



Autism Speaks strongly supports new rule to reduce barriers to health care services for many autistic people

Autism Speaks joined in [coalition](#) with other key health advocacy organizations to strongly support the Mental Health Parity and Addiction Equity Act (MHPAEA) [proposed rule](#), issued by the Department of Treasury, the Department of Labor, and the Department of Health and Human Services (“the Departments”). We commend the Departments’ efforts to address the bureaucratic red tape faced by autistic individuals and others when seeking access to care and the sometimes-illegal denials of care that occur far too often. Despite significant improvements in coverage for mental healthcare over the past decade, many autistic individuals continue to face substantial barriers and gaps in access to needed care, particularly as it relates to mental health-related services. This proposal, if finalized, would be an important step forward towards removing barriers to coverage of mental health services for autistic individuals.

Background:

Specifically, the Departments’ proposed rule would amend the non-quantitative treatment limit (NQTL) standard to prevent plans from using NQTLs to limit access to mental health and substance use disorder treatments. An NQTL is a limitation on the scope or duration of a treatment that is not numerical. A common NQTL is a preauthorization requirement, or a limitation or exclusion based on medical necessity. NQTLs are not inherently problematic. However, [federal parity law](#) states that a health plan cannot impose NQTLs on mental health treatments that is *more restrictive* when compared to limitations on medical or surgical benefits. [Reports](#) have illustrated how autistic individuals and their families are particularly vulnerable to non-compliant and arbitrary limits on access to mental healthcare. For example, in the Department of Labor’s (DOL) [July 2023 MHPAEA Comparative Analysis Report to Congress](#), a compliance demonstration request by the Employee Benefits Security Administration (EBSA), resulted in a service provider correcting the exclusion of applied behavior analysis (ABA) therapy treatment for autism spectrum disorder. This correction affected approximately 1,000 plans covering more than 1 million participants¹. We applaud the Departments’ efforts on NQTLs and commend them for their use of specific examples in the proposed rule illustrating that evidence-based autism services and treatment, such as applied behavior analysis, occupational therapy, and speech therapy, cannot be excluded from any individual or group health insurance plan subject to MHPAEA.

We also support the Departments’ proposed requirement to evaluate data on network adequacy and design to assess MHPAEA compliance. For many autistic individuals and their families, provider

¹ <https://www.dol.gov/agencies/ebsa/laws-and-regulations/laws/mental-health-parity/report-to-congress-2023-mhpaea-comparative-analysis>

networks are inadequate and prevent or delay timely care. Autistic individuals and their families often encounter phantom networks, navigating long lists of providers or facilities only to learn the list is outdated or providers are not accepting new patients. This is especially problematic for autistic individuals with higher support needs who are likely to need providers with specialized training. When faced with such problems, autistic individuals and their families report that payer care managers are unaware or refuse to investigate how autistic individuals with challenging behaviors can receive appropriate care. This lack of available specialty provider adequacy creates gaps and delays in care, leaving autistic individuals without access to providers trained to care for individuals with autism or specialists to treat and prevent more serious or worsened health conditions. Such problems often lead to autistic individuals seeking care in settings that are oriented toward crises or emergencies. For example, 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.² Researchers have found that heightened usage of inpatient care is a marker of inadequate primary care and management of autism and other conditions.³ We strongly support the Departments' proposal requiring insurers and health plans to collect and evaluate data on network composition, including in-network and out-of-network utilization rates, network adequacy metrics such as time and distance data, the availability of providers accepting new patients, and provider reimbursement rates.

Finally, we are grateful the Departments are moving forward in their rulemaking to implement recently passed legislation to eliminate harmful opt-outs from mental health and substance use disorder parity requirements for self-funded nonfederal government plans and hope that the Departments will take strong actions to ensure compliance with this provision as well as others included in the proposed rule.

Too often, autistic individuals and their families are left with no recourse or are unable to challenge discriminatory coverage practices or denials that violate parity requirements. For many autistic individuals, delays in access to mental health care services can be life-threatening. The proposed rule represents a strong step forward to address these concerns. Autism Speaks has long fought for equal access to care and anti-discrimination efforts to improve the quality of life for autistic individuals. We look forward to continued partnership with the Departments to center the experiences of the autism community – promoting positive solutions and outcomes for children and adults with autism, families, and caregivers.

Learn more about federal mental health parity law:

- [Know Your Rights: Parity for Mental Health and Substance Use Disorder Benefits](#)
- [Understanding Parity: A Guide to Resources for Families and Caregivers](#)

² <https://kffhealthnews.org/news/for-thousands-of-autistic-teens-hospital-ers-serve-as-home/>

³ <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>