

Dear Madam Secretary,

When you renewed the charge to us as an advisory committee for autism last July, you asked us to keep you informed of issues as they emerge from the broad autism community and to share input on priorities. We write to you now at a historic moment for health care in our country. Already the Affordable Care Act (ACA), actively being implemented by your Department, has eliminated exclusions based on pre-existing conditions and extended benefits from parental plans to offspring up to age 26. These are important changes with tangible benefits for millions of families in the autism community.

The next phase of implementing the ACA will define the essential health benefits (EHB) for certain individual and small group health plans. The EHB includes items and services within 10 benefit categories, including “mental health and substance use disorder services, *including behavioral health treatment.*” The words “including behavioral health treatment” were added by amendment in both the House and the Senate to ensure that the EHB covered behavioral interventions for individuals on the autism spectrum.

Roughly half of the states will offer plans that provide autism-specific behavioral interventions. Some states will specify interventions in the family of applied behavior analysis (ABA), the set of interventions with the most evidence to support them and the current standard of care for young children with autism. Other states will use broader language to include the growing number of interventions that meet a rigorous evidentiary standard and combine ABA-based approaches with more developmental approaches that focus on engagement and relationship development, two hallmark deficits of autism.

We wanted to call your attention to two recent assessments of the evidence for behavioral interventions for autism. A recent Technical Expert Panel from the HRSA-funded research center for behavioral treatments at UCLA reviewed over 300 studies of behavioral interventions.<sup>1</sup> This expert panel concluded that children with ASD should have access to at least 25 hours per week of comprehensive intervention to address social communication, language, play skills, and maladaptive behavior. They agreed that applied behavioral analysis, integrated behavioral/developmental programs, the Picture Exchange Communication System, and various social skills interventions have shown efficacy, and that the current level of evidence for the effectiveness of these therapies supports the goal of making these types of interventions widely available.

A similar conclusion was reached by a Cochrane analysis of early intensive behavioral intervention.<sup>2</sup> Reviewing the outcomes of delivering 20 – 40 hours/week of intensive behavioral treatment for children under age 6, Reichow et al found that, on average, children receiving EIBI had IQs 11 points higher and exhibited 20 more daily living skills compared with children who

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<sup>1</sup> Maglione MA, Gans D, Das L, Timbie J, Kasari C; Technical Expert Panel; HRSA Autism Intervention Research – Behavioral (AIR-B) Network. Nonmedical interventions for children with ASD: recommended guidelines and further research needs. *Pediatrics*. 2012 Nov;130 Suppl 2:S169-78. [PMID: 23118248]

<sup>2</sup> Reichow B, Barton EE, Boyd BA, Hume K. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2012 Oct 17.

received “treatment as usual”. Because IQ and adaptive behavior have been found to be predictive of longer term outcomes in individuals with ASD, these results argue for making EIBI widely available. While individuals with ASD certainly require other forms of care as well, we focus on early intervention because of the greater evidence base, the pressing need, and the immediate potential for their inclusion in insurance plans.

Most insurance plans covering autism-specific behavioral interventions will do so because it is a state-required benefit under the benchmark plan. To date, it appears that approximately half of the states have decided to offer some coverage. In a few states, it may be offered as a habilitative service under “rehabilitative and habilitative services and devices,” a separate benefit category under the EHB. But in some states, there may be little if any coverage for these evidence-based treatments. We are concerned that the absence of a national standard for insurance plans to cover these autism-specific treatments as part “behavioral health treatment” will lead to significant disparities in coverage across states.

Autism affects at least 1 in 88 children in the United States, including 1 in 54 boys. We have heard from many families with autism who are in crisis. Families with a child on the autism spectrum commonly report that their health insurance coverage is inadequate to meet their needs and that their child’s health condition has caused serious financial hardship for the family. Mothers of children with autism tend to earn less, work fewer hours per week, and are more likely to be unemployed than mothers of children with no disabilities.<sup>3</sup> Although ASD is typically a condition that lasts across the lifespan and may require supports throughout life, early treatment can help children make substantial gains. Children who are not treated face a lifetime of disability, increased health care, educational and services costs, and, in some cases, require costly 24-hour services and supports over the whole lifespan. While intensive behavioral interventions are expensive, they are effective and recent data support that they are cost effective, mitigating these long-term costs of disability.<sup>4</sup>

Research tells us that treatment works. As a result, the American Academy of Pediatrics and the United States Surgeon General have endorsed these interventions.<sup>5,6</sup> But if benchmark plans in all states do not provide robust and consistent coverage of autism-specific behavioral interventions, we are concerned that some families will be forced to migrate to find coverage while others will not have access to treatments that can mitigate lifelong disability.

The ACA requires new health insurance plans to cover preventive services without cost-sharing, including autism screening for children at 18 and 24 months. The potential gain from these

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<sup>3</sup> Cidav Z, Marcus SC, Mandell DS. Implications of childhood autism for parental employment and earnings. *Pediatrics*. 2012 Apr;129(4):617-23. [PMID: 22430453]

<sup>4</sup> Peters-Scheffer N, Didden R, Korzilius H, Matson J. Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in The Netherlands. *Res Dev Disabil*. 2012 Nov-Dec;33(6):1763-72.

<sup>5</sup> Scott M. Myers, MD, Chris Plauché Johnson, MD, MEd, the Council on Children With Disabilities. Statement of The American Academy of Pediatrics: Management of Children With Autism Spectrum Disorders. *Pediatrics* Vol. 120 No. 5 November 1, 2007, pp. 1162 -1182.

<sup>6</sup> Department of Health and Human Services, US Public Health Service. *Mental Health: Report of the Surgeon General*. 1999. <http://profiles.nlm.nih.gov/ps/access/NNBBHS.pdf>

screenings will be lost if families lack appropriate access to evidence-based treatments for their children. A Federal minimum standard of autism coverage should be set for all health plans offered in the individual and small group markets. Minimum coverage should include evidence-based early intervention – including but not limited to ABA – for children with ASD, at a level intensity indicated by the evidence. It is critically important that this medical coverage to be available to privately and publicly-insured children, so a 2-tiered system for autism care is not created.

Given recent updates regarding the evidence base for the effectiveness of early intervention in improving functioning in many different domains, the IACC recommends support for coverage of and broad access to these treatments for children diagnosed with ASD.

Sincerely,

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