>Page 11 of the report provides a summary of the services covered by the Department of Social and Health Services (DSHS) and Uniform Medical Plan (UMP) / Public Employee Benefit Plan (PEB).</i></p>
	<p>“Cost-benefit analyses of treatment interventions are founded on the evaluation of fiscal benefit of early and intensive behavioral intervention with individuals with autism.”</p>	<p><i>Cost and cost effectiveness for ABA therapies were outside the scope of the AHRQ and WA HTA reports.</i></p>

Eric Brechner, Microsoft Employee and Parent:

ABA COVERAGE COMMENTS FOR GOVERNMENT REVIEW

ERIC BRECHNER, MICROSOFT EMPLOYEE AND PARENT

In November of 1998, ten Microsoft employees wrote to the Microsoft Chief Operating Officer and the Director of Human Resources (see *Excerpt from the letter to Microsoft HR*). We talked about how the company, given the right guidelines, can cover behavioral intervention responsibly and practically. We talked about the impact to our families.

In January 2001, Microsoft introduced coverage for autism therapy, like Applied Behavioral Analysis (ABA). This coverage has been enhanced three times since.

- Removal of age limits in 2002
- Increase in the number of consultant visits in 2008
- Removal all lifetime limits in 2011

Microsoft regularly enhanced coverage because the coverage paid for itself within three years, increased employee productivity, helped with recruiting, and improved employee retention.

The precise impact of the Microsoft autism benefit is difficult to measure due to privacy regulations. Nonetheless in 2006, Microsoft employees decided to anonymously survey themselves.

- 60 total respondents—roughly half of the Microsoft autism distribution list at the time
- 50% considered the autism therapy benefit an “important factor” in their decision to join Microsoft
- 60% considered the autism therapy benefit an “important factor” for retention
- 19% indicated they were likely to leave if the autism therapy benefit expired

In 2006, the U.S. Department of Labor reported the average length someone stays at one job in the US was 3 to 5 years. In 2011, 6 of the 10 Microsoft employees who wrote about their autistic children are still at Microsoft 13 years later.

Although Microsoft HR reports that the autism therapy benefit provides a return on investment of about 7% after three years (roughly 70% of which is due to productivity gains), the literature

indicates potential gains of 250-350% over 20 years¹. However, these gains can only be realized through broad adoption of autism therapy. When government gets involved, we can all achieve that 250-350% return.

EXCERPT FROM THE LETTER TO MICROSOFT HR – NOVEMBER, 1998

Microsoft Benefits mentions five primary concerns. As a Microsoft stockholder, I am quite sensitive to the need to cover only narrowly prescribed rehabilitative therapies provided by licensed or otherwise credentialed providers. Doing otherwise exposes the company to excessive liability and expense. I believe the company, given the right guidelines, can cover behavioral intervention responsibly and practically.

Allow me to respond to each of Microsoft Benefits' primary concerns:

- Microsoft healthcare plan and prevailing benefit industry standards exclude educational therapy from coverage under health care plans

ABA therapy for autistic children is rehabilitative, not educational. The therapy develops basic imitation skills, speech, and the ability to interact with other people in fundamental ways that come naturally to every typically developing child. It is precisely these skills that children with developmental or neurological disorders need to have access to any of the educational services, even special education services, which a school district can provide. There is significant and compelling documented research demonstrating the effectiveness of this behavioral intervention as rehabilitative therapy for developmental and neurological disorders.

- Treatment is provided by unlicensed, non-credentialed graduate students

A credentialed psychologist designs and develops my son's ABA program. She regularly evaluates Peter's progress and trains and supervises the individuals that do the 20-30 hours a week of one-on-one therapy. The individuals she supervises are often students. As with any long-term intensive care, the day to day attention is not given by the credentialed professional, but instead by supervised apprentices. Many covered therapies, such as physical therapy, are done in an identical fashion. The key is that the liability goes back to the supervising licensed and/or credentialed professional.

Since this point is brought up several times, I'd like to make the following comparison. People who suffer strokes or head injuries that result in the loss of communication, cognitive, social, and daily living skills are routinely provided with intensive rehabilitation to re-train those skills. This kind of therapy has many things in common with intensive ABA for children with autism. It's provided 1-on-1 by specially trained, but not credentialed individuals, under the supervision of a credentialed professional. It's intrusive and intensive;

¹ Jacobson et al. (1998) ~\$250,000 per child 3-22 years; Hildebrand (1999) ~\$350,000 per child 3-22 years

it must be done for many hours over extended periods of time to be effective; and more than likely, it couldn't be done properly in a setting like a typical public school program. Insurance pays for much of this kind of rehabilitation, as long as it's prescribed and directed doctors. Autism is also a neurological disorder; the only difference is that, unlike stroke, autism affects brain functioning from birth (or more likely, prior to birth). So instead of re-learning how to function independently in regular environments, like stroke patients, children with autism have to learn how to do that from the get-go, and typical educational services simply don't suffice.

- Lack of regulation for licensed treatment providers

Both Psychology and Neurology are well established and credentialed fields. As long as someone with these credentials is directing the program this should not be an issue.

- Liability issues with treatment provided by unlicensed and/or non-credentialed providers

Again, this should not be an issue when the liability goes back to the supervising licensed and/or credentialed professional.

- ABA is also used to treat other diagnosis and would dramatically affect the Microsoft health care plan

ABA and behavioral intervention in general could be used for many different purposes. This fact is irrelevant to whether or not ABA should be used to treat autism. Many drugs and other treatments can be used for illegitimate purposes including performance enhancement and recreation. Behavioral intervention should only be covered when a licensed physician, psychologist, or neurologist prescribes it for a developmental or neurological disorder. The key is that a trusted professional is prescribing the behavioral intervention to treat only certain conditions for which it has been proven an effective rehabilitative therapy.

To summarize, if a licensed physician, psychologist, or neurologist prescribes behavioral intervention (ABA) for the treatment of a developmental or neurological disorder, and that treatment is directed by a licensed and/or credentialed professional (Psychologist, Speech Pathologist, Neurologist, etc.), then the therapy should be covered by the Microsoft Benefits plan. I believe by narrowly defining who can receive benefits and under what conditions, Microsoft can responsibly cover this therapy without exposing itself to undue liability or expense.

That said, you should know just how important it is to cover this therapy. Following the advice of the psychologist who diagnosed our son, my wife and I arranged for Peter to receive ABA therapy. In nine months he has gone from a completely silent, unaware, and unresponsive child to a darling little boy. Peter now greets me when he wakes up with, "Hi Daddy!" He kisses me and waves goodbye when I leave. He plays games with his older brother, whom he once didn't even know existed. And at night he snuggles under his covers, looks me right in the eye (something he never could do before), and says, "Night, night. Sweet dreams. I love you. See

you in the morning.”

Peter still has a long way to go. His speech is delayed, he can't perform many common skills like jumping or catching, he does not interact with others as he does with his immediate family, and he lacks many social and self-help skills that typical children his age have. None the less, when I compare where he was to where he is, tears come to my eyes. It is nothing short of a miracle.

Behavioral intervention has given me back my son from what was once thought a hopeless diagnosis. Although I would spend every penny I have to continue to provide it for him, coverage of this clearly rehabilitative therapy would insure that certified professionals will provide it at the level Peter needs. I have tried to show how this can be done responsibly.

[My son is now 15 years old and is a straight-A student at our local public Junior High School. His speech is no longer delayed, he can jump and catch, and he interacts with his friends in typical yet nerdy ways.]

Tam Dang [affiliation/interest not declared]:

“ABA therapy is very effective & helpful for Autistic children. I wish that my kid can have it but it’s not covered by our insurances.”

Scott Napolitan [affiliation/interest not declared]:

“My 6 year old son is autistic and ABA has done wonders for him after only about a year. He was almost non-verbal when he started and now he can talk in complete sentences, can play games, participates in circle time at school and is far more connected to us. We attribute a large part of this to ABA and expect it to be the key to generalizing him, so I’d like to help if I can, even if it doesn’t affect me directly.”

Maria Nardella, MA, RD, CD, Manager, Washington State Department of Health/Children with Special Health Care Needs Program

“Page 2 and page 10: The report states that “no Washington state agency covers ABA therapy”. The Department of Social & Health Services/Division of Developmental Disabilities is using ABA in the Children’s Intensive In-home Behavioral Supports (CIIBS) Program.

Page 12: ITEIP needs to be updated to Early Support for Infants & Toddlers (ESIT) now in the Department of Early Learning.

Page 60: It states that “National coverage policies were identified.” There is no mention in this report that I could find that includes services covered by the Department of Defense (DOD) for families serving in the military. There are in fact, significant numbers of children with ASD in Washington who are able to receive ABA because of this coverage. I am surprised that in the preparation for the report that the decision making process used by DOD to add this coverage was not explored, or at least acknowledged in the report. I suggest that this be added to the final report.

I understand needing to have some cut-offs for what research to consider. Is it well known among researchers that their studies need to be designed to include a minimum of 30 participants for medical studies and a minimum of 10 for allied health? I wonder what organizations are out there to fund studies of that size, particularly when no insurance reimbursement is available to supplement funding? But, I don’t know how you can address this in your report.

I think a “safety issue” to consider with ABA is the risk for children and families when something called “ABA” is provided by people without training and credentials who claim to be delivering it.

Thanks for the opportunity to review.”

Susan Ray [affiliation/interest not declared]:

Submitted the following two articles:

Motiwala SS et al. (2006). The Cost-Effectiveness of Expanding Intensive Behavioural Intervention to All Autistic Children in Ontario. Retrieved June 6, 2011 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585334/pdf/policy-01-135.pdf>

Eldevik S et al. (2010). Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children with Autism. Retrieved June 6, 2011 from <http://www.aaidjournals.org/doi/pdf/10.1352/1944-7558-115.5.381>

June 5, 2011

Health Technology Clinical Committee
c/o Denise Santoyo
Washington State Health Care Authority
Health Technology Assessment

Dear members of the Health Technology Clinical Committee,

RE: REQUEST FOR PUBLIC COMMENT ON THE USE OF APPLIED BEHAVIOR ANALYSIS THERAPY FOR AUTISM

I am writing this letter in response to your request for public comment on the matter of funding for applied behavior analysis therapy for autism. I understand that the committee will be relying on two key reports in making their decision, the Agency for Healthcare Research and Quality (AHRQ) report (April 2011) and the Healthcare Technology Agency (HTA) report (May 2011).

I will first comment on the inconsistencies that I see in each of the reports before making some more general comments about the treatment of individuals with autism.

The AHRQ report: Inconsistent and arbitrary

I found the AHRQ report to be extremely, and inappropriately, conservative in its assessment of the use of applied behavior analysis (ABA) to treat individuals with autism. The following are concerns that I had with the report:

1. It does not acknowledge that ABA is the intervention with the largest data base to support it.
 - a. While there are definitely weaknesses in the literature and more work to be done, this intervention methodology has more evidence to support it than do the medications which the report endorses.
2. One of the criticisms mentioned in the report is that there has not been any research done evaluating the comparison between treatment methodologies.
 - a. While, again, this research does need to be completed, it should be noted that there are no direct studies comparing medication treatments. However, the authors go on to endorse the use of medication with this population anyway. This is a curious double-standard.
 - b. Moreover, despite the authors' contention to the contrary, there are studies that directly address the comparison between treatment methodologies; the results show that intensive early behavioral intervention was superior to an eclectic approach in the treatment of individuals with autism (Howard, Sparkman, Cohen, Green, & Stanisiaw, 2005; Eikeseth, Smith, Jahr, & Eldevik, 2002; Eikeseth, Smith, Jahr, & Eldevik, 2007; Eldevik, Eikeseth, Jahr, & Smith, 2006).
3. It is also important to differentiate between the general field of ABA and the more specific form of intensive and comprehensive early behavioral intervention for individuals with autism.
 - a. The AHRQ report focuses on the latter, but fails to acknowledge the numerous studies that demonstrate the efficacy of general behavioral principles of ABA for behavior change in a variety of populations. (New York State Department of Health, 1999)
4. There are studies that address some of the concerns raised by the committee: e.g., better outcomes with more hours of intervention (Lovaas, 1987), equal outcomes for parent-led vs. agency-led intervention (Sallows & Graupner, 2005). However, the authors exclude them from the AHRQ report without explaining why.

5. The AHRQ report arbitrarily holds psychosocial interventions to a much higher standard than medication.
 - a. If one is to take this report at face value, it appears there are no interventions for autism that should be used -- aside from medication, despite the fact that medication has no effect on some of the more debilitating symptoms of social and adaptive skill development.
6. Of course RCT's are gold standard for intervention outcome studies. However, the authors fail to acknowledge that this type of research is extremely difficult, if not impossible, and perhaps ethically inappropriate, to implement with an intervention that is done intensively over 2 years of the individual's life.
 - a. There is enough evidence available to suggest that intensive and comprehensive behavioral intervention is an effective treatment for individuals with autism. Therefore there are serious ethical considerations involved in completing this type of research, specifically in terms of random assignment to groups, as control group individuals will then be denied effective treatment for the entire length of the study.
 - b. Additionally, these types of interventions require a great deal of time in order to determine efficacy (unlike medication trials in which effects may manifest within months), so such studies need to be carried out over a lengthier period of time.
 - c. While I understand the need for standardization of treatment, one of the hallmarks of behavioral intervention for individuals with autism is individualization. In order to be effective, treatment needs to be individualized, and therefore treatment fidelity scores may be lower if certain individuals require greater amounts of individualization.
 - d. Finally, creating a comparison group which is truly indistinguishable from the treatment group is excessively difficult given that treatment is 40 hours per week of intensive intervention adhering to a specific treatment protocol. Creating a comparison group that replicates that in a way that participants are truly blind to the condition they are assigned to is extremely challenging.
7. The reviewers are overly critical in the analysis of the literature (e.g., diagnostic standards are criticized along with the use of disparate outcome measures) without taking into account the validity of the measures or diagnostic procedures used.
8. Criticizing the behavioral literature for "the duration of treatment and follow-up being relatively short" is confusing. In the study done by Lovaas in 1987 treatment took place over 2 years with a follow-up 7 years later. There have also been several other studies done that have been several years in length (Howard et al., 2005; Eikeseth et al., 2002; Eikeseth et al., 2007 for example). Given that medication studies take place over several weeks with follow-up less than six months later, again this seems like an unfair and willfully arbitrary criticism of the behavioral literature.
9. Nowhere in the report does the review panel directly address that ABA is currently the treatment with the largest amount of research to back it done to date. While there are admittedly weaknesses in this body of literature, it is one of the most extensively studied interventions for individuals with autism and the results are better and more comprehensive than any other intervention.

In summary, the AHRQ report is inconsistent and arbitrary in its recommendations of intervention techniques for individuals with autism. Based on these recommendations the only available and funded treatments would be two medications, which have a relatively limited database of support in the literature, and which only target selected aspects of the overall deficits of individuals with autism. Again, while the shortcomings of the existing literature base are acknowledged, ABA is currently the most comprehensively researched intervention and to date the most effective for all deficit areas in individuals with autism.

The Healthcare Technology Agency report: Difficult to interpret and incomplete

1. The HTA report was difficult to interpret and incomplete. There was a lack of information on the ratings assigned to the studies under review, rendering such ratings difficult, if not impossible, to interpret. Additionally, several reports completed by other state or federal agencies were inexplicably omitted from the HTA review. The following reports were omitted from the review (annotations are mine):

2. 1. Maine Department of Health and Human Services & The Maine Department of Education (2009)
 - a. Early Intensive Behavioral Intervention – *Established evidence*
 - b. Applied Behavior Analysis for Challenging Behavior – *Established evidence*
 - c. Applied Behavior Analysis for Communication – *Established evidence*
 - d. Applied Behavior Analysis for Social Skills – *Established evidence*
3. New York State Department of Health (1999)
 - a. Principles of ABA and behavior intervention strategies should be included as an important element of any intervention program for young children with autism – *Strong evidence*
 - b. Intensive behavioral programs include as a minimum approximately 20 hours per week of individualized behavioral intervention using ABA techniques (not including time spent by parents) – *Strong evidence*
 - c. Precise number of hours of behavioral intervention vary depending on a variety of child and family characteristics. Considerations in determining the frequency and intensity of intervention include age, severity of autistic symptoms, rate of progress, other health considerations, tolerance of the child for the intervention and family participation – *Strong evidence*
 - d. Effective interventions based on ABA techniques used between 18 and 40 hours per week of intensive behavioral intervention by a therapist trained in this method – *Strong evidence*
4. American Academy of Pediatrics (2007) – Management of Autism Spectrum Disorders
 - a. ‘The effectiveness of ABA-based intervention in ASD’s has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.’
5. Department of Defense Report and Plan on Services to Military Dependent Children with Autism (2007)
 - a. ‘Applied behavior analysis (ABA), a systematized process of collecting data on a child’s behaviors and using a variety of behavioral conditioning techniques to teach and reinforce desired behaviors while extinguishing harmful or undesired behaviors, is one of the best studied interventions. Time-limited, focused ABA methods have been shown to reduce or eliminate specific program behaviors and teach new skills to individuals with autism.’ Page 4
 - b. ‘A large body of research has demonstrated substantial progress in response to specific intervention techniques in relatively short periods of time (e.g., several months) in many specific areas, including social skills, language acquisition, nonverbal communication, and reductions in challenging behaviors. Longitudinal studies over longer periods of time have documents changes in IQ scores and in core deficits (e.g., joint attention), in some cases related to treatment, that are predictive of longer term outcomes. However, children’s outcomes are variable, with some children making substantial progress and others showing very slow gains.’ Page 7
6. US Surgeon General (1999)
 - a. ‘Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.’
7. National Institute of Mental Health - <http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml>
 - a. ‘Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. *Mental Health: A Report of the Surgeon General* states, “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior”’. The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a

week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential.'

8. National Research Council (2001) – Educating Children with Autism
 - a. 'There is general agreement across comprehensive intervention programs about a number of features of effective programs. However, practical and, sometimes, ethical considerations have made well-controlled studies with random assignment (e.g., studies of treatments that systematically vary only one dimension) almost impossible to conduct.' Page 6

In summary, the HTA report is difficult to interpret, given the lack of clarity about how selected studies were rated, and, more bewilderingly, incomplete, given the inexplicable omission of critical reports, authored by highly reputable institutions – among them the NIMH, the United States Surgeon General, and the American Academy of Pediatrics.

Understanding Efficacious Treatment for Children with Autism

It should be noted that within Washington State there are agencies that support the use of ABA for individuals with developmental disabilities. For example in the Children' Intensive In-Home Behavior Support Services (CIIBS) program, the primary modality of treatment is Positive Behavioral Support Model, which is one branch of ABA. Children with autism can access these services, and thus the state is already funding ABA for children with autism at some level.

Finally and most importantly, cost-benefit analyses of treatment interventions are founded on the evaluation of fiscal benefit of early and intensive behavioral intervention with individuals with autism. While not every individual will be a best outcome case, there are other benefits to intensive behavioral intervention (e.g., increased functional vocabulary, increased self-help skills, decreases in problematic behaviors, etc.). Thus, even if an individual does not respond optimally to intervention, there are lifetime benefits to intervention, which result in lower levels of care throughout the individual's adult life. Estimates vary, but the conservative estimate on lifetime savings per individual is \$850,000 to \$1,200,000 (Jacobson, Mulick, & Green, 1998). In a report by Columbia Pacific Consulting firm, in an affidavit to Douglas G. Hildebrand, the authors report that even in the lowest success group savings are likely to amount to \$642,200 (individuals with better outcomes are associated with cost savings up to \$1,368,900). With the increasing prevalence of autism, early intervention has the potential to save the government – and by extension, all taxpayers – a significantly massive amount of money across the lifespan of an individual with autism.

In summary, ABA intervention is a well researched and well-established intervention for individuals with autism.

While – as across many domains of child mental health -- there is still a significant amount of research that remains to be done, the reports submitted as information for this committee's decision would suggest no intervention aside from two medications should be funded in the treatment of children with autism. If that is the case, why do we send children with autism to school? It is a cynical and false argument to claim there is no effective form of intervention that is worth spending taxpayers' money on. We might as well revert back to simply institutionalizing individuals with autism shortly after they are born, if we truly believe there is no hope of their either learning more adaptive behavior or of learning to control their problematic behavior, aside from long-term use of medication with some relatively serious side effects.

By contrast, I would argue that the data shows that we can teach individuals on the spectrum many skills and decrease problematic behaviors using the principles of ABA. These strategies and techniques not only have the short-term benefit of increasing desirable behaviors and decreasing problematic behaviors, they also have the long-term benefit of decreasing the level of care an individual will require throughout their life span, thus saving taxpayers a significant amount of money.

The decision the Committee makes will have profound, significant and lasting impact on not only the lives of individuals affected by autism, but also on the taxpayers of this state. A scenario in which children are denied efficacious treatment, and taxpayers are burdened with the care of untreated adults is both tragic and wasteful.

It is critical that a decision of this magnitude and significance be made in a manner that is transparent, reasoned, credible and evidence-based.

I respectfully suggest that the AHRQ and HTA reports do not meet this standard, and as such, are an inappropriate foundation for decision-making.

I hope you will consider the points made in this letter in making your decision.

Yours truly,
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Co-signatory:
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