

Mandating Autism Policy - A Closer Look at the Evidence

A Fact Sheet for Law Makers, Parents and Health Professionals

Autism is a developmental disorder classified by deficits in three areas: communication, social interaction and repetitive behaviors. The DSM-IV¹ lists specific characteristics within these three areas including:

- ◆ a delay or absence of language
- ◆ stereotyped and repetitive use of language
- ◆ an inability to initiate or sustain a conversation with another
- ◆ a lack of spontaneously sharing enjoyment and interests with others
- ◆ a lack of social or emotional reciprocity
- ◆ a lack of varied, spontaneous make-believe play or social imitative play
- ◆ persistent preoccupation with parts of objects

The rate of autism is growing and policymakers are facing enormous pressure to pass legislation that guarantees effective treatment to individuals and families affected by autism. At this time, bills are circulating in state and federal legislative houses that call for health insurance coverage of autism treatment. The wording varies, but all the bills share the underlying assertion that ABA (Applied Behavioral Analysis) is an evidence-based treatment for autism.² Going one step further, some versions of the bill take away a parent's right to choose the type of intervention best suited to their family. Instead, these versions mandate health coverage for ABA treatment only.

Informed decision-making requires a thorough review of existing research. Are claims and assertions that support one method of intervention, ABA, founded on solid, unbiased science and evidence-based research? This fact sheet reviews up to date research and autism literature to address this and other related questions. Included in the research are recent systematic reviews that provide meta-analysis of studies from the last 30 years. Systematic reviews and meta-analysis are considered the highest level of evidence among evidence based clinical guidelines.³

Question #1: What is the evidence for autism treatment?

treatment over another.⁴ While there is evidence for

¹ APA (1994). Diagnostic Criteria from DSM-IV™. Washington, DC: American Psychological Association.

² Autism Votes (2009). State Initiatives, retrieved from: http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiativ es.htm

³ Harbour, R. & Miller, J. (2001). A new system for grading recommendations in evidence based guidelines. *BMJ*, 323.

⁴ National Research Council (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

ABA and developmental approaches, the evidence for both is incomplete or inconclusive. Two systematic reviews published in 2009 support the academy's findings. The authors of one systematic review state, "There is no clear answer regarding the most effective therapy to improve symptoms associated with ASD [Autism Spectrum Disorders]."⁵

A review by the National Institute of Mental Health (NIMH) states, "There is no single best treatment package for all children with ASD. Decisions about the best treatment, or combination of treatments, should be made by the parents with the assistance of a trusted expert diagnostic team."⁶

Question #2: What is the evidence for ABA?

Answer: There are hundreds of studies researching the efficacy of ABA with autistic children. Meta-analysis shows very few of the studies provide unbiased and viable results. Poor design and follow-up, weak methodology, small sample sizes, and a lack of external validity find contradictory results. Only four studies met the criteria for inclusion in a recently published meta-analysis.⁷ Two of the four studies were conducted by the same authors (one listed the initial study and the second was a follow-up evaluation).

The original study of ABA by Lovaas⁸ did not meet the requirements of a rigorous study and was excluded from the meta-analysis. Lovaas' study has been criticized by several authors⁹ for methodological problems including a

⁵ Ospina, M., Krebs Seida, J., Clark, B., Karkhaneh, M., Hartling, L., Tjosvold, L., Vandermeer, B., Smith, V. (2008) Behavioural and Developmental Interventions for Autism Spectrum Disorder: A Clinical Systematic Review, *PLoS ONE* 3(11): e3755. doi:10.1371/journal.pone.0003755.

⁶ NIMH. (June 2, 2009). *Autism Spectrum Disorders (Pervasive Developmental Disorders)*. Retrieved June 8, 2009, from <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml>

⁷ Spreckley, M., Boyd, R. (2009) Efficacy of Applied Behavioral Intervention in Preschool Children with Autism for Improving Cognitive, Language, and Adaptive Behavior: A Systematic Review and Meta-analysis. *The Journal of Pediatrics*, 154(3): 338-344.

⁸ Lovaas, O.I., (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.

⁹ Schopler, Short & Mesibov (1989). Relation of behavioral treatment to "normal functioning". Comments on Lovaas. *Journal of Consulting and Clinical Psychology*, 57, 162-164.

Mundi (1993). Normal versus high-functioning status in children with autism. *American Journal of Mental Retardation*, 97, 381-384.

Gresham & MacMillan (1998). Early intervention project: Can its claims be substantiated and its effects replicated? *Journal of Autism and developmental Disorders*, 28, 5-13.

Herbert, J., Brandsma, L. (2002) Applied Behavior Analysis for Childhood Autism: Does the Emperor Have Clothes?, *The Behavior Analyst Today*, 3(1): 45-50.

Shea, V. (2004) A perspective on the research literature related to early intensive behavioral intervention (Lovaas) for young children with autism, *Autism*, 8(4): 349-367.

Mandating Autism Policy - A Closer Look at the Evidence

A Fact Sheet for Law Makers, Parents and Health Professionals

lack of randomization, possible bias in group allocation, and outcome measures with results that could be explained by factors other than the intervention. Despite criticisms and weak methodology, the Lovaas study is used to advocate for mandated health coverage of ABA in state and federal bills.¹⁰

The combined intervention sample size of the four, more rigorous studies included in the meta-analysis is very small (n=41) with little to no fidelity between the studies. That is, according to the authors of the meta-analysis, the theoretical construct and program content of the intervention varied substantially in all 4 studies. Two studies were implemented in a school setting and the intervention was provided by teachers and aides. In the other two studies, intervention was provided by student therapists. The children studied ranged in age from 34-65 months. Based on meta-analysis, there is no evidence supporting the use of ABA for children younger than 34 months old, a critical period for early intervention.

The authors of the meta-analysis concluded that, "Current evidence does not support ABI [Applied Behavior Intervention] as a superior intervention for children with ASD."⁷

Question #3: *Does ABA address the core deficits of autism?*

Answer: No study has found evidence that ABA increases spontaneity, initiation of conversation or social and emotional reciprocity—core deficits of autism. The meta-analysis found that ABA, "did not result in significant improvement in cognitive, language or adaptive behavior outcomes compared with standard care."⁷

Question #4: *What is the cost of ABA, in terms of time and money?*

Answer: ABA typically recommends 30-40 hours a week of intensive, 1-1 intervention for the child, which includes parent training. A 2009 study estimates the yearly cost of this treatment at \$30,000-60,000.¹¹ With

¹⁰ Autism Speaks (2009) Arguments in Support of Private Insurance Coverage of Autism-Related Services: Eight arguments defining the justification for autism insurance reform legislation, retrieved from: http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Arguments_for_private_insurance_%20coverage.pdf

⁷

¹¹ Wyman, O. (2009). An act relating to insurance coverage for autism. Actuarial Cost Estimate: Georgia Senate Bill 161.

so many hours required, this high intensity intervention can preclude other kinds of beneficial treatment¹² as well as cause stress for the family.

When comparing outcomes, the meta-analysis⁷ shows, however, there is inadequate evidence that this intensive ABA care has better outcomes than standard care for children with autism, including parent-administered ABA care or eclectic Kindergarten teacher/aide-directed care, which can be implemented at much lower cost.

Children with Autism need health insurance coverage. Parents and policy makers need accurate information to make educated decisions. Choice of treatment is an essential component.

¹² Prizant, B. (2009). Is ABA the only way? Autism Spectrum Quarterly, Spring 2009.

⁷