



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

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:

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) appreciates the opportunity to offer comments in response to the Notice of Proposed Rulemaking “Discrimination on the Basis of Disability in Health and Human Service Programs or Activities.”

NASDDDS represents the nation’s state agencies, and those of the District of Columbia and Puerto Rico, providing services to children and adults with intellectual and developmental disabilities (I/DD) and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families. The NASDDDS mission is to assist member state agencies in building effective, efficient person-centered systems of services and supports. NASDDDS members administer a significant portion of the Medicaid program, managing approximately one third of Medicaid Long Term Services and Supports (LTSS) spending and within that, three quarters of Medicaid Home and Community Based Services (HCBS) spending.

NASDDDS congratulates the Office of Civil Rights at the Department of Health and Human Services (OCR/HHS) submitting these proposed updates to the regulations implementing Section 504 of the Rehabilitation Act. The adoption of the original Section 504 regulations was a historic moment in the disability rights story. The present proposal, bringing the regulations up to date for the first time in decades and incorporating important principles developed through litigation enforcing the Olmstead decision of the US Supreme Court, has the potential to be similarly significant.

While Section 504 and Olmstead enforcement is structured as an adversarial process, NASDDDS views this process as a collaboration in which all parties, while each serving their own particular function, must engage with the shared goal of maximizing the ability of people with disabilities to exercise their civil rights. As stewards of the service system

that strives to support individuals with I/DD to live lives of full community integration characterized by individual choice and autonomy, our members are keenly aware of their important role as partners in advancing, protecting, and promoting the rights of people with disabilities. We value the role that OCR and the US Department of Justice (DOJ) have played in ensuring that our systems continue to move forward. We offer these comments in the spirit of our shared responsibility to ensure that the rights of people with disabilities are secured and elevated.

Medical Treatment (§ 84.56)

NASDDDS strongly supports the new regulatory provisions on discrimination in medical treatment (§ 84.56) and value assessment methods (§ 84.57). Access to healthcare for individuals with I/DD is a continual challenge. Medical professionals rarely have the requisite expertise and experience to serve these individuals, who may have communication and other challenges that require specific supports to ensure successful health care visits. Too, individuals with I/DD often need assistance with navigating the health care system, including finding practitioners, scheduling visits, and transportation. Our members have long reported significant challenges assisting individuals with I/DD to access medical and dental care, and their experience demonstrates that insufficient medical care leads to much greater challenges in providing successful HCBS. The experience of people with I/DD during the COVID-19 pandemic, including pervasive examples of discriminatory treatment decisions, denial of access to care, and decision-making criteria that devalued their lives, reaffirms the necessity of these new protections against discrimination. These impacts are magnified for individuals with I/DD who also face inequitable access to medical care because of race, ethnicity, socio-economic status, or other factors.

Medical Treatment Question 2: The Department seeks comment on other examples of the discriminatory provision of medical treatment to people with disabilities.

In addition to the examples already listed in the preamble, we draw OCR's attention to longstanding obstacles encountered by individuals with I/DD attempting to access mental health care. Prevalence of mental illness among persons with intellectual and/or developmental disabilities is three to four times higher than in the general population, and include illnesses such as major depressive disorder, bipolar disorders, psychotic disorders, anxiety disorders, impulse control disorders, major neurocognitive disorders, and stereotypic movement disorder.¹ Although we do not have robust prevalence

¹ Pinals DA, Hovermale L, Mauch D, et al.: Persons with intellectual and developmental disabilities in the mental health system: part 1. clinical considerations. **Psychiatr Serv** (Epub ahead of print, Aug 4, 2021)

studies in the United States, a recent meta-analysis estimated that 33.6% of individuals with intellectual and developmental disabilities also have a mental health condition.²

The challenges surrounding access to community-based behavioral health services for individuals with co-occurring mental health (MH) conditions and developmental disabilities are rooted in longstanding biases about individuals with I/DD and their capacity to experience mental illness. These biases have shaped entrenched federal and state policy that creates organizational and funding silos. For example, almost all states provide mental health, substance abuse, and physical health services in the community under the state plan rehabilitation option. However, a persistent misperception about individuals with I/DD results in their exclusion from this option on the basis that mental health services cannot provide “restoration of function” for this population.

While these issues have historic roots in policies stemming from bias and misperception, the present-day outcome is a shortage of mental health practitioners with appropriate training to understand needed accommodations to effectively serve people with I/DD and other disabilities, and payment policies across all relevant systems that have reinforced practices that exclude people.

This results in a chronic lack of a whole-person approach supporting individuals with co-occurring ID/DD and MH issues, with and without Substance Use Disorders (SUDs), and prevents individuals with complex support needs from getting a coordinated approach to clinical services and community-based supports. Because of inadequate support, an increasing number of individuals with ID/DD experiencing a MH crisis suffer adverse outcomes, including negative health outcomes, difficulties accessing community-based services, and even routing through criminal and forensic processes when behaviors are seen as more problematic for the public at large.

This lack of access and capacity has significant discriminatory impact on individuals with disabilities, leading to segregation. NASDDDS members report that these obstacles represent one of the most significant barriers to transitioning many of those remaining in institutional settings into the community and to effectively supporting individuals in community settings more broadly.

Individuals with I/DD and mental health needs also face issues with both access to and over-prescription of psychotropic medication that are rooted in this same bias. Intellectual and cognitive symptoms may “overshadow” other behavioral observations, and this coupled with the widespread bias that individuals with I/DD are unable to or less likely to experience mental illness can lead to conditions that would benefit from

² Mazza, Rossetti, Crespi, Clerici, 2020

medication and other interventions being overlooked. Conversely, practitioners may misinterpret functional behaviors such as vocalization, repetition, or abnormal speech as evidence of psychosis. These complex presentations can be challenging for insufficiently trained practitioners, who are often making treatment decisions when individuals are in crisis. This can contribute both to inappropriate referrals for psychiatric treatment among individuals with I/DD and to inappropriate non-referral. Such individuals may be treated with medication or other interventions that are not actually indicated, such as sedatives and antipsychotics or environmental interventions such as seclusion and restraints; or they may be denied appropriate medication and other interventions.

NASDDDS members report an even more troubling scenario in which individuals with I/DD are prescribed anti-psychotics and other medications as a response to behaviors, with no diagnosis to support the intervention. A National Core Indicators (NCI) 2019 data brief notes that respondents with dual diagnosis were more likely to take medications for a co-occurring mental health condition, but also more likely to report taking medications for a behavioral challenge³. More recent NCI data from the 2021-22 survey tool showed that 66% of respondents takes one or two medications for mood, anxiety, and/or psychotic disorders and 26% takes medications for behavioral challenges⁴. These data illustrate the widespread nature of the practice of prescribing medication to address behavioral challenges in the absence of a corresponding mental health diagnosis. The use of these medications to manage behavior in the absence of any supporting diagnosis reflects discriminatory attitudes about people with I/DD, their right to autonomy, self-expression, and appropriate medical care.

Each of these scenarios is an act of discrimination in and of itself, and has long-term effects that make it more difficult for individuals with I/DD to exercise their rights to full participation in their communities as delineated by Olmstead and in the integration mandate section of this rule.

The use of aversive interventions, especially of electric stimulation devices (ESD) and the administration of contingent electric shock for behavior modification (as distinct from ECT), is another example of a discriminatory medical decision. This intervention is imposed only on people with disabilities. State and federal agencies, disability professionals, provider associations, family groups, consumer run organizations, and even the United Nations have unequivocally disavowed the use of contingent electric shock precisely because it violates legal, ethical, and professional standards for the

³ NCI Data Brief: Dual Diagnosis https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf

⁴ IPS 21-22 National Report https://idd.nationalcoreindicators.org/wp-content/uploads/2023/05/IPS-21-22-Medications_FINAL.pdf

care and treatment of people with disabilities. All NASDDDS members support people with I/DD who also have significant behavioral support needs and none of them, with the exception of Massachusetts, where they are only used in the Judge Rotenberg Center, use electrical stimulation devices as a way of controlling behavior. Contingent electric shock is not supported by modern research, and as determined by the federal Food and Drug Administration (FDA), electrical stimulation devices create a substantial risk of injury and harm with no reliable evidence of long-term efficacy⁵ Inclusion of this example in the preamble is consistent with the federal government's goal of prohibiting discriminatory medical treatment decisions.

Consent to treatment

At 84.56(c)(2), the proposed regulations address the concept of consent to treatment, and 84.5(c)(2)(ii) indicates that a recipient may not “discriminate against a qualified individual with a disability on the basis of disability in seeking to obtain consent from an individual or their authorized representative for the recipient to provide, withhold, or withdraw treatment.” NASDDDS believes this protection would be strengthened by adding a reminder of the affirmative obligation on the part of the recipient to provide reasonable modifications needed to ensure effective communication and informed choice. This may include modification of hospital visitor policies to allow for a designated support person to facilitate effective communication, offer behavioral support, provide information in plain language, and assist with access to care, and including this example in the regulation's preamble would further underscore the legal obligation of recipients to make reasonable modifications, both individually and program wide, and to ensure effective communication and informed choice for individuals with disabilities seeking medical treatment.

Such an example would be especially salient in light of a statutory change made in 2020 by Section 3715 of the Coronavirus Aid, Relief, and Economic Security (CARES) Act that allows state Medicaid programs to pay for HCBS services during short-term hospital stays, and subsequent challenges states have faced adopting this practice. The change was made specifically so that people receiving home and community-based services (HCBS) under 1915c waivers could have a direct support professional (DSP) with whom they have a relationship assist them during a short-term hospital stay to assist them with understanding treatment options and hospital requests. While many states are eager to, or already have, added this option to their HCBS waivers, NASDDDS members report that hospitals are sometimes reluctant, especially in light of

⁵ U.S. Food & Drug Admin., Final Rule: Banned Devices; Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior, 85 Fed. Reg. 13,312 (Mar. 6, 2020), <https://www.govinfo.gov/content/pkg/FR-2020-03-06/pdf/2020-04328.pdf>.

the pandemic, to allow DSPs to accompany patients in the hospital. Explicitly connecting this practice to the requirement to provide reasonable accommodations under Section 504 would help hospitals better understand their relevant civil rights obligations.

Finally, the preamble should note that cultural responsiveness should be embedded in both the treatment decision-making process as well as access to all necessary treatment options. For people with disabilities, including those from BIPOC communities, accommodating cultural differences and language requirements is necessary in all aspects of medical treatment.

Value Assessment Methods (§84.57)

NASDDDS supports the requirements that address discrimination on the basis of disability in the use of value assessment methods. In particular, we agree that the use of QALYs is discriminatory and prevents people with disabilities from accessing much needed health care. The concept of the QALY is based on the premise that a year of life with a disability is of lower quality and value than a year of life without a disability. This perception is rooted in long-standing misconceptions about the lives of people with disabilities, which have never been accurate and are certainly out of touch with today's reality, in which it has become abundantly clear that people with disabilities can live high quality lives as valuable and contributing members of their communities. The QALY methodology flies in the face of this truth by assigning lower value to treatments that address an individual's immediate health need while not eliminating their disability.

Children, Parents, Caregivers, Foster Parents, and Prospective Parents in the Child Welfare System (§ 84.60)

NASDDDS applauds the inclusion of new provisions in the NPRM that address discrimination against people with disabilities by the child welfare system. As noted in the joint letter from HRSA, SAMHSA, CMS, CDC, ACF, and ACL on May 22, 2022⁶ State agencies can make significant improvements in coordinating efforts to ensure an expanded capacity to serve children with co-occurring I/DD and mental health support needs in child welfare system.

State I/DD agencies are increasingly identifying transition aged youth and young adults entering our service system who have been involved with the child welfare system. Our

⁶ <https://www.hrsa.gov/sites/default/files/hrsa/about/news/2022-joint-letter-childrens-mental-health.pdf>

members report that these individuals often present with the most challenging support needs, noting the need for improved communication, data sharing and shared approaches to holistic supports across systems to ensure strong proactive collaboration. Youth with I/DD who have experienced institutional placement often have greater skill deficits, less experience exercising autonomy, and, especially, greater trauma than peers who grew up in family settings. As a result, avoidable institutional placements are not only discriminatory in and of themselves, but also create lifelong additional challenges to individuals with I/DD in exercising their rights, especially those discussed in the integration mandate section of the proposed rule. These placements have a disproportionate impact on Black and brown children, who on average remain separated from their families longer, are segregated more from non-disabled peers, and are less likely to have a permanent placement than white children⁷.

Ensuring that the child welfare and foster care systems have the needed capacity to support children with all types of support needs and to work collaboratively across systems will assist in ensuring stronger childhood services and support and facilitating smoother transitions to adulthood. State child welfare agencies are often operating complex systems with inadequate funding, including a lack of resources to acquire deep expertise in disability support needs, and significant capacity challenges. In this context, clear guidelines from federal funders regarding the civil rights obligations attendant to serving children with disabilities can be a helpful driver of systems change. We appreciate, therefore, the strong language in the preamble that states that “Congregate care should never be considered the most appropriate long-term placement for children, regardless of their level of disability.”

NASDDDS members have experience supporting individuals with I/DD to be successful parents. We appreciate OCR emphasizing that “child welfare programs must ensure that they provide equal opportunities for caregivers, foster parents, companions, or prospective parents with disabilities to benefit from [child welfare] programs, including by providing auxiliary aids and services and reasonable modifications.” This should include a recognition that parental assessments should take into account the context of natural and paid supports already in place or available to assist a parent with disabilities, and all due efforts to ensure that the parents have the support necessary to avoid and out-of-home placement.

Further, we recommend that OCR make explicit that assisting parents to access the full range of supports available for them or their children is an important part of meeting this obligation. To ensure that child welfare agencies can make a comprehensive assessment of the paid supports a parent with an intellectual disability is or could be

⁷ U.S. Comm’n on Civil Rights, *The Multiethnic Placement Act: Minorities in Foster Care and Adoption* (July 2010) https://www.usccr.gov/files/pubs/docs/MEPABriefingFinal_07-01-10.pdf

using, and ensure that those supports are in place, child welfare agencies will need to familiarize themselves with the adult home- and community-based service (HCBS) systems in their states. They will also need to learn how to support parents in navigating these systems to get the services they need to successfully raise their children. The facilitation of HCBS for the parent, the child, or both should be explicitly framed as a reasonable modification that could potentially be required under the Rehabilitation Act.

Accessible Medical Equipment (§§ 84.90–84.94)

NASDDDS strongly supports OCR’s efforts to apply specific requirements for accessible medical equipment. Inaccessible medical diagnostic equipment (MDE) makes even the most basic preventive care out of reach for many people with I/DD. Due to inaccessible equipment, people with I/DD may be excluded from certain types of exams or treatment, may be delayed in receiving medical treatment because of an inability to access medical care, or receive subpar medical examinations. This can result in undetected medical conditions, exacerbation of their known disabilities, and the development of secondary conditions. We agree that regulated entities, physicians, and other healthcare professionals would benefit from specific technical guidance, and where possible, resources and training on how to fulfill their obligations and make their services accessible. Support to meet these requirements should have a dedicated focus on supporting medical practitioners serving underserved communities to ensure that the obligations for updated equipment do not exacerbate a sometimes fragile medical ecosystem in socio-economically disadvantaged communities.

“Most Integrated Setting” (§ 84.10)

NASDDDS appreciates OCR’s decision to provide a definition of most integrated setting. State I/DD directors manage large state systems that function as federal/state partnerships, and clarity regarding federal expectations provides certainty and facilitates compliance. We concur that each of the characteristics in the definition found in the proposed regulatory language is a salient characteristic of any setting that should be considered “integrated” rather than “segregated.” However, we are concerned that the definition takes a binary approach that is contrary to the actual meaning in context of the phrase “most integrated setting” and will lead to confusion and misapplication.

The full obligation generally referenced with the phrase “most integrated setting,” as it is understood in the context of Olmstead and other articulations of integration rights for people with disabilities, is to administer programs in “the most integrated setting **appropriate to the needs of the individual.**” Indeed, OCR has included this fuller version of the phrase several times in its proposed regulatory language, most notably at

§ 84.76(b) and (d)(1), which define the integration mandate proposed herein. In its full context, the phrase is clearly meant to provide a standard by which to judge the suitability of any particular setting for any particular individual, not to delineate a bright line between an “integrated” setting and a “segregated” one.

As such, the phrase necessarily envisions a spectrum, in which settings may be integrated to varying degrees. Further, it requires a relative assessment, one based on the relation between the level of integration of the setting and the needs of the individual. While the beginning of the proposed definition, “a setting that provides individuals with disabilities the opportunity to interact with non-disabled persons **to the fullest extent possible**,” is consonant with the intended meaning of the phrase, the rest of the definition offers concrete rather than relative characteristics.

This shift in the meaning of “most integrated setting” can lead to implementation and enforcement challenges. Firstly, such an approach requires adherence to an exact meaning of each component part of the definition. In order to comply with the requirement to “administer programs and activities in the most integrated setting,” where most integrated setting has an absolute meaning, recipients will need to know exactly what constitutes, for example, being “located in mainstream society.” Further, if the definition is absolute rather than relative, several of its constituent parts become standards which must be met in their entirety. If the absolute definition of the most integrated setting includes that it “offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing,” then any modification whatsoever of that access would put a recipient out of compliance unless it can demonstrate that to remove the modification would be a fundamental alteration.

More importantly, treating “most integrated setting” as an absolute divorced from the modifier “appropriate to the needs of the individual” will inevitably lead to inappropriate placements in lowest common denominator settings that do not maximize the integration rights of the individual. Under the current understanding of the integrated setting mandate, even if an individual is receiving services in a setting that can check all the boxes of the proposed definition, the funding recipient has an affirmative obligation to support them in an even more integrated setting if such is appropriate to their needs. For example, if a group home on a small cul de sac in a residential neighborhood is determined to meet the characteristics in the proposed definition, a funding recipient who provides residential services would have no obligation to support individuals in their own apartment in a non-disability specific building. Conversely, if the proposed definition were interpreted to mean that each of the component characteristics must be present to the maximum extent possible, this would create an unworkable obligation for funding recipients and result in chaos.



We recommend that OCR replace the proposed definition with the following, which would provide a clear principle to guide compliance with the integration rights of individuals with disabilities:

“The most integrated setting is a setting that enables people with disabilities to live as much as possible like people without disabilities.”

Alternatively, we request that OCR modify the proposed definition as follows:

“Most integrated setting appropriate to the needs of the individual” means “a setting that provides individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible; offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing *to the fullest extent possible*; and affords individuals choice in their daily life activities *to the fullest extent possible*.”

Such a definition would clarify the standards by which a funding recipient should determine whether any given setting is the most integrated setting appropriate to any individual. NASDDDS would support language in the preamble or regulation describing integrated settings as ones that generally have the characteristics delineated in the proposed definition, and establishing an expectation that any deviation from or modification of these characteristics should be minimal and justified by the needs of the individuals served in the setting.

Reasonable Modifications and Supported Decision-Making (§ 84.68(b)(7))

We appreciate OCR's express recognition of the value of supported decision-making in its preamble discussion of NPRM section 84.68(b)(7), which addresses Section 504's long-standing 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. The right to make choices for oneself is essential to the exercise of any of the other rights Section 504 seeks to enforce, and is a fundamental expectation of individuals without disabilities. When a person with a disability requires additional supports to exercise this right as a non-disabled person would, funding recipients should be expected to make those supports available. In particular, in instances where the rule suggests that an individual may give consent to waive their rights, as for example at 84.56(c)(2), which deals with consent to provide, withhold, or withdraw medical treatment, NASDDDS members believe it is especially important that funding recipients recognize an obligation to provide support to an individual with



disabilities where needed to ensure that the consent is informed. The absence of a full understanding of the supports an individual with disabilities might need to make an informed decision risks the notion of consent becoming a box-checking exercise that does not safeguard their rights.

We applaud OCR's recognition of this in the preamble's general discussion of reasonable modifications by including in the definition of supported decision making that it "may include a supporter providing such assistance in the informed consent process," and offering an example directly related to medical treatment. We believe that the proposed regulation's emphasis on supported decision making would be made even stronger by direct mention of supported decision-making as a reasonable modification throughout its provisions, especially where the concept of informed choice or informed consent is raised. Our members' experience supporting individuals with I/DD demonstrates that this concept is so essential to upholding the right of individuals with disabilities to self-determination that it merits this level of elevation throughout the rule.

Integration § 84.76

NASDDDS applauds OCR's proposal to "update the section 504 regulation consistent with cases from the U.S. Supreme Court and lower courts, as well as DOJ's interpretation of the integration mandate under title II" of the Americans with Disabilities Act (ADA). The Olmstead decision has played a significant role in moving the I/DD system forward, driving increased reliance on home and community-based settings and individualized services that support people with I/DD to be independent, exercise choice, and participate in family, community, and work life. Embedding Olmstead obligations in federal regulation will remove them from the potential of interpretation and reinterpretation by each successive court decision, creating stability and certainty for states, and preventing these valuable protections from being rolled back by decisions like the recent fifth circuit decision in *US v. Mississippi*. We share the goal of making this section as impactful as possible and our comments are aimed at simultaneously creating strong standards and avoiding unintended consequences on the system that will make it harder to protect the rights of people with I/DD. In particular we are concerned that a plain reading of certain areas of the proposed integration mandate, without the contextual element usually present in Olmstead enforcement, may too broadly implicate essential service types and providers and hamper the ability of state I/DD systems to effectively support the community integration of the individuals they serve.

We recognize that OCR's stated aim is to replicate as closely as possible the requirements commonly understood to arise from the interpretation, in Olmstead and succeeding court cases that rely on Olmstead as a precedent, of Title II of the



ADA. OCR summarizes the Supreme Court's interpretation to mean that "public entities are required to provide community-based services to persons with disabilities when such services are appropriate, the affected persons do not oppose community-based treatment, and the placement in a community setting can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity." We concur with this understanding and believe the regulatory language and preamble in the proposed rule largely accomplish OCR's intention.

The requirements articulated by Title II case law have been valuable in driving systems change toward the provision of services in more integrated settings. It is important to recognize that this impact is strengthened, not limited, by the recognition intrinsic to the Olmstead decision, and articulated in OCR's summary, that systems change inescapably occurs in the context of available resources and the state's obligation to provide services to a broad population of individuals with disabilities. We have made considerable progress over the last 25 years precisely because courts have taken an approach to Olmstead enforcement that defends the integration rights of individuals with disabilities by continually raising the bar of expectations for service systems while ensuring that those expectations are formulated such that they can be absorbed by state systems without jeopardizing system stability. While affirming that an individual's rights are not in any way modified by the level of resources available to an entity required to uphold them, NASDDDS emphasizes that this balanced approach has both expanded and protected the capacity of state I/DD systems to support the rights of individuals with I/DD. Therefore, we support the inclusion of the "limitation" at § 84.76 that "a recipient may establish a defense to the application of this section if it can demonstrate that a requested modification would fundamentally alter the nature of its program or activity." We believe that the appropriate application of the fundamental alteration defense, as defined in the preamble, in language drawn from the Olmstead decision, as meaning that a State must show "that, in the allocation of available resources, immediate relief for plaintiffs would be inequitable, given the responsibility the State [or local government] has taken for the care and treatment of a large and diverse population of persons [with disabilities]," can help ensure that Section 504 integration mandate enforcement activities continue to improve the protection of the rights of people with disabilities.

We recommend that OCR clarify that "resources" has a meaning beyond funding; especially in the current workforce crisis, state I/DD agencies are even more often limited in efforts to expand or modify services by lack of available staff than by lack of money. We also recommend that OCR make explicit that a determination of whether something constitutes a fundamental alteration is fact and context specific. Elsewhere in the preamble, OCR points out 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.” We support this interpretation; any understanding of the integration mandate that considered changing waiver caps a per se fundamental alteration would reduce the mandate’s value to state I/DD systems as a tool to expand services. However, in keeping with the understanding expressed by OCR that integration mandate enforcement must “[take] into account the resources available to the entity” responsible for the services, OCR should clarify manifestations of limited resources such as waiver caps may in fact sometimes be relevant to a fundamental alteration claim, depending on a fact specific analysis. In particular, the Olmstead decision itself indicates that if a state can meet its obligation to make a reasonable modification to its waiver policy if it has a “comprehensive, effectively working plan for placing qualified persons with...disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state’s endeavors to keep its institutions fully populated.” The proposed integration mandate provisions of this regulation would be strengthened if OCR made explicit reference to the Olmstead plan concept as a reasonable modification.

NASDDDS supports OCR’s vision of the scope of the integration mandate. We concur that “Segregation can occur in residential services, day and employment services, and other services that people with disabilities may receive,” and is not limited to residential institutions. Additionally, we support the codification in federal regulation that “Protections from discrimination on the basis of disability are violated by policies that place individuals at serious risk of institutionalization or segregation.” These are widely accepted interpretations of the rights of individuals with disabilities as articulated by the Olmstead decision and the Section 504 statute, which many state I/DD agencies have used as levers to support changes to service design and settings requirements, and we appreciate OCR codifying them in federal regulation so that states can rely on their continued application.

We appreciate OCR’s clarification that “the section 504 proposed rule would not change the requirements of the Medicaid program in the Social Security Act or in Medicaid regulations, nor would it require CMS to assess compliance with section 504 as part of their work approving Medicaid proposals.” This comports with our understanding of the distinct roles that Title XIX of the Social Security Act and Section 504 of the Rehabilitation Act/Title II of the ADA play in shaping state obligations in the provision of Medicaid-funded services to individuals with I/DD. While it is certainly helpful for CMS to have a strong understanding of state obligations under the Section 504 integration mandate, we agree that it would be inappropriate for CMS to be responsible for assessing the application of these proposed regulations to specific circumstances. We also appreciate OCR’s reaffirmation that Medicaid law does not pre-empt the civil rights protections enshrined in Section 504 of the Rehabilitation Act.



States have an affirmative obligation, under the present and the proposed integration mandate, to support individuals in the most integrated setting appropriate to their needs. Proposed § 84.76(d)(4) indicates that “failure to provide community-based services that results in institutionalization or serious risk of institutionalization” would constitute a violation of this obligation, and describes “planning, service system design, funding, or service implementation practices that result in institutionalization or serious risk of institutionalization” as potentially constituting such a failure. In the context of this language, we request clarification of OCR’s indication that “Section 504 does not require states to create new programs to assist people with disabilities, nor does it require states to provide a particular standard of care or level of benefits.” What would OCR consider a “new program,” or a change in standard of care or level of benefits, such that a failure to adopt it would not constitute a violation under proposed § 84.76(d)(4)? The proposed rule also indicates that “A State may violate the integration mandate in administering its system of services, including approved HCBS services under Medicaid waivers or other authorities, if it does so in a manner that unnecessarily segregates people with disabilities and fails to make available sufficient services in integrated, community-based settings.” We request similar clarification about the concepts of “sufficient services,” “standard of care,” and “level of benefits,” and how sufficiency of services will be evaluated without reference to either of the latter concepts.

Thank you for the opportunity to comment. Please reach out to Dan Berland at dberland@nasddds.org with any questions.

Sincerely,

A handwritten signature in blue ink that reads "Mary Sowers".

Mary Sowers
Executive Director
NASDDDS