



October 3, 2022

Melanie Fontes Rainer  
Director  
Office for Civil Rights  
Department of Health and Human Services  
200 Independence Avenue, SW  
Room 509F, HHH Building  
Washington, D.C. 20201

RE: Nondiscrimination in Health Programs and Activities (Section 1557 NPRM), RIN 0945-AA17

Dear Director Fontes Rainer,

We write to express our strong support for the Department of Health and Human Services (HHS), Office for Civil Rights proposed changes to Section 1557 of the Patient Protection and Affordable Care Act (ACA). Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder (ASD); and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

We applaud the goals inherent to this proposed rule -- to advance health equity, dismantle barriers to quality health care, and reduce health disparities. Autism Speaks is committed to advancing measures that ensure that people with autism have equal access to health care, such as those provided in the Affordable Care Act.

We join with our colleagues in the Consortium for Constituents with Disabilities, the Habilitation Benefits Coalition, and other colleague health advocacy organizations in our strong support of the provisions included in the proposed rule. In particular, this includes the restoration of Section 1557's intended statutory scope in ensuring that programs, providers, and insurers receiving federal financial assistance are covered subject to Section 1557 protections. The application of civil rights principles and nondiscrimination protections will help ensure members of the autism community have improved access to the health plans, benefits, and services they require – including coverage for critical condition-specific therapies, like applied behavior analysis (ABA) therapy.

Our colleagues in those organizations have submitted comments that highlight many of the important ways in which this proposed rule would prevent discrimination and improve access to

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health care for autistic individuals and others with disabilities. As such, our comments will focus on several specific areas related to coverage for services for autistic individuals that we urge the Department to take into consideration as it finalizes the rule and moves towards implementation.

Autism Speaks is pleased the proposed rule prohibits a covered entity from denying, canceling, or limiting health insurance policies based on disability, and from discriminating in marketing practices or market design. For years, insurers have routinely excluded services for autism spectrum disorder. In every market at both the state and national level, Autism Speaks has long fought against discriminatory plans that have carried exclusions. We believe that Section 1557 is crucial to preventing health insurers from re-establishing discriminatory benefit design that would allow coverage of services for autism spectrum disorder and related co-occurring conditions to be eliminated. People with autism have disparate access to health care, which makes strong regulations implementing and enforcing Section 1557 crucial to our community.

In particular, we urge the Department to consider the following concerns as it moves from finalizing to enforcing this rule to ensure that autistic individuals do not experience discrimination in their health insurance coverage and services.

### **1. Plan designs should not have blanket exclusions for services for autism or ABA**

According to the Department of Labor’s 2022 report to Congress, as required by the Mental Health Parity and Addiction Equity Act (MHPAEA), the Employee Benefits Security Administration (EBSA) found that a large service provider was administering claims for hundreds of self-funded plans across the country that specifically excluded coverage for ABA therapy for autistic beneficiaries.<sup>i</sup> Issuing requests for comparative analyses and initial findings of non-compliance, the Los Angeles Regional Office has confirmed three plans’ removal of the ABA exclusion going forward. These corrections affect over 18,000 participants.<sup>ii</sup> This is just one example, however in the same report, EBSA found that one of the top non quantitative treatment limitations, for which it requested comparative analyses was” limitations on applied behavior analysis or treatment for autism spectrum disorder.”

We commend EBSA’s ongoing work and leadership protect the rights of those with autism proactively address parity concerns – related to exclusions for ABA therapy. We encourage the Department to consider these types of exclusions of coverage for autism and services for autistic beneficiaries as it works to finalize and implement this rule.



## **2. Plan designs should not have age caps on services for autistic individuals nor should an ASD diagnosis by a certain age be required to access autism-related health care**

The 2023 HHS Notice of Benefit and Payment Parameters characterized the use of age limits for autism-related benefits—ostensibly permitted under some states’ autism insurance mandates—as an example of a presumptively discriminatory benefit design. There should be no cap on age for autism services, and no requirements for an autism diagnosis by a certain age.

“Age limits are presumptively discriminatory under § 156.125 when applied to services that are covered as EHB and there is no clinical basis for the age limitation. A plan subject to § 156.125 that covers diagnoses and treatment of ASD as an EHB, but limits such coverage in its plan benefit design based on age is presumptively discriminatory under § 156.125 unless the limitation is clinically based.”<sup>iii</sup>

Another age-based barrier that we are concerned about is a treatment limitation related to diagnosis age. For example, plans in Florida commonly require that the affected individual be diagnosed by age 8 to access services related to autism. While this limitation is included in the state’s autism insurance law at F.S. s. 627.6686, which resulted from legislation passed in 2008, it is by its very design an age-based limitation that discriminates against those who were diagnosed at age 8 or later. While research indicates that the average age of diagnosis for a U.S. child with ASD is a little under 4 and a half years, 30% of autistic children do not have a formal ASD diagnosis until after age 8. Therefore, health benefit plans that limit access to treatment based on diagnosis age prevent many from the health care they need and deserve.

We strongly recommend the Department issue additional federal guidance on payer policies that likely run afoul of MHPAEA and clarify that age-based discrimination, like the example described here, runs afoul of Section 1557.

## **3. Plans should not have provider networks that discriminate against autistic individuals by not including health professionals who specialize in care for people with autism and other developmental disabilities**

An overall shortage of certain autism service providers is a relevant factor to the barriers many experience when seeking health care related to the challenges caused by ASD. Many health plans seem to neglect network adequacy standards for behavioral health and for many autistic individuals and their families, network inadequacy is a significant barrier to timely care. Autistics and their families often encounter inadequate or phantom networks – navigating exceptionally long lists of providers or facilities, only to learn that there is nothing appropriate – especially for individuals with severe autism. Autistics and their families have also found that



payer care managers are often unaware or refuse to investigate appropriate care for autistic individuals with severe behaviors. This lack of available specialty provider adequacy creates gaps and delays in care – leaving those affected by ASD with virtually no access to autism specific providers or specialists to treat and help to prevent more serious or worsened health conditions. Data show that young people with autism, ages 12 to 21, are four times more likely to go to the emergency room than peers without autism.<sup>iv</sup> Researchers have found that enhanced usage of inpatient care is a marker of inadequate primary care and management of autism and other conditions.<sup>v</sup> While we understand that setting uniform or minimum network adequacy standards is outside the scope of Section 1557, we appreciate the Department asking for input about how inadequate networks can be discriminatory.

We believe that this is an area that the Department should pursue further in this rulemaking process as we believe that many autistic individuals face a discriminatory system of coverage due to limited networks. Furthermore, even though it is outside the scope of this proposed rulemaking we urge the Department to take action to support the autism community to help ensure network adequacy. We strongly recommend the Department issue guidance to provide information to consumers as they determine their plan's network adequacy policy and how to challenge instances of network inadequacy.

#### **4. Plans should not be allowed to discriminate against autistics who need gender-affirming care**

A [September 2020 study](#) published in *Nature Communications* found that transgender and gender-diverse individuals have higher rates of autism than their cisgender peers.

Researchers found that transgender and gender-diverse individuals were 3 to 6 percent more likely to be diagnosed with autism and participants experienced challenges outside of autism, citing other psychiatric conditions that play a role in their everyday lives.

Almost 70 percent of autistic individuals who also identify as transgender and gender diverse said they needed gender identity related medical care but could not get appropriate care due to their autism diagnosis. In study published in June 2020, more than 35 percent of autistic LGBTQ adults surveyed said they were refused services by a medical provider, despite this group having greater health care needs overall. Researchers concluded that current medical and mental health care for transgender and gender-diverse autistic people is inadequate.<sup>vi</sup>

We strongly support the Department's proposal to prevent discriminatory exclusions and limitations on gender-affirming care.



Autism Speaks strongly supports HHS's anti-discrimination efforts and looks forward to continued partnership with the Department to center the experiences of children and adults with autism, families, and caregivers. Autism Speaks is grateful for the opportunity to provide input to the Department of Health and Human Services. We are eager to work with you to promote positive outcomes for the autism community. For more information, please contact Alyssa Brockington, Director, Public Policy at [Alyssa.Brockington@autismspeaks.org](mailto:Alyssa.Brockington@autismspeaks.org)

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<sup>i</sup> 2022 MHPAEA Report to Congress. <https://www.dol.gov/sites/dolgov/files/EBSA/laws-and-regulations/laws/mental-health-parity/report-to-congress-2022-realizing-parity-reducing-stigma-and-raising-awareness.pdf>

<sup>ii</sup> 2022 MHPAEA Report to Congress. <https://www.dol.gov/sites/dolgov/files/EBSA/laws-and-regulations/laws/mental-health-parity/report-to-congress-2022-realizing-parity-reducing-stigma-and-raising-awareness.pdf>

<sup>iii</sup> Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2023. <https://www.federalregister.gov/documents/2022/05/06/2022-09438/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2023>

<sup>iv</sup> Nowhere To Go: Young People With Severe Autism Languish In Hospitals. <https://khn.org/news/for-thousands-of-autistic-teens-hospital-ers-serve-as-home/>

<sup>v</sup> Hospital Inpatient Stays for Autistic Youth and Youth With Other Disabilities <https://publications.aap.org/pediatrics/article/149/Supplement%204/e2020049437R/185642/Hospital-Inpatient-Stays-for-Autistic-Youth-and?autologincheck=redirected?nfToken=00000000-0000-0000-0000-000000000000>

<sup>vi</sup> Study finds higher rates of gender diversity among autistic individuals <https://www.autismspeaks.org/science-news/study-finds-higher-rates-gender-diversity-among-autistic-individuals>