November 13, 2023

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

Submitted electronically via: www.regulations.gov

Dear Director Fontes Rainer:

On behalf of ADvancing States, I am writing to you in response to the Notice of Proposed Rulemaking: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities. Docket No: HHS-OCR-2023-0013, RIN: 0945-AA15.

ADvancing States is a nonpartisan association of state government agencies that represents the nation's 56 state and territorial agencies on aging and disabilities and long-term services and supports directors. We work to support visionary state leadership, the advancement of state systems innovation, and the development of national policies that support home and community-based services (HCBS) for older adults and persons with disabilities. Our members administer services and supports for older adults and people with disabilities, including overseeing a wide range of Medicaid HCBS programs and Older American Act (OAA) programs. Together with our members, we work to design, improve, and sustain state systems delivering long-term services and supports (LTSS) for people who are older or have a disability and their caregivers.

ADvancing States strongly supports the HHS Office of Civil Rights in issuing this Notice of Proposed Rulemaking (NPRM). As the first substantive update to Section 504 of the Rehabilitation Act, the NPRM strengthens the law with necessary updates and underscores the critical importance of non-discrimination in the administration of the many programs and activities within the purview of HHS – including state and territory Medicaid, Disability, and Aging programs that receive federal funding through the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS).

The NPRM preamble shares multiple narratives, examples, and data that further emphasize the need for updates to the rule. We strongly agree that equal and non-discriminatory access to HHS-funded services is critical to quality of life, health, and welfare for all of those who rely or may rely on them in the future.

As we note in detail below, the intent of the proposed rule may be better realized with clarification of intended scope, small revisions, and permitting certain flexibilities for states who must implement the final rule while maintaining critical service delivery. We present general overarching comments and then speak to individual provisions where the agency has requested specific comments.

OVERARCHING COMMENTS

Institutional Bias

As we discuss in the integration section below, the NPRM is an opportunity for HHS (and CMS) to correct the institutional bias that is present within the current Medicaid LTSS delivery system. States strongly support the *Olmstead* holding. Yet, this NPRM and recent rule promulgation are silent on several fundamental areas that would support the remediation of institutional bias and increase access to HCBS:

1. Strengthening and investing in the Direct Service Workforce (DSW), including supporting interagency collaboration at both the state and federal levels on these efforts;
2. Allocating permanent funding to initiatives such as Money Follows the Person to support relocation from institutional settings to the community;
3. Creating supports to address the lack of available affordable housing;
4. Lifting the prohibition on paying room and board in community settings while permitting Medicaid funds to be used for the costs of similar services in institutional settings; and
5. Actualizing a mandatory HCBS benefit instead of (NOT in addition to) requiring states to cover institutional care.

Without acknowledgment and further support of these critical issues, systemic gaps will remain in realizing the goals of the NPRM.

Compounded Impact of Current Regulatory & Operational Landscape

This NPRM is not released in isolation. While states strongly support the NPRM's goals of anti-discrimination and integration, the current administrative and regulatory realities ride on the tails of Public Health Emergency (PHE) unwinding, the upcoming end of American Rescue Plan Act (ARPA) HCBS funding, and the most active regulatory session for rule promulgation in

recent memory. States tasked with implementing this critical rule must do so within the realities of their budgets and workforce to implement competing priorities, while never compromising essential service delivery for those who rely on it.

Several states expressed concern that, in tandem with other rule promulgation, Medicaid providers—including primary care, dental, those reliant on direct service workers, and residential providers — may not find continued participation in Medicaid reimbursement "worth the squeeze." States further commented that in many areas there are already provider shortages, and these shortages are exacerbated in rural, frontier, and otherwise underserved areas, raising additional fears about equity of access. If Medicaid providers in these areas terminate participation in the program, this could further limit recipients' access to services.

One of our members highlighted the potential trickle-down effect throughout provider networks. Rural and frontier areas, in particular, rely on shared and donated spaces. Our member provided an example of an HCBS provider leaving a shared space to join a private pay practice. This resulted in an Older Americans Act (OAA) program that relied on the shared space losing access to it and facing challenges to provide critical programs and services. The lesson shared – based on this state's real experience, and that other state members echoed, was that when one provider is impacted there is often a downstream impact throughout the network felt by many.

Conflicting Laws

In several places, the proposed changes in the NPRM appear to conflict with authorities that govern HHS programs and activities. For example, the NPRM directly conflicts with Title XIX regarding waiting lists and people at risk of institutionalization, as to what is allowable and what is not. States strive to follow the applicable regulations in program design and operations, and face uncertainty where laws are in direct conflict. As noted below, we request further guidance and collaboration from HHS agencies to ensure states can successfully implement the final rule.

Conflicting HHS Regulations

Recently, HHS has issued multiple proposed regulations that impact the long-term services and supports system. The regulations include the proposed HCBS Access Rule, the proposed OAA Rule, the proposed Adult Protective Services rule, and the proposed Minimum Staffing Standards for Long-Term Care Facilities rule. These proposed regulations will impact state and local entities' ability to meet the integration mandate. They are not aligned across funding and service delivery systems, which may have the unintended consequences of further exacerbating the institutional biases and creating barriers in addressing the integration mandate. Examples include:

- The Access rule proposes an 80 percent wage pass-through for HCBS direct care workers (DCWs), while the Minimum Standards for Long-Term Care Facilities proposes only minimum staffing standards for institutional DCWs. The discrepancy in requirements for HCBS and institutional DCWs could reduce the availability of HCBS DCW providers, particularly in rural areas.
- Clarification is needed on the intent of the application of 504 to OAA programs and activities.
- The Minimum Standards for Long-Term Care Facilities rule proposes an increase in the nursing staffing ratio. Given the short supply of nurses available across the LTSS continuum, this could create challenges for hiring private duty nurses in the HCBS service setting.

Application to OAA Programs

In addition to the definition of 'recipient' offered in the NPRM, ACL in public briefings has explicitly stated that the NPRM applies to OAA programs. Neither the published precedent of OCR enforcement of 504 actions, nor *Olmstead* cases have historically included OAA programs. States have submitted numerous questions regarding the specific intent of applying 504 to OAA programs and activities. These include:

- Does HHS intend to apply HCBS settings-like requirements to OAA programs?
- Who bears the onus for enforcement of these requirements?
    - What responsibilities do recipients carry regarding enforcement of subcontractors and other downstream entities that receive grants or other funding from recipients?
        - For example, what responsibilities do State Units on Aging (SUA) bear with monitoring compliance across the network that receives some funding?
        - States voiced concern about how realistic it will be for OCR to implement this within its current enforcement structure and if HHS will further expand the state's responsibility for this rule's implementation.
- Could a 504-enforcement action potentially be taken in any of the following examples?
    - An older adult with a disability receives medically tailored home-delivered meals to help them stay independent in the community; but, due to budget cuts and inflation, the meal provider is unable to continue providing the medically tailored meals to the individual, creating a potential risk for institutionalization.
    - A social worker encourages an older adult with a disability to apply for home-delivered meals, as it is one factor that would help them to avoid or delay moving to a nursing home, but there is a waiting list for home-delivered meals.
    - An older adult with dementia attends day services that are specifically available only to older adults with dementia.

- How does ACL/HHS view OAA "multipurpose senior centers," which are targeted at and geared for older adults, as potential segregation?
    - A state commented, "While there is a high likelihood of co-occurring disabilities, if the primary criteria for entry is age, not disability, does ACL still see this as a potentially segregated setting? [T]his scenario differs from an adult day program for older adults with cognitive impairment[.] Both these instances and the myriad of others that fall in between and along the spectrum warrant additional discussion within the network to truly understand the intent, implications, and unintended consequences." States ask for guidance on this scenario.
- How would application of these standards apply for time-limited demonstration grants through the OAA or other HHS funding channels? For example, if a state partners with a university or higher education institution to help with evaluating a project's outcomes results, or with a private entity that typically does not receive HHS funding (perhaps a tech company, consultant, or a PR agency), to support a three- or five-year NIDLRR, OAA Title IV, or other federal grant, what are requirements for the contracted entity's compliance and who is responsible for enforcement?

Clarification and additional guidance are needed from HHS and ACL if *Olmstead* integration and segregation requirements are to be considered as a primary factor of OAA service delivery. While federal partners assert these standards have always applied, without enforcement or guidance, the implications are unclear to the network and will cause confusion. Under the OAA, all adults aged 60 and over are eligible for services. Title III of the OAA requires programs to target or prioritize service to older individuals with the greatest economic and social need. It would be a major operational, administrative, and costly shift for programs and activities to act otherwise.

Cost Burdens

ADvancing States and its members are concerned that the cost burdens outlined in the NPRM significantly underestimate the expected costs to states and service providers. The NPRM states that Section 504 has applied to medical care providers that receive Federal financial assistance from the Department for approximately fifty years and provides significant figures representing the scope of the rule to medical providers that receive HHS funding. While these data emphasize the far-reaching scope of the rule for medical providers that are recipients of funding, they do not account for the scope or impact in other recipient networks, notably within OAA and Medicaid HCBS programs that deliver non-clinical services.

The NPRM further provides cost assumptions on Medical Diagnostic Equipment (MDE) and web content and mobile applications, assuming costs for: updating policies and procedures, obtaining MDE, and staff training. ADvancing States and our members are concerned that the

figures given for the number of providers that are impacted and the financial costs of compliance are not fully representative. Yet, without knowledge of the full scope of intended recipients we cannot currently provide an accurate and alternative cost assumption for web and mobile applications. However, our members have repeatedly voiced the concern that they operate with extremely limited budgets (this is especially true for OAA providers, who often rely on volunteer staff to implement critical service delivery), and any new compliance costs will detract from their services budget.

Our members voiced significant concern regarding the NPRM's assertion that the proposed requirements will be cost neutral. The NPRM states: "Concerning the proposed provisions to ensure consistency with the ADA, statutory amendments to the Rehabilitation Act, and Supreme Court and other significant court cases, the [Regulatory Impact Assessment] finds that these proposed provisions will likely result in no additional costs to recipients." As states support the intent of the rule, yet grapple with intent, scope, and potential compliance or enforcements, it is likely that implementation of the proposed 504 rule would require alteration of program design, potential for expanded programs if waitlists are disallowed, or compliance with new/additional enforcement measures. For state agencies, implementation of the NPRM will likely require additional staff time to update policies and procedures, implement operational and systems changes, and engage with impacted Aging, Disability, and Medicaid communities and networks. In addition, both state agencies and providers will likely incur costs to purchase new equipment and operational/IT systems.

SPECIFIC COMMENTS

Nondiscrimination in Programs and Activities

Medical Treatment §84.56

The proposed rule makes explicit that recipients are prohibited from denying or limiting medical treatment when that denial is based on:

- Bias or stereotypes about a patient's disability;
- Judgements that an individual will be a burden on others due to their disability;
- A belief that the life of a person with a disability has lesser value than that of a person without a disability, or that life with a disability is not worth living.

The NPRM further expands on the prohibition of discriminatory medical treatment in specific areas, including organ donation, life-sustaining treatment, crisis standards of care, and clinical research participation. The NPRM permits recipients to make medically necessary professional judgements or decline to treat an individual with a disability if the care falls outside of a provider's scope.

Comment(s) to HHS: ADvancing States and our members support these protections of persons with disabilities against discriminatory medical treatment.

Subpart I: Web, Mobile, and Kiosk §§80.82 – 80.88

The NPRM requires any internet or mobile app content, including social media content, recipients make available to the public to be readily accessible. HHS proposes adoption of the Web Content Accessibility Guidelines 2.1 Level AA (WCAG 2.1) as the technical standard for web and mobile app accessibility under section 504. The rule also includes prohibiting discrimination on the basis of disability in programs or activities provided through or with the use of kiosks but does not provide specific technical requirements for kiosk accessibility.

Comment(s) to HHS:

- ADvancing States proposes HHS utilize the four principles of web accessibility — *perceivable, operable, understandable, and robust* — within the published rule to set an expectation for accessibility without codifying a specific standard. Issuing sub-regulatory guidance about web accessibility would allow HHS the flexibility to update accessibility criteria without undergoing the rulemaking process every time new accessibility standards are published.
- While we support the NPRM's intent to establish a standard for web accessibility, we have concerns about codifying a specific standard in the regulation as the internet is likely to evolve at an increasingly fast pace. WCAG standards were updated in 2008 and in 2018, and on October 5, 2023, WCAG 2.2 was published as a World Wide Web Consortium (W3C) recommendation web standard[1], meaning WCAG 2.1 proposed in the NPRM is no longer the recommended standard.
- Currently, 48 states use or strive to use WCAG 2.0 and only four states use or are striving to use WCAG 2.1. Implementing a two- or three-year timeline for recipients to make all applicable content compliant does not accurately reflect the operational burden most states will face. The NPRM suggests that familiarity with WCAG 2.0 will make adoption of WCAG 2.1 easier. However, we note that WCAG 2.0 was published in 2008 and some states have not yet met that standard. We recommend at least a five-year timeline for compliance.
- We appreciate HHS' proposed alignment with the Department of Justice's proposed web and mobile app accessibility guidelines for entities covered under title II of the ADA but call attention to section 508 guidelines using WCAG 2.0 as the technical standard and potential confusion between different technical standards for entities that might be covered under section 504, section 508, and/or the ADA.
- ADvancing States members expressed concern regarding the onus of monitoring and

[1] "What's New in WCAG 2.2," W3C Web Accessibility Initiative, last modified October 5, 2023, www.w3.org/WAI/standards-guidelines/wcag/new-in-22.

enforcement of web accessibility standards. States do not have the bandwidth to monitor and enforce compliance of all contracted entities (for example, monitoring AAA and service provider websites for accessibility compliance).

- Some smaller recipients may lack sophisticated website design and maintaining compliance with accessibility standards could be particularly challenging. ADvancing States requests HHS provides technical assistance and guidance for recipients that do not have the technological expertise needed to maintain accessible websites.

Subpart J: Medical Equipment §§84.90-84.94

The proposed rule adopts the U.S. Access Board's Standards for Accessible Medical Diagnostic Equipment (MDE Standards), which require recipients' programs and medical practices be accessible to persons with disabilities by utilizing accessible medical equipment. The proposed rule prohibits a recipient from denying services to patients with disabilities because the recipient lacks accessible MDE and requires that all MDE recipients purchase, lease, or otherwise acquire be accessible until proposed scoping requirements are met.

Comment(s) to HHS:

- ADvancing States supports the requirement that medical practices utilize accessible medical equipment, which will help ensure individuals with disabilities are able to receive equivalent care in the same offices and hospitals as individuals without disabilities.
- We support the proposed requirement that when obtaining new equipment, recipients must purchase, lease, or otherwise acquire accessible equipment until scoping requirements are met, as this will allow for a phased-in approach, limiting strain on the supply chain and allowing recipients to budget and plan for accessible equipment.
- Members have expressed concerns about the requirement that all recipients obtain one accessible exam table and one accessible scale within two years of the rule's publication, as this will create a surge in demand with possible corresponding price increases, creating additional strain on small recipients. We propose a longer implementation timeframe of five years for smaller recipients.
- ADvancing States supports retaining §84.22(c) in the Existing Facilities of the current section 504 rule, which allows a recipient with 15 or fewer employees to refer patients to another provider that is accessible within a reasonable distance, if the recipient finds there is no method of complying with the requirements other than making a significant alteration in its existing facilities. While we support this exception if the recipient has no method of complying, we have concerns about equity implications, particularly in rural areas, as there is potential for creating greater disparities and/or limiting an individual's choice in selecting their healthcare providers if too many providers are unable to comply with the requirements.

- We suggest 'reasonable distance' also includes the consideration of the availability of accessible transportation to the referred provider. If a patient is referred to another recipient that has accessible equipment, but the patient does not have access to transportation to that provider, they should be provided with alternate provider options (for example, if the patient uses fixed bus routes to access medical appointments and the referred provider is not on a fixed bus route, the patient should be offered an alternative provider option).

- Philosophically, states support accessibility requirements; however, they have expressed concern that providers will choose to terminate their participation in Medicaid in the face of the operational challenges to meet these requirements. This is a concern particularly for rural and frontier providers. State members raised the specific example of dental providers, as there is already a shortage of dental providers willing to accept Medicaid. Adding the operational challenge of obtaining accessible equipment will likely result in some providers choosing to no longer accept Medicaid, exacerbating the provider shortage.
    - Some states voiced strong concern about provider retention because of the accessible MDE requirement, while other states had fewer concerns, demonstrating there will be undue burden in some areas and flexibilities are needed, such as longer implementation timeframes and the availability of grant funding to offset the cost of accessible equipment for recipients with smaller operating budgets.

Integration §84.76

Application §84.76(a)

The proposed rule clarifies that the integration mandate applies to all HHS-funded programs and activities, including OAA-funded programs. Although the *Olmstead* decision was specific to residential services financed through the Medicaid program, the integration mandate is applied more broadly to the administration of programs or activities by a recipient. This includes application to state and local government service systems that rely on a range of residential and non-residential settings and segregated non-residential settings. Additionally, the integration mandate applies to all types of disabilities, notably older adults who develop disabilities as they age.

Comment(s) to HHS:

- ADvancing States supports the intent of the rule to prohibit discrimination in the provision of services to individuals with disabilities and ensure services are delivered in the most integrated setting. However, many of our members express concerns about the application of the regulation in the following areas:

- *OAA Funded Services*: In our review of the *2020 Statement of the Department of Justice on the Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.,* no precedent is included for the application of the integration mandate nor information on the procedure for enforcement with OAA funded services. Without specific reference or case law it is difficult to determine the implications for OAA funded programs and services. Our members voiced concerns that this broad-sweeping regulation could result in unintended impacts when applied to the complex array of OAA funded service delivery systems.
    - Many OAA funded programs provide services to older adults with disabilities in non-residential settings. ADvancing States and our members request clarification and guidance on the application of the regulation to congregate meal sites, senior centers, adult day programs, programs specifically targeted to older adults with dementia, etc. We request additional sub-regulatory guidance if the regulation will be broadly applied to these services and settings.
    - OAA funding is intended to serve older adults who have the greatest economic and social need. The OAA funded aging network offers a well-established and diverse service system that successfully serves older adults across the aging spectrum, including individuals who are not disabled. The NPRM frames service delivery from a disability lens. While supporting service delivery in a non-discriminatory manner, state members are concerned that the application of the integration mandate could create a fundamental alteration of OAA funding distribution and negatively impact the aging service network.
- *Medicaid Institutional Bias:* ADvancing States encourages HHS to continue to look broadly across its regulatory spectrum to ensure that regulations and funding streams support state agency and service providers' ability to successfully meet the integration mandate. Since the 1999 *Olmstead* decision, State Medicaid agencies have continued to prioritize community services, rather than institutional care, and expand HCBS programs. Nonetheless, challenges remain for states to fully realize the integration mandate. These challenges include an institutional bias in federal Medicaid statue that limits a state's ability to create sufficient access and funding for HCBS. For example:
    - Coverage of the nursing facility benefit under Medicaid is a mandatory state plan benefit, while coverage of the majority of HCBS benefits is optional and falls under waiver and demonstration authorities. Medicaid HCBS authorities, such as the 1915(c) waiver, 1915(i) and 1915(k) state plan authorities, and 1115 demonstrations, are administratively complex and burdensome for states.

        - Expedited Medicaid eligibility determinations and retroactive payment for Medicaid services create pathways to institutional services. These same opportunities do not apply to HCBS.
        - Medicaid payment is allowed to cover room and board in nursing facilities but is not allowed in HCBS settings.
        - Medicaid 1915(c) and 1915(k) authorities require an individual to meet an institutional level of care, thereby limiting a Medicaid agency's ability to deliver HCBS that could delay hospitalization and/or institutional placement.
    - ADvancing States recommends HHS coordinate internally with the Office of Civil Rights, Administration for Community Living, and CMS to ensure alignment across the HCBS Access rule, Section 504 rule, updates to OAA regulations, and LTC Facility Staffing rule to ensure consistency in proposed regulations across the LTSS spectrum.

Definition: Most Integrated Setting §84.10 and Segregated Settings §84.76(c)

The proposed rule adopts the most integrated setting definition found in the DOJ title II. In addition, it describes characteristics of segregated settings, which includes a variety of settings, such as board-and-care homes, sheltered workshops, and other congregate settings populated exclusively or primarily with individuals with disabilities.

Comment(s) to HHS:

- ADvancing States supports the incorporation of the definition of most integrated setting. The definition includes the following terms that we believe serve as the hallmark of all LTSS delivery:
    - Offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; and
    - Affords individual choice in their daily life activities.
- ADvancing States members have concerns that the application of the integration mandate, when enforced, may not fully support an "individual choice" framework. We encourage HHS to include "consistent with the individual's choice" in all sections of the integration regulation.
- The requirement in 84.76 (c) notes that "segregated settings are populated exclusively or primarily with individuals with disabilities…" ADvancing States members voice concerns about the interpretation of the proposed definition. For example:
    - One commentor noted the potential for DOJ enforcement of *Olmstead* and Medicaid HCBS Settings Rule to require Medicaid beneficiaries to live and be served solely in their individually owned or rented home, rather than a congregate/group setting, regardless of their preference. Under the proposed segregation requirement, further limits may be issued on residential options covered by Medicaid. This would have far-reaching implications for states; for

example, housing with multiple individuals who have disabilities may be deemed segregated, regardless of the individuals' preference to live there.

- HCBS and aging programs provide a continuum of services with broad and diverse networks and providers. The diversity of program design, service options, and service providers is a key to the success of these programs to serve diverse populations. We encourage HHS to ensure that, across the service continuum, diversity and choice are not limited through the designation of shared residential settings as segregated, without including considerations of individual choice. For example:
  - Adult day programs have been targeted in implementation of the Medicaid HCBS settings rule as potentially isolating individuals receiving HCBS from the broader community of those not receiving HCBS (e.g., the third prong of heightened scrutiny). However, for many individuals, the selection of an adult day program is the individual's expression and choice for full inclusion and interaction in the community. The individual's participation in the program provides an opportunity for the individual to remain in their home, living with family, while also providing community integration and family caregiver respite.

- Several commenters read the proposed rule and interpreted segregated settings to broadly apply to a variety of congregate settings, including senior centers, adult day programs, dementia care programs, and congregate meal programs. As noted above, we request that HHS provide additional guidance to clarify the application of segregated settings for the aging service delivery network.

Discriminatory Action Prohibited §84.76(b) and Specific Prohibitions §84.76(d)

The NPRM requires recipients to ensure service delivery occurs in the most integrated setting possible for an individual with a disability. The regulation articulates that administering a program or activity in a manner that results in unnecessary segregation of person with a disability, including through the failure to make reasonable modifications to policies, practices, and procedures, constitutes discrimination under this section. The regulation provides a non-exhaustive list of actions that may result in unnecessary segregation, or serious risk of unnecessary segregation.

Comment(s) to HHS:

- ADvancing States and members laud the goal to ensure services are occurring in the most integrated setting, and further support the intent of the rule to ensure program administration does not discriminate against individuals with disabilities. The preamble provides detailed examples of types of action that would be considered discriminatory

but fails to highlight an important hallmark of successful service integration: individual choice. Person-centered planning and the dignity of risk should be emphasized in all sections of the integration regulation. Without this context, an assumption could be made that segregated settings may not, by their very nature, be an individual-driven choice. Our members provided individual stories where services may not be delivered in settings that are fully integrated in the community but do align with an individual's choice. For example:

  - An older adult may select an adult day program over receiving meals and services in his/her home.
  - An individual may prefer to live in a group setting for social interaction, instead of receiving services while living alone in their home.
  - An older adult with a disability may choose to receive adult day services at a Jewish community center to share meals and engage with their peers and their religious/faith community.

- Medicaid HCBS and OAA programs face workforce shortages and housing challenges that may limit opportunities to deliver integrated services for every individual with a disability. State members are concerned that these challenges could lead to discriminatory actions. The discriminatory action section should consider and account for variables that are beyond any single entity's control. In addition, HHS should provide sub-regulatory guidance and support for states to address the overarching challenges that impact integrated service delivery.
  - Does HHS have best practice suggestions or clarification on how recipients can mitigate discrimination action related to staffing and/or housing shortages?
- The preamble indicates that a recipient, where they choose to provide a service, must do so in a nondiscriminatory fashion by ensuring access to such services in the most integrated setting. Our members are concerned that the application of this requirement will limit options for states and local providers to implement unique and creative approaches to HCBS service delivery. For example:
  - The LTSS system benefits when state and local provider agencies partner to drive innovations through creativity. These opportunities may not, on their surface, comply with the proposed 504 integration mandate, creating potential for state and private entities to disengage from innovative service delivery opportunities over concerns about regulatory compliance.
  - Members raised concerns that some service providers may choose to terminate participation in HHS-funded programs, in fear of a discrimination claim or lawsuit. We recommend that HHS provide additional guidance on the scope of discriminatory action, especially for targeted or specialized service providers. Below are a few examples:

- A local area agency on aging that also operates a PACE program raised concerns that the full array of PACE-funded services would also have to be offered in a more integrated setting to comply with the 504.
- A local senior center that provides congregate meals and a specialized adult day program for individuals with dementia raised concerns that they would also have to provide similar services in an individual's home.

Fundamental Alteration §84.76(e)

The NPRM includes limitations to the obligation under the integration mandate. A recipient may be excused in instances where it can provide that the requested modification would result in a "fundamental alteration" of its services, program, or activity.

Comment(s) to HHS:

- As identified previously, ADvancing States has concerns that the application to all recipients of HHS funding in the *discriminatory action prohibited* section could lead to unintended consequences, especially for non-public entities. There is limited information from *Olmstead* cases to understand the criteria an entity would need to meet to make a case of fundamental alteration.
- We believe the process to demonstrate fundamental alteration on many non-public entities delivering community-based services could pose a significant administrative challenge.
- The preamble indicates that: "providing services beyond what a State currently provides under its Medicaid program may not be a fundamental alteration, and the ADA and section 504 may require states to provide those services, under certain circumstances. For example, the fact that a State is permitted to "cap" the number of individuals it serves in a particular waiver under Medicaid does not exempt the State from serving individuals in the community to comply with the ADA or other laws." Our members ask for clarification on how Title XIX, which allows for a limit on the number of individuals who receive HCBS, interfaces with the ADA and section 504 integration requirements. Specifically, we would like further clarification, including the context and parameters, in circumstances when the provision of HCBS services would be required when a state caps enrollment into a 1915(c) HCBS waiver program.

Notice

§84.8

One state asked for additional guidance regarding notice requirements for recipients. Does the NPRM elevate requirements beyond the current requirements? For example, states will likely have a statement about ADA and 504 on their websites. Is this continued practice sufficient, or do recipients have a more proactive obligation regarding notice?

Direct Threat

§84.75

One commentor raised concerns about the potential unintended consequences of implementing the direct threat provisions as proposed, acknowledging a subgroup of individuals with disabilities who have impulsive and explosive behaviors that can and do result in injury at times for themselves or others. In some cases, individuals continue to exhibit these dangerous behaviors even when the best and exhaustive behavior modification efforts have been made. They are often persons who have suffered extensive abuse or trauma in their lives and often have been institutionalized repeatedly over the years. In lieu of providing services in more restrictive settings like state institutions, states developed community services as accommodations; service settings were typically very small (with often 1:1 and sometimes 2:1 staffing ratios and additional staff on call to intervene when events that might result in injury to self or others). The commentor noted concern that unless the language in this section specifically mentions certain individuals who will need extraordinary measures to keep themselves and others safe, these individuals will be permanently consigned to institutional care. We suggest the following revision:

Change 84.75 (a) to say: “A recipient shall permit an individual to participate in or benefit from the programs or activities of that recipient when that individual poses a direct threat only under conditions described in (b) or (new (c) of this section.”

Then add a new (c) to read as follows: “in the event that all reasonable modifications have been made to mitigate the risk, and the probability of potential injury still persists, the recipient shall structure the program or activity with sufficient staff well trained to disarm and defend against the threatening behavior.”

Communication

§§84.77-84.81

The NPRM asks if “plain language” should be included in the definition of auxiliary aids: whether plain language is more appropriately considered a reasonable modification that an individual must request, or if it should be considered an auxiliary aid or service. States comment that plain language should be requested as a reasonable accommodation; while there is significant value in providing plain language documents when needed, there is a burden associated in producing them. As noted in the NPRM, sometimes, a plain language oral explanation, instead of a written one, may be a sufficient modification. However, in many circumstances, it may be a fundamental alteration of the nature of a recipient's program or activity to require extensive technical documents to be produced in plain language.

CONCLUSION

ADvancing States reiterates our support for the goals of ensuring non-discrimination in the delivery of programs and activities funded by HHS, including the wide array of HCBS and OAA programs that members implement. HCBS is an essential component of the continuum of LTSS and deserves continued attention and prioritization as a means of honoring individual's preferences, supporting caregivers, addressing disparities, and optimizing use of public funding.

This NPRM is particularly wide-reaching and touches upon many substantive areas, some detailed with specificity in the NPRM, while others' applications are abstract. As noted above, members voiced concerns that this broad-sweeping regulation could result in unintended impacts, particularly when applied to the complex array of OAA funded service delivery systems. Further guidance is needed where there are conflicts of laws or regulation, such as an entity being in compliance with CMS regulations while out of compliance with 504 non-discrimination requirements. To realize the intent of non-discrimination, we strongly support more coordination between HHS, and CMS and ACL in the implementation of the final rule.

We appreciate the opportunity to comment on this most important proposed rule. If you have any comments or questions, please contact Rosa Plasencia at rplasencia@advancingstates.org.

Sincerely,

Martha Roherty
Executive Director