

COMMITTEE ON
ENERGY AND COMMERCE

SUBCOMMITTEES:
ENERGY AND AIR QUALITY
TELECOMMUNICATIONS AND THE
INTERNET
OVERSIGHT AND INVESTIGATIONS

CO-CHAIR:
COALITION FOR AUTISM
RESEARCH AND EDUCATION

CONGRESSIONAL CAUCUS ON ROBOTICS



Congress of the United States
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January 4, 2011

Harvey Feinberg, President
Institute of Medicine
500 Fifth St NW
Washington DC 20001

Dear President Feinberg:

As the original author of an amendment to the Patient Protection and Affordable Care Act regarding the essential benefits package of qualified health plans, and as Co-Chair of the Coalition on Autism Research and Education, also known as the Autism Caucus, I write to explain my intent when I crafted related language in the law and to ask that the Institute of Medicine recognize people with autism spectrum disorders (ASDs) and their families in the IOM's work.

Autism spectrum disorders are characterized by impaired verbal and nonverbal communication skills and social interactions, and restricted, repetitive, and stereotyped patterns of behavior, ranging in impact from mild to significantly disabling. Two decades ago, ASDs were little understood and uncommon. But today, the Centers for Disease Control estimate that 1 in 110 U.S. children are diagnosed with an ASD; clearly, this disorder has become a top national health priority.

As you may know, there is no cure for autism. But early interventions, such as specialized educational and behavioral treatments are proven to reduce the prevalence and severity of symptoms, and improve outcomes.

Some behavioral treatments are prescribed for children without ASDs, such as speech and occupational therapy, but claims can be harder to get paid for children with autism. Parents report of the "scarlet letter" of an autism diagnosis, even when seeking treatments that other young children routinely receive. Those burdens get higher when parents seek other behavioral treatments such as Applied Behavioral Analysis.

The federal government has been giving a mixed message to parents. The National Institutes of Health is confirming the effectiveness of these critical treatments, the Surgeon General and the Health Resources and Services Administration (HRSA) are steering parents toward them, and then no one is there to make sure they're covered. This is the reason why I

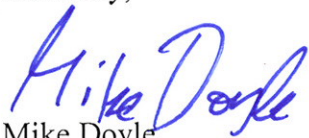
worked with the Committee on Energy and Commerce, counsel, outside stakeholders, and the Administration to ensure that behavioral health treatments are a part of the complete mental health services package so that parents wouldn't have to refuse treatments that could double their child's increase in IQ because they weren't covered by their insurance.

As the Department of Health and Human Services reported to Congress late last week, NIH has found that "behavioral interventions have been previously shown to be effective, research since 2006 has demonstrated the impact of implementing behavioral interventions for children before age 3. A randomized comparison of a modification of Applied Behavioral Analysis (ABA) versus typical community-based treatment for children as young as 18 months resulted in significant greater improvement over two years. In this NIH-supported study, the group receiving the modified early intervention showed more than double the increase in IQ (average increase of 17.6 points) and greater gains in adaptive behavior relative to usual care. These results support the importance of intervening early and demonstrate that aggressive behavioral treatment can be an effective treatment for many children with ASD, conferring improvements in social behavior." Additionally, HRSA's AIR-P program is developing a behavioral treatments toolkit for parents that includes ABA.

Additionally, the 2001 U.S. Surgeon General's Report on Mental Health, the National Institute of Child Health and Human Development, and the American Academy of Pediatrics all include ABA in their recommended treatment plan for autism. These treatments are not experimental, and insurance companies should not hide under those objections to avoid paying claims.

As the IOM evaluate the recommendations it will make to the Secretary of Health and Human Services regarding the essential benefits package, I would just reiterate that ABA has been vitally important to families with a child with autism and that these services demand parity in health care coverage. Meanwhile, it was the intent of Congress that ABA be included in the essential benefits package.

Sincerely,



Mike Doyle
Member of Congress