



Autism Society of America
6110 Executive Blvd, Suite 305
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Submitted via regulations.gov

Melanie Fontes Rainer, Director
Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Notice of Proposed Rulemaking on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities. Docket No: 2023-19149, RIN: 0945-AA15

Dear Director Fontes Rainer:

On behalf of the Autism Society of America, we commend the Administration's dedication to upholding and strengthening the rights of individuals with disabilities by updating and improving Section 504 of the Rehabilitation Act of 1973. We appreciate that the Department updated the Rule to incorporate changes in the landscape since the 1977 enactment of the original law. These include the ADA and ADA Amendments Act of 2008 (ADAAA), the Affordable Care Act (ACA), Supreme Court and other significant court cases, and recent executive orders.

Thank you for allowing us to provide the following comments for consideration:

Community Integration: The emphasis on providing services in the most integrated setting is commendable and is in line with the *Olmstead v. L.C.* decision. Ensuring community living and integration enhances the quality of life and social inclusion of individuals with Autism and other disabilities. The Supreme Court's *Olmstead* decision found the unjustified segregation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). The Court held that states are required to provide community-based services for people with disabilities who would otherwise be entitled to institutional services when such placement is appropriate.

We agree with the proposed Rule's commentary that, despite the Office of Civil Right's enforcement efforts, *Olmstead* issues continue to comprise a significant portion of disability-related complaints



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received by OCR. This means that we must continue to be vigilant in protecting individual rights to the community. This rule does that by applying Olmstead in the context of section 504. The most integrated setting is defined in the proposed rule as “a setting that provides individuals with disabilities the opportunity to interact with nondisabled persons to the fullest extent possible; is located in mainstream society; offers access to community activities and opportunities at times, frequencies and with persons of an individual’s choosing; and affords individuals choice in their daily life activities.

We believe this definition of “the most integrated setting” is appropriate. This language is consistent with the description of “most integrated setting” in Title II guidance; and it reflects most people’s desire to remain with their families and peers in the community - not to be placed in a setting away from everyone else as though they are a burden or different and don’t belong.

This definition also aligns with values of other laws, such as the Developmental Disabilities Act which is rooted in the belief that “disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”

We appreciate the Department’s recognition that providing services beyond what a State currently provides under its Medicaid program is not, in and of itself, a fundamental alteration. In particular, we agree that a state increasing the number of individuals it may serve in a particular Medicaid waiver program (expanding “the cap”) is not, in and of itself, a fundamental alteration. The fact that Medicaid permits a State to limit the number of people it will serve in a waiver program does not exempt the State from serving additional people in the waiver program to comply with the ADA and Section 504.

Combating Medical Discrimination: We wholeheartedly support the provision ensuring that medical decisions are not influenced by biases, stereotypes, or misconceived notions about people with disabilities. People with disabilities have reduced access to medical treatment, a reality that leads to significant health disparities and poorer health outcomes. Every life, regardless of physical or intellectual ability, holds intrinsic value, and medical decisions should reflect that fact.

We strongly support the proposed rule to protect the right to bring a support or communication partner to medical settings. During the COVID pandemic, many individuals were prevented from bringing family members and personal assistants to health care facilities preventing individuals from their health care or communication advocates. This lack of access to healthcare advocates was especially harmful to those who are non-speaking, experience severe anxiety, or with intellectual or other communication disabilities. It is also essential that staff are trained on the importance of ensuring patients with disabilities are not discriminated against and receive full access to the supports they need to make informed decisions.

Accessibility of Medical Equipment: We believe that ensuring accessibility in medical equipment is fundamental to providing equitable healthcare. The adoption of the U.S. Access Board's accessibility standards is a commendable step in the right direction, ensuring that every patient, irrespective of their disability, can access essential medical examinations and treatments.

Digital Accessibility: Given the technological advancements and the shift towards digital health platforms, adopting WCAG 2.1, Level AA standards is both timely and necessary. Ensuring web, mobile app, and kiosk accessibility ensures that individuals with disabilities can seamlessly access health information and services. This is especially important since most medical offices use online medical platforms to make appointments, check in, and exchange important medical information. It is also important given the availability of telehealth. This must be accessible for both physical disabilities and intellectual and other developmental disabilities, such as ensuring materials are in plain language.

Child Welfare: It is paramount that HHS-funded child welfare programs and activities function without any form of discrimination. Clarifying the rights and needs of children, parents, and caregivers with disabilities in these settings is crucial to ensuring that they are treated equitably and that their unique needs are addressed.

The most integrated setting for a child with a disability is the most homelike setting appropriate to meet the child's needs, and there is a presumption that the most integrated setting is a family setting. A failure to provide home- and community-based services, including intensive services, is a violation of the integration mandate because it puts children at serious risk of needless institutionalization or segregation.

In addition, childcare, daycare, preschool, and adult care settings that receive HHS funding must also protect against discrimination for individuals enrolled with disabilities and their parents. They must provide all accommodations necessary to ensure individuals are achieving the highest quality care such as accessible content in plain language and necessary support professionals.

In order to ensure that states provide a sufficient array of placement options, the regulations and their supporting documents should describe the "continuum of family settings" that a state must provide. That continuum is this: First, the most integrated setting is home with their parents, with supports as needed. Next, properly supported kinship placements, which are critical to keeping the child connected to family, culture, and community. Third, foster care in a family setting, including when appropriate therapeutic foster care. Only once those options have been exhausted, along with the timely provision of reasonable modifications and services (with adjustments as necessary) can congregate care be considered for a child with a disability, and then only for as brief a time as is necessary.

As DOJ and HHS have explained, covered entities cannot base decisions about removal of a child on a parent's disability, diagnosis, or intelligence measures (e.g., IQ scores) alone. Rather, they must base such decisions on an individualized assessment of the parent with a disability and objective facts about



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their parenting abilities. We appreciate and support the proposed regulatory language further clarifying this. Just like any other adults, parents with Autism can be exemplary parents. Many parents, including those with Autism, may need support; however, they should never be discriminated against in the child welfare system. Public support systems must do everything possible to keep children with their parents. Very few families parent entirely on their own, and families in the child welfare system are no different. Child welfare agencies should consider natural supports when analyzing the ability of the family of origin to parent, including relatives, neighbors, friends and their religious community.

Value Assessment Methods: We appreciate the foresight in addressing potential discrimination in "value assessment methods." It is essential that cost containment and quality improvement do not come at the expense of marginalized groups. The explicit prohibition against discriminatory use of such methods is a significant step towards ensuring equal access to treatments and services for all.

We agree with the preamble's analysis highlighting the deep problems with the Quality-Adjusted Life Year (QALY) value assessment tool. QALY relies on the discriminatory premise that using a treatment to extend the lives of people with disabilities and other chronic conditions is inherently less valuable than using that treatment to extend the lives of people without such conditions. For this reason, and as noted in the proposed rule's preamble, it has been broadly criticized by disability experts and its uses limited in federal programs like Medicare. A close analysis of existing federal restrictions on the use of QALYs indicates they are not comprehensive enough to fully safeguard the rights of people with disabilities, which supports the necessity of the proposed rule.

Thank you again to the HHS leadership, Office of Civil Rights and staff for your significant efforts to propose these rules. We believe that the proposed rulemaking is a comprehensive and forward-looking approach to address the multifaceted challenges faced by individuals with disabilities. We urge the Administration to adopt and implement these rules to further the rights and dignity of every citizen, irrespective of their physical or intellectual abilities. The passing of Judith Heumann this year, a staunch advocate for the rights of the disabled community, serves as a poignant reminder of the need for continued commitment to the cause.

In addition to these comments, the Autism Society of America also supports and signed onto the more extensive comments developed by the Consortium for Constituents with Disabilities.

Sincerely,

Kim Musheno
Vice President of Public Policy
Autism Society of America