NAELA
National Academy of Elder Law Attorneys

1577 Spring Hill Road, Suite 310 // Vienna, Virginia 22182
naela@naela.org // 703-942-5711 // www.NAELA.org

November 13, 2023

Melanie Fontes Rainer
Director
Office of Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

via www.regulations.gov

Re: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities (HHS–OCR–2023–0013)

Dear Ms. Fontes Rainer:

As advocates for older adults, people with disabilities, and their families, we appreciate the opportunity to comment on this Notice of Proposed Rulemaking (Proposed Rule), focused on Section 504 of the Rehabilitation Act of 1973.

NAELA represents over 4,000 elder and special needs law attorneys and 31 chapters, with members in every state and even some abroad. We are the only professional, non-profit association of attorneys that conditions membership on a commitment to the Aspirational Standards for the Practice of Elder and Special Needs Law Attorneys. Extending beyond the benchmark set by the American Bar Association's Model Rules of Professional Conduct, these standards recognize the need for holistic, person-centered legal services to meet the needs of older adults, people with disabilities, and their caregivers. Supporting the dignity and independence of these vulnerable populations is at the center of what we do.

NAELA strongly supports updating the Section 504 regulations to conform to subsequent legislative updates to the Rehabilitation Act of 1973, bring the regulations in line with relevant and well-established case law, and align with the Americans with Disabilities Act's mandate, which provides similar obligations for state and certain other government actors. These regulations, when finalized, will create greater uniformity and consistency regarding access to person-centered services by individuals with disabilities. Our comments, as discussed further below, center on two areas of the Proposed Rule. First, we support the Proposed Rule's general recognition of supported decision-making as a reasonable modification. Given our experience in the field seeing firsthand how recipients operationalize their responsibilities, we provide additional ways the Office of Civil Rights (OCR) can provide clearer direction and guidance on recipients' facilitation of supported decision-making where appropriate. Second, we ask that OCR further enhance the reach of these Section 504 regulations to strengthen the protections for individuals with disabilities by playing a more proactive role in the review of state HCBS waivers.

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Reasonable Modifications to comply with General Prohibitions Against Discrimination (45 CFR §84.68(b)(7))

As with other sections of the Proposed Rule, OCR proposes several changes to ensure consistency between Section 504 and the Americans with Disabilities Act (ADA) by incorporating all general prohibitions against discrimination under proposed 45 CFR §84.68(a) and (b). The Proposed Rule would add a new paragraph (45 CFR §84.68(b)(7)) that reflects Section 504's longstanding obligation that a recipient make "reasonable modifications" in policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability, unless the recipient can demonstrate that making the modifications would fundamentally alter the nature of the program or activity. OCR states this provision is meant to be consistent with the same established provisions applicable under the ADA (35 CFR §130(b)(7)). Further, unlike in other sections of the proposed regulations, OCR does not address financial and administrative burdens as a limitation to providing a modification because it believes the "reasonableness" limitation already circumscribes the scope of the underlying obligation.

In the preamble, OCR identifies "permitting the use of supported decision-making or a third-party support, where needed by a person with a disability" as a reasonable modification within the meaning of Section 504 obligations. The preamble discusses what supported decisionmaking is as "an approach used to assist individuals with disabilities in making decisions in an informed and accessible way, through the provision of person-centered decision-making that focuses on the wants and needs of the individual receiving support." The preamble explains that avoiding substitute decision-making and reinforcing individual autonomy are the OCR's policy goals. OCR also clarifies that "it is the role of the supporter to help the individual with a disability understand the range of options and the implications of each, leaving the ultimate decision to the individual with a disability." Citing the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act, which has been enacted or partially enacted in several states, the preamble appears to recognize a definition for "supported decision-making" as "assistance from one or more persons of an individual's choosing in understanding the nature and consequences of potential personal and financial decisions, including health-related decisions, which enables the individual to make the decisions, and in communicating a decision once made, consistent with the individual's wishes."

The rule also provides two examples of supported decision-making in practice:

- A health care provider may need to modify their policy on disclosing information to third parties about a medical procedure if the individual with a disability needs their supporter to help understand their treatment options.
- A human service provider who normally does not share benefit applicant information with third parties may need to make additional copies of information about an individual with a disability's benefits eligibility to share with their supporter so the supporter can help explain the options available.

NAELA Comments:

The clarifications OCR seeks to provide to recipients about their Section 504 obligations are appreciated and long overdue. As NAELA members' experiences reflect, substantial

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improvements are needed from recipients, particularly residential settings, in how they inform residents (current and future) about their rights and the options available to residents and their chosen representatives, including supported decision-makers. Effective communications at these critical junctures can help residents and their representatives make good decisions about a change of setting, either temporarily or permanently. While recognizing supported decision-making as a reasonable modification is a welcome addition to Section 504 standards, we offer recommendations for additional measures relating to: (1) privacy, particularly for HIPAA covered entities who are recipients, (2) explicit recognition of medical/legal partnerships, and (3) added training and technical assistance opportunities that the final rule should address to ensure that recipients overcome perceived obstacles to communicate with and serve individuals with disabilities more effectively.

NAELA appreciates the OCR's recognition that supported decision-making is a potential appropriate alternative to guardianship for those individuals with disabilities who can make decisions through third-party support of trusted resources. NAELA believes guardianship should be a last resort; less restrictive alternatives such as appropriate durable powers of attorney, advance directives, trusts, representative payment arrangements, and other legal and social mechanisms should be explored and exhausted prior to judicial intervention. Utilizing supported decision-making where appropriate can also avoid potential tensions under state law and professional rules of responsibility for attorneys that arise in the context of guardianship appointments.

We ask that the final rule build upon the explanation and examples in the preamble to provide recipients with additional clarification and guidance so that recipients can be better trained on identifying and facilitating supported decision-making as a reasonable accommodation. For example, the final rule could more explicitly identify medical/legal partnerships, which have grown over the last decade or more, as a subvariant of supported decision-making. In our experience, medical/legal partnerships have been useful in facilitating the often complex and daunting task of financing community-based options when sought by the individual.

With respect to the examples provided in the preamble on supported decision-making, we offer a few other potential scenarios that we request OCR include in the final rule:

- A nursing home or hospital may need to modify their privacy policy on disclosing information to third parties about a potential discharge to the nursing home if the individual with a disability needs their supporter to help in understanding their options for community-based vs. institutional-based treatment settings, including allowing home- and community-based services (HCBS) to continue for individuals who are temporarily hospitalized. To put a finer point on the scenario, we have observed that a HIPAA covered entity like a nursing home or hospital too often incorrectly interprets their HIPAA obligations in such a way that frustrates the facilitation of supported decision-making and by extension, the goals of Section 504, the ADA, and *Olmstead*'s directive. OCR should recognize and reinforce in the final rule that HIPAA permits disclosure of protected health information (PHI) to a supported decision-maker, as this third party would be involved with the individual's health care or payment related to the individual's health care within the meaning of the HIPAA Privacy Rule (45 CFR 164.510(b)). The covered entity should accept oral authorization to disclose protected health information (PHI) to

third parties pursuant to 45 CFR 164.512. OCR should also make clear that a covered entity must, as part of a reasonable modification required by Section 504, inquire about whether a third party is the individual's personal representative, accept oral authorization to disclose information, and document this authorization into the individual's medical record and other appropriate systems.

- A state Medicaid agency whose policies and procedures only recognize the ability of an individual to consult with their family member, legal guardian, or treating health and support professionals in the home- and community-based setting assessment and care planning process, may need to amend their policies to explicitly recognize and define supported decision-making. We ask the final rule clarify this point particularly given that the concept of supported decision-making is not explicitly mentioned or discussed in the HCBS Settings Final Rule (79 FR 2948, January 16, 2014).

One additional policy lever OCR should explore is to make training materials available to recipients so that supported decision-making is more accessible and affordable to recipients to implement. If this type of resource is widely available and disseminated, supported decision-making could be more likely to be a reasonable modification. It is critical the training materials address privacy issues and the different ways that a covered entity/recipient can recognize a supported decision-maker as a personal representative or otherwise authorized third party who directly receives information related to the individual's care and housing decision-making. Template forms like a supported decision-making agreement might also be incorporated to facilitate compliance with this reasonable modification. NAELA stands ready to assist OCR and relevant agency partners (e.g., DOJ, ACL) with developing such a training and technical resources package based on real-world scenarios that we encounter on a regular basis.

Integration Mandate/Compliance with *Olmstead* to Comply with General Prohibitions Against Discrimination (45 CFR §§ 84.10, 84.68(d) and 84.76)

The Proposed Rule would add new provisions to incorporate case law and HHS guidance to date interpreting Section 504's requirement on recipients to administer programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. Pursuant to proposed §84.76, the Proposed Rule provides more detailed standards on the obligation by recipients to administer programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities, given the substantial body of case law developed on this issue and the integration mandate under the ADA. Specifically, the "most integrated setting" is defined 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." (proposed 45 CFR §84.10).

NAELA comments: OCR specifically asks whether the definition proposed should be expanded. NAELA recommends that the definition be broadened in two ways to be more consistent with DOJ guidance regarding the integration mandate under 28 CFR § 35.130(d). First, the DOJ guidance for the integration mandate clarifies that there are two components of this mandate: the setting enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible, *and that persons with disabilities must be provided the*

option of declining to accept a particular accommodation" (emphasis added).[1] However, the proposed definition does not acknowledge explicitly this component of the integration mandate, as there is no language indicating an individual may decline a particular activity or opportunity, even if this accommodation might have been chosen by the individual in the past or is the predominant preference among individuals in a particular class. Therefore, one recommended change to the "most integrated setting" definition under proposed 45 CFR 84.10 is to specify after "…offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing…" the following text: "and provides an individual the option of declining to accept a particular activity or opportunity…" This added component of the definition will further align Section 504 to the ADA integration mandate and corresponding case law as well as reinforce person-centered care planning and autonomy that could lead to a declination of an opportunity as an aspect of being offered choice. Second, in a frequently asked questions document issued by DOJ in 2011, DOJ clarified the types of opportunities that recipients must accommodate to include the most important aspects of one's life and livelihood, namely: "Integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities."[2] Accordingly, we recommend amending the definition to specify that the most integrated setting is also one that "provides individuals with disabilities opportunities to live, work, and receive services in the greater community, like nondisabled persons."

In conclusion, with these underlined changes, the "most integrated setting" definition that NAELA recommends for the final rule would read as follows: "a setting that provides individuals with disabilities the opportunity to interact with nondisabled persons to the fullest extent possible; <u>provides individuals with disabilities opportunities to live, work, and receive services in the greater community, like nondisabled persons</u>; is located in mainstream society; offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing <u>and provides an individual the option of declining to accept a particular activity or opportunity</u>; and affords individuals choice in their daily life activities."

We also ask OCR to harmonize Section 504's requirements with the integration mandate under the ADA and *Olmstead* to state that recipients subject to Section 504, regardless of the type of setting they operate, must administer their programs at all times in ways that reduce restrictions on residents. For example, a nursing home must offer transportation to off-site activities in integrated settings. The nursing home must also facilitate off-site outings to see family and friends, or to any other important outings of the resident's choosing that provide that individual with the opportunity to access the "most integrated setting." These activities and service offerings must also be documented in the resident's care plan.

Lastly, the Proposed Rule addresses the intersection between Section 504 and compliance with other legal requirements—for a recipient, this is often federal Medicaid regulations or the terms

[1] 28 CFR Appendix B to Part 35 - Appendix B to Part 35—Guidance on ADA Regulation on Nondiscrimination on the Basis of Disability in State and Local Government Services Originally Published July 26, 1991, available at: https://www.govinfo.gov/app/details/CFR-2016-title28-vol1/CFR-2016-title28-vol1-part35-appB.

[2] Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, June 22, 2011, available at: https://archive.ada.gov/olmstead/q&a_olmstead.htm.

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and conditions set forth by CMS in approving a state's home- and community-based services (HCBS) waiver program. Importantly, the Proposed Rule's preamble clarifies that compliance with regulations under Medicaid or another payer does not necessarily mean compliance with the integration mandate (88 FR 63484). For example, a service or budget cut might be permitted under Medicaid or other public program rules, but if such a cut results in the recipient effectuating cuts in a discriminatory manner—such as providing only some services to individuals in less integrated settings while denying or reducing services to individuals in more integrated settings—the state has violated Section 504. Moreover, as the Proposed Rule notes, a state may violate the integration mandate by making cuts to HCBS programs while at the same time increasing funding to institutional services.

It is critical to improve recipients' understanding and compliance with Section 504 in the Medicaid program context, and we ask for increased federal oversight and enforcement. For example, under rules in New Jersey, at least 10 percent of assisted living beds must be occupied by Medicaid HCBS waiver recipients. We are aware that many of these assisted living facilities misinterpret this threshold as a ceiling, rather than a floor, and have threatened to discharge Medicaid-eligible residents because the individual facility's waiting list was full and the guarantor was not willing (or able) to pay the facility to get off the list. In another scenario, assisted living facilities refuse to cooperate with procedural requirements for the Medicaid-eligibility process (which is necessary for obtaining integration) because the resident is in a "private pay" contractual period, and the facility would not admit the same resident if their payment source became Medicaid. We ask that OCR use these real-world examples in the final rule to further clarify how Section 504 applies to recipients in the Medicaid waiver program context.

We appreciate the OCR's thoughtful attention to distinguish Medicaid law and regulations from civil rights obligations under Section 504 and the Americans with Disabilities (ADA) Act. Rather than OCR simply issuing a warning to recipients that they may violate Section 504 notwithstanding CMS's approval (as it relates to Medicaid program standards), OCR should play a more proactive part in reviewing state HCBS programs at the outset (e.g., Section 1915(c) and Section 1115 waiver applications, including renewals). Providing feedback to the recipient early about potential Section 504 compliance risks could allow recipients to obtain a greater understanding of their obligations and avoid violations in the future.

We understand that today, OCR does not play a meaningful role in consulting with CMS to review HCBS programs. We ask that OCR address this gap in its forthcoming proposed rule that will update standards for programs and activities conducted by the U.S. Department of Health and Human Services (as current regulations have not been updated since 1998). Specifically, OCR should interpret Section 504 in this context to require HHS, through CMS, to conduct (or obtain from OCR) a Section 504 compliance review alongside a review of Medicaid law and regulations to spot potential issues and incorporate mitigations for these risks within the terms and conditions of the application's approval. In so doing, HHS is not precluded from finding a violation of Section 504 as the state implements the program—just as it is not precluded from finding a violation of the Medicaid law and regulations during implementation. If HHS does not review HCBS waiver programs for Section 504 compliance, then OCR should play a more consultative role to proactively identify potential issues to the state that might be uncovered further through an OCR-initiated investigation or if OCR received a complaint.

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Conclusion

We thank OCR again for its commitment to policies that strive to ensure all people, regardless of age or disability, are able to live independently and participate fully in their communities. We thank OCR for its thoughtful consideration of the important issues discussed in the NPRM. We appreciate this and future opportunities to work with you. If you have any questions or would like to set up a discussion, please reach out to Thomas Harlow, NAELA's interim Chief Executive Officer, at tharlow@naela.org.

Sincerely,

Bridget O'Brien Swartz
President
National Academy of Elder Law Attorneys