



November 13, 2023

The Honorable Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

RE: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, RIN 0945-AA15

Dear Secretary Becerra:

On behalf of the American Network of Community Options and Resources (ANCOR), we are grateful for the opportunity to provide feedback to the Department of Health and Human Services' proposed rule regarding *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*. We support the Department's goals to provide greater protections for people with disabilities and to update the regulations governing Section 504 of the Rehabilitation Act of 1973 (Section 504) to modernize the regulations and ensure consistency with Title II of the Americans with Disabilities Act (ADA), the Supreme Court's *Olmstead v. L.C.* decision, and other relevant case law.

ANCOR is pleased to see a strong emphasis on integration in this proposed rule and on the importance of better clarifying entities' responsibilities for providing services in the most integrated settings. We have concerns that the proposed rule's revised integration mandate attempts to provide greater specificity than what is currently required under Title II of the ADA, thus setting up different standards between enforcement of Section 504 and the ADA. We are also concerned that the revised integration mandate does not adequately address insufficiency of reimbursement rates, the resulting direct support workforce crisis, and its subsequent impact on access to community-based services. We ask that the Department acknowledge the direct support workforce shortage and incorporate considerations relevant to its impact on access and compliance into its final rule.

ANCOR

Founded more than 50 years ago, ANCOR is a national, nonprofit association representing more than 2,100 private community-based providers of long-term supports and services to people with I/DD, as well as 55 state provider associations. Combined, our members support more than

one million individuals with I/DD across their lifespan and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

ANCOR offers the following comments, questions, and recommendations regarding the proposed Section 504 regulations. We have organized our feedback by section below, touching upon broad themes and specific recommendations that arise within those topics.

The Department Must Provide Better Clarity About Enforcement of Section 504

The Department should be lauded for its efforts to modernize the regulations governing Section 504. The updates included in this proposed rule are a significant step forward for expanding protections for people with disabilities in health care, medical treatment, child welfare services, and other social service programs. In the more than four decades since the Section 504 regulations were first promulgated, the prevalence of services for individuals with intellectual and developmental disabilities (I/DD) has changed greatly, shifting from mostly institutional settings toward home and community-based settings.¹ The Department's intention to strengthen Section 504's integration section by incorporating the DOJ's interpretation of the integration mandate under Title II of the ADA and subsequent caselaw is well-intentioned.

ANCOR supports the modernization of this regulation to codify and provide clarity consistent with the integration mandate within Title II of the ADA. However, we are concerned that in an attempt to provide a greater degree of specificity, this proposed rule would inadvertently create a higher legal standard for recipients of federal financial assistance than what is currently required in the ADA for states. Given insufficiency of funding and the resulting direct support workforce crisis, we have concerns that community-based providers may be disadvantaged in meeting a higher standard of individualized services.

Title II of the ADA prohibits discrimination on the basis of disability by states and local governments within their programs, services, and activities. The integration mandate, in subsequent regulations governing Title II of the ADA, states "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."² In the Supreme Court decision of *Olmstead v. L.C.*, the Court further expanded on the integration mandate holding that Title II of the ADA requires public entities to provide community-based services to individuals with disabilities when such services are appropriate, the individuals do not oppose community-based treatment, and the placement in a community setting can be reasonably accommodated.³

¹ See Medicaid and CHIP Payment and Access Commission, [Home- and Community-Based Services](#) (last visited Nov. 13, 2023).

² 28 C.F.R. § 35.130(d).

³ 527 U.S. 581, 607 (1999).

While the ADA’s integration mandate applies only to public entities, Section 504 applies to all recipients of federal financial assistance, including private organizations and community-based providers. The increased specificity in this proposed rule risks establishing a different, more expansive standard than that of the ADA, leading to inconsistency in enforcement. Further, it would extend its application beyond public entities to community-based providers adhering to state programs with little to no ability to change the way the program operates. The integration mandate within Title II is appropriately applied to states, given their ability to administer their own programs. In contrast, community-based providers are tightly regulated by states and service agreements with limited ability to change the way a Medicaid-funded service is administered.

The proposed rule articulates specific prohibitions that would violate the proposed integration subsection of the Section 504 regulations. The list is not exhaustive, noting that discriminatory actions include but are not limited to the enumerated prohibitions. While there are benefits to providing additional guidance about what constitutes discrimination, there are dangers to extending examples drawn from ADA caselaw applying a Title II standard to all recipients of federal funding, including those at the community-based provider level. For example, the prohibition against failing to provide community-based alternatives to institutional settings articulated in *Olmstead* applied to public entities administering governmental programs. This standard was not adjudicated or intended to apply to Medicaid-funded providers of community-based services that have no authority to change eligibility standards or expand services funded by Medicaid. It is the role of state governments, working in partnership with the Centers for Medicare and Medicaid Services (CMS), to oversee and approve state Medicaid programs and determine sufficient payment to ensure equal access to community-based services.

An example of how funding outside of the control of community-based providers impacts integrated settings for people with I/DD is the maintenance of waiting lists for services. There are currently more than 400,000 people with intellectual and developmental disabilities on waiting lists for home and community-based services.⁴ This is a result of states’ ability to cap the number of people enrolled in HCBS waivers. Providers have no ability to adjust or remove people from those waiting lists to deliver services in a more integrated setting from the services they may currently be receiving. The responsibility for ensuring access to services, therefore, lies with states.

The preamble of this proposed rule also notes that service reductions resulting from budget cuts—even if permitted under Medicaid and other public program rules—may violate the proposed integration subsection if they result in more favorable access to services in segregated settings than integrated settings and create serious risk of institutionalization or segregation. Once again, it must be made clear that liability for any service reductions due to inadequate funding or service restructuring falls on state governmental entities determining the payment

⁴ Kaiser Family Foundation, [Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility](#) (2021).

rates for community-based services, and not providers attempting to deliver services within those systems. Providers have no ability to set or establish funding sources for programs, and community-based providers' attempts to judicially enforce adequacy of rates have failed, with courts finding that the responsibility and oversight falls exclusively to states and the Department.⁵

Furthermore, while the prohibitions in subsections 1, 2, and 4 of the proposed language in § 84.76(d)(4) are statedly rooted in caselaw and DOJ guidance applying the Title II standard, the Department does not provide citation for the prohibition in subsection 3, which prohibits "establishing or applying more restrictive eligibility rules and requirements for individuals with disabilities in integrated settings than for individuals with disabilities in segregated settings." Without further elaboration on this prohibition, it is unclear how the Department intends this prohibition to be interpreted or enforced. Community-based providers should not be held liable for their inability to offer services for which the state has determined someone is ineligible. Without reimbursement, community-based providers do not have the ability to continue delivering services to those deemed ineligible.

The Final Rule Must Incorporate Acknowledgment of the Direct Support Workforce Crisis

There is, and has been for many decades, a workforce crisis in community-based settings, due to stagnant reimbursement rates and the inability of providers to offer wages that enable them to compete with industries offering entry-level positions, such as fast-food restaurants or retail and convenience stores. This crisis is the greatest barrier to accessing community-based support and services for people with I/DD. The effects of underinvestment in the direct support workforce can be seen in turnover rates of approximately 44% nationally.⁶ The onset of COVID-19, brought new pressures and hazards of providing essential, close-contact services and further exacerbated and accelerated the workforce crisis with full-time vacancy rates rising to 16.5% in 2021—a roughly 94% increase from 2019.⁷

Without sufficient and qualified staffing, community-based providers have been forced to close programs and reject referrals at a rapid pace. The recent results of ANCOR's *The State of America's Direct Support Workforce Crisis* found that 83% of providers are turning away new referrals, 63% of providers are discontinuing services, and 55% of providers are considering additional service discontinuations due to the direct support workforce shortage. This represents a staggering 85.3% increase in service closures since the beginning of the COVID-19 pandemic.⁸

This administration has frequently referenced ANCOR's survey findings and cited to them in numerous presentations, reports, and grant proposals that identify the direct support workforce

⁵ See *Armstrong v. Exceptional Child Center*, 575 U.S. 320 (2015).

⁶ NAT'L CORE INDICATORS INTELLECTUAL & DEVELOPMENTAL DISABILITIES, [2021 STATE OF THE WORKFORCE](#) (2022).

⁷ *Id.*

⁸ AM. NETWORK OF CMTY. OPTIONS & RES, [THE STATE OF AMERICA'S DIRECT SUPPORT WORKFORCE CRISIS 2022](#) (Oct. 2022).

crisis and its impact on the community.⁹ The findings were also incorporated into the recent executive order to strengthen caregiving, which was signed by President Biden earlier this year.¹⁰ We urge the Department to continue to acknowledge the stark realities providers face as a result of the workforce crisis and ask that policies seeking to expand access to home and community-based services also address the root cause of the direct support workforce crisis: stagnant and insufficient Medicaid payment rates that do not include adequate funding for competitive direct support wages and can lead to diminished access to integrated settings.

We appreciate the Department's focus on codifying the integration mandate into these Section 504 regulations. However, we offer recommendations for clarifying the language in the proposed integration subsection to adequately account for the impact of the workforce shortage.

Segregated Settings

This proposed rule states that once a recipient provides a service, it cannot discriminate in the provision of that service by denying individuals access to the most integrated setting appropriate to their needs. The proposed integration subsection also includes a definition of segregated settings, noting that a segregated setting is one that unnecessarily separates people with disabilities from those without disabilities. It then goes further to state that segregated settings *may have* the characteristics of settings that isolate people through “regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals’ ability to engage freely in community activities and to manage their own activities of daily living.”¹¹

ANCOR continues to be supportive of the HCBS Settings Rule, which emphasizes the critical importance of autonomy, self-determination and access to quality home and community-based services. However, we have some concerns that while the characteristics outlined in this proposed section largely mirror those included in the HCBS Settings Rule, they are not identical and risk inconsistent enforcement. What is more, many of these characteristics hinge on the ability of direct support staff to provide them. In 2022, CMS issued guidance for states for complying with the HCBS Settings Rule, noting that while states should be working toward compliance to the greatest extent possible, the impact of the COVID-19 public health emergency and resulting workforce shortages have resulted in many states’ inability to meet certain HCBS Settings Rule criteria. This criteria includes ensuring access to the broader community, opportunities for employment, and options for a private unit or choice of a roommate.¹²

Just as this Department acknowledged the impact of the workforce shortage on compliance with the HCBS Settings Rule, we ask that proposed definitions remain in alignment with the HCBS Settings Rule and CMS’ guidance. Rather than providing additional suggestion of what may constitute a segregated setting, which may be interpreted too broadly or too narrowly, we

⁹ *E.g.*, Admin. for Cmty. Living Ctr. for Innovation & P’ship, [Strengthening the Direct Care Workforce: A Technical Assistance and Capacity Building Initiative](#), HHS-2022-ACL-CIP-DNCW-0086 (2022).

¹⁰ Exec. Order No. 14,095 88 Fed. Reg. 24,669 (2023).

¹¹ Ctrs. for Medicare & Medicaid Svcs., [HCBS Settings Rule Implementation—Moving Forward Toward March 2023 & Beyond](#) (May 24, 2022).

¹² *Id.*

recommend the definition of segregated setting as: “A segregated setting is one in which people with disabilities are unnecessarily separated from people without disabilities.” Should the Department determine further description is necessary, the regulations should more closely align with the HCBS Settings Rule to prevent inconsistency in enforcement. Accordingly, a segregated setting would be one that does not maintain an individual’s privacy, dignity, respect; allows for coercion and restraint; or fails to ensure an individual’s control of personal resources.¹³

Fundamental Alteration

The Supreme Court’s *Olmstead* decision determined that an entity’s obligation under the ADA to provide services in the most integrated setting is limited by the fundamental alteration defense, whereby the entity must prove that the provision of such services would be inequitable given the entity’s responsibility for the care and treatment of other people with disabilities. While the *Olmstead* decision was focused on the responsibility of state and local governmental entities, this proposed rule seeks input specific to “what may constitute a fundamental alteration for recipients who are not public entities” (Integration Question 2).

We recommend that in response to Integration Question 2, the Department acknowledge that the direct support workforce shortage limits the availability of services—requiring a fundamental alteration to provide those services in certain circumstances. For example, it would be a fundamental alteration for recipients who are not public entities to provide entirely new services that they have not provided in the past and are not otherwise required to provide. This is because non-public entities are beholden to the services covered by the reimbursement rates set at the state level and are not able to expand services without additional commensurate funding.

Requiring providers to provide new services or programs where they do not have a sufficient workforce to do so would be inequitable given that it may force providers to reduce or terminate other services to redirect funding. As noted in the preamble, *Olmstead* dictates that limitations of the integration mandate must take “into account the resources available to the entity and the needs of others who are receiving disability services from the entity.” Given that providers are reliant on state-determined Medicaid reimbursement rates, they cannot simply expand services or hire new workers without commensurate funding increases. While cost alone is not determinative in a fundamental alteration defense, additional funding to support the direct support workforce is necessary to enable providers to continue to sustain services for individuals in the most integrated settings. Accordingly, we urge the Department to acknowledge the impact of insufficient reimbursement rates and the resulting shortage of workforce that restricts non-public entities from expanding or increasing services.

Conclusion

ANCOR appreciates this administration’s strong commitment to supporting people with disabilities and to promoting better access to home and community-based services. We are grateful for the updates the Department is making to the foundational nondiscrimination

¹³ See *id.*

protections in Section 504 and we value the opportunity to provide input and urge better recognition of the challenges providers face as a result of the direct support workforce crisis. We remain a committed partner in fulfilling the promises of the *Olmstead* decision and look forward to continued collaboration in strengthening home and community-based supports for people with I/DD.

Sincerely,

A handwritten signature in black ink that reads "Barbara Merrill". The signature is written in a cursive, flowing style.

Barbara Merrill
Chief Executive Officer