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The Power of Connection

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November 13, 2023

The Honorable Xavier Becerra, Secretary
Department of Health and Human Services
200 Independence Ave.
SW Washington, D.C. 20201

Re: Public Comment on HHS–OCR–2023–0013

Dear Secretary Becerra:

Thank you for the opportunity to comment on the Department of Health and Human Services' (HHS) *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities* rule proposal. Autism New Jersey commends HHS for proposing these significant and long overdue updates to better protect the civil rights of individuals with intellectual, developmental, and physical disabilities and improve their access to quality healthcare.

To meet this goal, Autism New Jersey urges HHS to explicitly discuss adaptive approaches to medical care that consider the unique needs of individuals with autism in this regulatory proposal. Specifically, HHS should include explicit language to help providers understand that "accessible" medical care and treatment goes beyond physical improvements or adaptations to medical equipment. To avoid narrow and ableist interpretations of accessibility, the rule proposal must also include an understanding that many individuals with autism may require sensory, communication, and/or behavioral accommodations to receive in medical care. Flexible appointment times, pre-appointment planning sessions, reasonable location requests, and other individualized and flexible practices and processes may be necessary to access medical treatment.

For example, Autism New Jersey's 800.4.AUTISM Helpline recently received a call from the mother of an adult daughter with profound autism who is unable to access basic medical care without these non-physical accommodations. This individual is non-verbal and engages in both aggressive and self-injurious behavior. The mother explained that her daughter has foregone both doctors' and dental appointments because of those professionals' unwillingness to make the necessary accommodations.

When she does pursue medical care for her daughter, her medical avoidance and challenging behavior must be addressed before medical care can occur. The mother must work extensively with her daughter's healthcare professionals in advance of each routine medical appointment to increase the likelihood of achieving the appointment's goals. Her daughter requires a flexible scheduling team who can ensure her either the first or last appointment of the day to minimize the unpredictability of a crowded waiting room. She needs the staff to have discussed and strategized in advance ways to keep both themselves and her daughter safe. She requires the accompaniment of her Board Certified Behavior Analyst during her appointment to help meet her behavioral needs in real time.

Plainly stated, more accommodations should be the norm, and they are not.

Without reasonable accommodations and flexibility in these healthcare practices and processes, many individuals with autism are excluded from participating in necessary medical treatment and experience poorer health outcomes. Fortunately, many such accommodations do not require significant resources. Sometimes, it's as simple as a common-sense shift in perspective. For example, a behavioral accommodation could be changing the location of the service to a place where the patient is less likely to exhibit avoidance and challenging behavior.

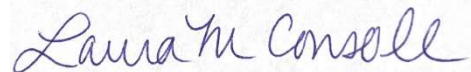
In fact, Autism New Jersey's partnership with the Visiting Nurse Association Health Group resulted in many pre-planning conversations and individually tailored accommodations to ensure that more than 400 adults with autism were vaccinated against COVID-19. Some vaccinations were delivered immediately upon arrival in the clinic parking lot to reduce individuals' anxiety, wait times, and behavior that could have made vaccine administration unsafe or impossible.

For these reasons, a broader range of accommodations needs to be explicitly included in the rule proposal to do more to illustrate the scope of accessibility and reasonable accommodations for individuals with autism in healthcare settings. More specifically, we recommend that any reference to accommodation should extend beyond physical accommodations and explicitly include sensory, communication, and behavioral accommodations to address the difficulties experienced by individuals with autism. Failure to explicitly address less obvious or visible disabilities is ableist, which is antithetical to the purpose of this rule change. Providing specific, explicit guidance to healthcare providers on this point will help mitigate the pervasive healthcare discrimination experienced by individuals with autism.

Respectfully,



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