NAMD
National Association of Medicaid Directors

November 13, 2023

The Honorable Xavier Becerra
Secretary of U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Becerra,

On behalf of the nation's Medicaid Directors, NAMD is pleased to offer comments on the proposed rule, Discrimination on the Basis of Disability in Health and Human Service Programs or Activities [2023-19149]. The proposed rule reinterprets Section 504 of the Rehabilitation Act, which addresses discrimination on the basis of disability. The proposed rule would impact Medicaid agencies' use of value assessment methods, provision of home- and community-based services, and accessibility standards for websites and mobile applications.

Medicaid Directors are strongly committed to preventing discrimination on the basis of disability. Medicaid leaders acknowledge the barriers faced by people with disabilities and are focused on improving choice, autonomy, and integration through expansion of home and community-based services (HCBS), implementation of the HCBS settings rule, direct engagement with members and advocates, and use of pandemic flexibilities. However, some of the policies proposed in this rule, including the integration and value assessment provisions, may have unintended consequences on the Medicaid program. NAMD encourages the Department of Health and Human Services (HHS) to consider more targeted policy interventions and to carefully evaluate interactions between the integration provisions in this rule, the HCBS provisions in the proposed access rule, and the proposed long-term care minimum staffing standards.

NAMD is a professional community of state and territory leaders who provide health insurance to more than 91 million individuals and families through Medicaid and the Children's Health Insurance Program in each of the 50 states, the District of Columbia, and the U.S. Territories. NAMD elevates thought leadership on core and emerging policy matters, amplifies the experience and expertise of Medicaid and CHIP directors, supports state programs in continuous improvement and innovation, and optimizes federal-state partnerships to help millions live their healthiest lives.

HHS Should Consider a Broad Array of Strategies to Facilitate Integration

Congress and the Administration Must Act to Facilitate Rebalancing of the Long-Term Care Continuum

Over the past several decades, Medicaid agencies have built out the HCBS system, with spending on HCBS surpassing spending on institutional care for the first time in 2013. The 1999 *Olmstead* decision was a landmark case in this process, accelerating

the expansion of HCBS and creating new protections for people who receive long-term care. NAMD recognizes and affirms *Olmstead's* long-standing principles around community integration and supporting people in living in the least restrictive setting that is appropriate.

Federal Medicaid law does not align with these principles. The "institutional bias" in the Medicaid program – by which coverage of nursing benefits is mandatory but coverage of most HCBS is optional – is a fundamental barrier to rebalancing the care continuum. Because of this bias, Medicaid agencies must leverage waivers and targeted state plan options to provide HCBS, with approximately 69% of HCBS spending delivered through Section 1915(c) and 1115 waivers in FY2020. These authorities come with cost neutrality requirements, periodic renewals, and other administrative burdens that make it substantially more difficult for Medicaid agencies to deliver HCBS than institutional care. Similarly, Medicaid agencies pay for room and board in nursing facilities but are not allowed to pay for room and board under HCBS, representing a major barrier to community living.

For these reasons, NAMD supports the correction of the institutional bias in Medicaid. HCBS, not institutional care, should be the default option for long-term care. Actualizing a mandatory HCBS benefit would, however, require significant federal investments in HCBS infrastructure and workforce. **We urge Congress to make investments in the HCBS system, through federal match increases or targeted demonstration opportunities, and to permanently authorize the Money Follows the Person (MFP) program.** We also strongly encourage the HHS Office of Civil Rights (OCR) to work in partnership with the Health Resources and Services Administration (HRSA), the Department of Labor (DOL), and other federal partners to strengthen the direct care workforce.

HHS Should Pursue Policies that Address On-the-Ground Barriers to HCBS, Not Broad Legal Remedies

In this rule, HHS proposes to codify their interpretation of the *Olmstead* decision and subsequent case law into regulation. This proposal would have significant legal, fiscal, and operational implications for Medicaid agencies and long-term care providers.

Medicaid agencies, as health care payors, are tasked with allocating limited resources. Medicaid budgets are set by state/territory legislatures, who are constrained by balanced budget requirements and local economic conditions. Because of this reality, states and territories are granted the autonomy to make certain choices about how they prioritize Medicaid spending. It is also important to recognize that the HCBS system has been built out incrementally, with the proportion of Medicaid funds spent on HCBS increasing from 10% in 1988 to 62% in 2020. This reflects the on-the-ground realities of building out a service, including state/territory fiscal constraints and the time needed to grow a provider base and a direct care workforce. While *Olmstead* was a landmark

decision in the development of HCBS, it is important to note that many states have rebalanced their long-term care systems without a formal *Olmstead* action.

Given these realities, NAMD strongly encourages HHS to consider policies that facilitate the continued development of the HCBS system, instead of pursuing broad legal remedies. Medicaid Directors support HHS OCR's aim of ensuring all individuals can live in the most integrated setting that is appropriate to their needs. Policy interventions, however, should meaningfully support providers and states/territories in moving closer to this goal. NAMD is concerned that HHS OCR's proposal may have the unintended consequence of turning HCBS expansion into an adversarial process between states and the federal government, without meaningfully addressing existing barriers to integration. It is also important to note that settlement agreements do not come with the federal resources needed to effectuate them, which may necessitate benefit or eligibility cuts elsewhere in Medicaid programs. Given these dynamics, NAMD strongly encourages HHS to consider policy changes that make it easier for state/territories and providers to actualize *Olmstead's* aims, instead of holding them accountable for factors (such as affordable housing supply) over which they do not have direct control. Medicaid agencies need more resources and flexibilities to improve the long-term care system – not less.

Fortunately, we have a strong understanding of the on-the-ground barriers to receiving services in the community. Data from the Money Follows the Person demonstration, which provides Medicaid agencies with flexible funding to support individuals in moving from institutional care to HCBS, consistently points to affordable housing as the biggest barrier to HCBS. Medicaid provides de facto funding for room and board in institutional settings but is not allowed to pay for room and board in HCBS. Evaluations also indicate that hospitals are pressured to discharge patients as quickly as possible, and because nursing facilities are easier to discharge to than HCBS, many nursing facility admissions follow acute hospitalizations. We encourage HHS and Congress to directly address these barriers through investments in housing supports, permanent authorization of the Money Follows the Person program, and hospital discharge planning initiatives.

We also have good, recent examples of policies that facilitate integration. The American Rescue Plan Act (ARPA) of 2021 provided flexible funding for states and territories to enhance, expand, or strengthen HCBS. Medicaid agencies are using these funds on housing supports, including rental assistance; direct care recruitment, wage increases, and training; technology and telehealth investments; infrastructure improvements; services to help individuals transition for institutions to the community; caregiver supports; and new HCBS services, including enhanced mental health supports. This demonstrates that when Medicaid agencies are given resources and federal flexibilities, they make meaningful improvements to the HCBS system.

Medicaid Directors Report Concerns Around Unintended Consequences on Services and Providers

Medicaid Directors note specific concerns with HHS's proposed interpretation of *Olmstead*. In the rule, HHS states that, "once a recipient chooses to provide certain services, it must do so in a nondiscriminatory fashion by ensuring access to such services in the most integrated setting appropriate to the needs of the qualified individual." Medicaid Directors report substantial confusion over the real-world implications of this proposal. If a state added new 1115 waiver services – such as housing supports – in some settings but not others, would this violate the integration mandate? It is typically not possible for states/territories to stand up new services in every setting at once, due to fiscal constraints and availability of providers. Many Medicaid agencies also prefer to pilot innovative new services in specific settings, with the aim of learning from smaller scale implementation before expanding to additional locations. If finalized, this provision could deter states from adding innovative services to their programs.

This provision may also have unintended consequences on providers. Medicaid agencies rely on providers to *choose* to stand up services that the state makes available for reimbursement. Providers make these choices based off their abilities, expertise, and capacity. If a behavioral health provider has both inpatient and community-based settings and chooses to provide specialized services in an inpatient mental health facility by hiring a clinician with expertise in a specific service modality, would they also be required to provide these services in their community clinics? If so, this rule would deter providers from choosing to offer new services. Given fiscal and workforce constraints, it is unreasonable to expect providers to be able to stand up new service arrays in all settings simultaneously.

Medicaid Directors note further concerns around unintended impacts on providers. The proposed rule states that providers may be in violation of Section 504 if they routinely discharge persons with disabilities into nursing homes due to inadequate discharge planning procedures or if they continue an individual's inpatient placement when the individual could live in a more integrated setting. Given national workforce shortages among nursing staff and direct care workers, providers may not be able to find appropriate HCBS placements for reasons outside of their direct influence. Medicaid agencies report, for example, significant challenges finding appropriate placements for young people with acute behavioral health needs due to severe provider shortages and maldistribution issues. Medicaid agencies also note that the proposed rule may have significant impacts on rural providers, who face the greatest challenges finding community-based placements and offering access to community activities at times, frequencies, and with persons of an individual's choosing. If finalized, these provisions would place new fiscal and legal pressures on providers, which may ultimately limit access to care and network adequacy.

The rule would also have serious implications for state/territory budget processes. HHS OCR notes that "service reductions resulting from budget cuts – even where permitted under Medicaid and other public program rules – may violate the integration mandate" and that "budget cuts or otherwise permissible actions may also violate obligations under section 504's integration mandate if they result in more favorable access to services in segregated settings than in integrated settings." Medicaid agencies note the considerable misalignment between this proposal and federal Medicaid law, under which most HCBS services are optional. They also report that the balance of expenditures between long-term care facilities and HCBS is substantially driven by factors outside of a state or territories' control, such as changes in utilization trends or patient acuity. Ultimately, Medicaid appropriations are squarely the jurisdiction of state/territory legislatures, not the Medicaid agency. This means that Medicaid agencies sometimes must make difficult choices in constrained economic environments around which benefits to prioritize. It is important that state and territory governments retain this autonomy.

As discussed in the proposed rule, the *Olmstead* decision requires states/territories to provide community-based services to individuals with disabilities when such placement is appropriate, the individual does not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities. It is important that HHS OCR continues to observe all three components of the community integration requirement, including availability of state/territory fiscal and administrative resources.

Finally, Medicaid Directors note that the proposed sixty-day effective date for the integration provisions is not feasible. If finalized, Medicaid agencies would need to evaluate the rule's implications for current program operations, providers, Medicaid members, and sister agencies focused on aging and disability. Making changes to program policies is a lengthy process: Medicaid agencies may need to amend provider contracts, seek new appropriations from their legislatures, conduct stakeholder engagement, and seek public comment. These processes would take years, not months, to complete. NAMD recommends HHS OCR set a more reasonable implementation timeframe if it proceeds with these proposals.

HHS's Recent Proposed Rules May Have Unpredictable Impacts on the Long-Term Care System

Over the past months, HHS has issued multiple proposed regulations that would impact the long-term care system, including this rule, the proposed access rule, and proposed minimum staffing standards for long-term care facilities. Among other policies, these rules would require states/territories to establish incident management systems for HCBS, create an 80 percent wage pass-through for HCBS, create significant new reporting on rates, create quantitative minimum staffing standards for facilities, and restrict states' ability to add new services to specific settings.

Independently, these rules each have a commendable aim, internal coherence, and reasonable policy proposals. Taken together, however, these rules would result in significant administrative burden on Medicaid agencies and providers and may have unpredictable impacts on the long-term care workforce.

It is important to acknowledge the realities of the long-term care workforce. Our aging population has increased demand for long-term care, with research estimating 7.9 million new job openings in direct care from 2020 to 2023. Researchers also project widespread nursing shortages by 2030, driven by a national deficit of approximately 918,000 registered nurses (RNs). This means that HCBS providers and long-term care facilities are competing for the same pool of workers.

These three rules propose different policy constructs in different parts of the long-term care system. If all three rules were finalized as proposed, HCBS providers would be subject to an 80 percent wage pass through, long-term care facilities would be subject to minimum staffing standards, and providers may face new requirements around ensuring services are equally accessible across settings. It is unclear how providers would manage these competing requirements, given existing workforce shortages.

Similarly, Medicaid agencies would face competing fiscal pressures. The proposed minimum staffing standards would almost certainly generate significant upward pressure on rates for long-term care facilities, thereby shifting state and territory spending to institutional care. Simultaneously, this rule would limit states' and territories' ability to reduce benefits or services if these cuts result in increased access to institutional care in comparison to HCBS. It is unclear how this fiscal dynamic would be managed without impacts on Medicaid benefits or eligibility groups.

Medicaid Directors support HHS's aims of rebalancing the long-term care continuum towards HCBS while improving quality in long-term care facilities. **We urge our federal partners, however, to be mindful of the potential unintended consequences of finalizing three separate proposed rules with significant impacts on the long-term care system and to carefully consider potential interactions.**

Proposed Restrictions on the Use of Quality-Adjusted Life Years and Similar Value Assessment Methods May Have Unintended Consequences

Medicaid Directors Report Serious Concerns Over Rising Drug Costs

Medicaid Directors have serious concerns over increases in prescription drug costs. In fiscal year 2021, Medicaid agencies spent $38.1 billion on outpatient prescription drugs, representing a 45 percent increase since 2018. This trend is projected to accelerate as new high-cost cell and gene therapies enter the market. These therapies have the potential to transform care for patients but may also create significant fiscal challenges for Medicaid agencies.

Like other payors, Medicaid agencies are tasked with making decisions around how to allocate health care resources. Medicaid programs are limited to the budgets that are appropriated by their state or territory legislatures, which, in turn, are limited by balanced budget requirements and local economic conditions. This means that large increases in prescription drug spending can crowd out other important Medicaid services, leading to benefit or eligibility cuts elsewhere in the program.

Due to the constraints of the Medicaid Drug Rebate Program (MDRP), Medicaid agencies have limited tools to ensure they are paying a fair and sustainable price for prescription drugs. Some of the most successful models for managing rising drug costs are Drug Utilization Review Boards, which conduct cost-effectiveness reviews and negotiate with manufacturers for supplemental rebates. These models help Medicaid agencies get a fair price for new therapies, which allows limited resources to support to the wide range of benefits – including HCBS – that Medicaid programs cover.

Cost-Effectiveness Analyses Help Ensure the Sustainability of the Healthcare System

Cost-effectiveness analyses are a central tool in health policymaking. Cost-effectiveness analyses allow policymakers to compare different treatment options, including new prescription medications, to ensure that effective treatments are valued fairly and that taxpayer dollars are not spent on treatments that don't offer substantial benefits. Medicaid agencies operate under set budgets, so it is crucial that they make informed choices around how to allocate resources. When Medicaid agencies pay unfair costs for new treatments, this represents an opportunity cost: Medicaid dollars that go to drug manufacturers cannot be spent on other Medicaid benefits and eligibility groups.

Quality-adjusted life years (QALYs) are one of the most commonly used cost-effectiveness measures in academic research. QALYs quantify impacts on both morbidity and mortality, allowing researchers to compare treatments "apples to apples" across different conditions. Many European countries – which spend significantly less on health care than the US but have consistently better health outcomes – use QALYs and similar value assessment methods to determine fair prices for new drugs.

In this rule, HHS OCR raises concerns around potentially discriminatory use of QALYs, as QALYs weight a year of life extension by disability status. NAMD appreciates HHS's aim of preventing discrimination in decisions around benefit coverage. It is important to understand, however, that Medicaid agencies consider a wide range of evidence when making policy decisions around coverage and utilization management, including peer-reviewed research, information about relevant clinical benefits and harms, recommendations from physicians and professional societies, and patient values and preferences. **NAMD strongly believes that this kind of multi-factor decision-making is appropriate. There are circumstances in which analyses that use QALYs may**

be an appropriate, productive, and non-discriminatory component of multi-factor decision-making.

In this rule, HHS OCR proposes restrictions on the use of QALYs and other measures that discount the value of life extension on the basis of disability. NAMD's understanding is that this proposal would allow Medicaid agencies to continue using measures like the Equal Value of Life Years Gained (evLYG) metric, which values a year of life extension the same across patient populations. **It is crucial that that Medicaid agencies be allowed to use the evLYG and similar cost-effectiveness measures without restriction, and we recommend that HHS OCR explicitly clarify that use of this type of measure would not be considered a violation of Section 504.**

Medicaid Agencies Must Be Allowed to Use Academic Research

In the proposed rule, HHS OCR states that "otherwise making use of [QALYs and similar value assessment] analyses to inform reimbursement or utilization management decisions even if they are not by themselves dispositive" may be a violation of Section 504. **NAMD has serious concerns that this provision may prevent Medicaid agencies from being able to use peer-reviewed academic research to inform coverage decisions.**

As discussed above, the QALY is one of the most commonly used cost-effectiveness measures in academic research. Although academic researchers acknowledge the limitations of the QALY, there are not widely used alternatives in peer-reviewed literature, and researchers report feasibility concerns about proposed alternative measures. Notably, some of the measures discussed as alternatives in the National Council on Disability's report on QALYs (such as the Patient Perspective Value Framework) are theoretical and have not been operationalized. This report also discusses the use of multi-criteria decision analyses as an alternative to the QALY. There is, however, significant debate in academic research around if multi-criteria decision analyses should use cost-effectiveness measures (including QALYs) as a component of these analyses or if multi-criteria decisions analyses should be compared to conventional cost-effectiveness analyses.

Due to these dynamics, many peer-reviewed health services articles reference QALYs and similar value assessment methods. **NAMD is highly concerned that the proposed provision would restrict Medicaid agencies from reviewing studies that contain references to QALYs.** In the proposed rule, HHS states that they do not intend to have a "chilling effect" on academic research. However, most health services research explicitly aims to inform policymaking, so if policymakers were restricted from even reviewing academic research, the impact of this research would be severely attenuated.

Medicaid agencies and Drug Utilization Review Boards make the best decisions when they are allowed to consider all available evidence – including academic analyses. Given the lack of widely utilized alternatives to the QALY in health services research, HHS's proposed provision would prevent Medicaid agencies from reviewing academic research on new treatments. **Given these dynamics, NAMD urges HHS to clarify that academic research – including research that references QALYs – can be used to inform multi-factor Medicaid agency decision making.**

HHS Should Provide Technical Assistance for Medicaid Agencies on the WCAG 2.1 Web and App Accessibility Standards

In this rule, HHS OCR proposes to adopt the Web Content Accessibility Guidelines (WCAG) 2.1 as the technical standard for web and mobile application accessibility under Section 504. Medicaid agencies are committed to ensuring that their websites and mobile apps are accessible and many states have made significant improvements around website accessibility. **To support states and territories in meeting the WCAG 2.1 standards, NAMD strongly encourages HHS to provide technical assistance and other resources.**

Although Medicaid agencies support web accessibility, they often lack dedicated resources around staff training, accessibility reviews, and software. HHS should provide hands-on technical resources through the U.S. Digital Service and other entities to support states and territories in meeting these requirements. Medicaid agencies report specific challenges around creating accessible data collection forms.

NAMD supports HHS's proposed exceptions for archived web content, pre-existing conventional electronic documents, web content posted by third parties or linked from a recipient's website, and conventional electronic documents that are about a specific individual. NAMD also supports an exception for pre-existing social media posts and videos that were posted before the effective date of the rule. These exceptions will help increase the feasibility of the proposed provision.

Medicaid agencies also note the importance of ensuring all CMS resources meet WCAG 2.1 accessibility standards. Medicaid agencies often link to State Plan Amendment approval letters and CMCS guidance to ensure members and providers are informed of programmatic changes, so it is important that these CMS documents meet accessibility standards.

Conclusion

Medicaid Directors strongly support HHS's aim of preventing discrimination on the basis of disability. However, some of the proposed provisions, including the integration and value assessment provisions, may have unintended consequences on providers and on Medicaid agencies. NAMD strongly encourages HHS to preserve Medicaid agencies'

ability to consider academic research when making coverage decisions. NAMD also encourages HHS to pursue more targeted policy interventions that address on-the-ground barriers to HCBS access and to carefully consider interactions between the proposed access rule, proposed minimum staffing standards, and this rule.

Thank you for the opportunity to provide comments on this proposed rule. NAMD looks forward to continuing to work with HHS to ensure Medicaid members are protected from discrimination on the basis of disability.

Sincerely,

Cynthia Beane, MSW, LSCSW

Cindy Beane
NAMD Board President
Commissioner
West Virginia Department of Health and Human Resources

Lynnette R. Rhodes

Lynnette Rhodes
NAMD Board President-Elect
Executive Director
Medical Assistance Plans Division,
Georgia Department of Community Health