



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

January 14, 2019

VIA ELECTRONIC SUBMISSION

The Honorable Alex Azar
Secretary, U.S. Department of Health and Human Services
200 Independence Ave SW
Washington, DC 20201

RE: Public Comments on Medicaid Managed Care Rule (RIN 0938–AT40, CMS–2408–P)

Dear Secretary Azar:

The co-chairs of the Consortium for Citizens with Disabilities (CCD) Health Task Force write in response to the proposed rule, Medicaid Program; Medicaid and Children’s Health Insurance Plan (CHIP) Managed Care, RIN 0938–AT40, CMS–2408–P. CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Over the last 15 years, states have increasingly chosen to cover long-term services and supports (LTSS) for people with disabilities, older adults, and children and adults with special health care needs through Medicaid managed care.¹ The number of states with MLTSS programs has tripled in that time, from eight in 2004 to 24 in January 2018.² As we noted in our comments on the proposed rule finalized in 2016, people who use LTSS often face particular challenges in managed care, including inaccessible plan information and services, discrimination in enrollment and provision of services, difficulty finding appropriate providers in network, and

¹ Consortium for Citizens with Disabilities Health and Long Term Services and Supports Task Forces Comments on CMS-2390-P Medicaid and Children’s Health Insurance Program (CHIP) Programs; Medicaid Managed Care, CHIP Delivered in Managed Care, Medicaid and CHIP Comprehensive Quality Strategies, and Revisions Related to Third Party Liability (July 27, 2015), <http://www.c-c-d.org/fichiers/CCD-Comments-on-NPRM-Final.pdf>.

² MACPAC, Managed Long-Term Services and Supports: Status of State Adoption and Areas of Program Evolution (June 2018), <https://www.macpac.gov/wp-content/uploads/2018/06/Managed-Long-Term-Services-and-Supports-Status-of-State-Adoption-and-Areas-of-Program-Evolution.pdf>.

barriers to navigating managed care generally. We are concerned about several of the proposals in this notice of proposed rule-making and detail our concerns by section below.

1. § 438.3: Standard Contract Requirements, § 438.4: Actuarial Soundness Standards, § 438.6: Special Contract Provisions Related to Payment, and § 438.7: Rate Certification Submission

As mentioned above, managed care organizations often have little experience providing LTSS for people with disabilities and there have been serious implementation issues when states have “carved in” LTSS.³ Part of the challenge in this transition has been establishing actuarially sound rates, since LTSS needed by people with disabilities are generally paid exclusively by Medicaid, leaving LTSS providers with little to no experience with rate-setting.⁴ The failure of states to gather and analyze baseline data and to invest sufficiently in targeted quality measures for LTSS complicates the process for establishing adequate and accurate rates.⁵ Workforce capacity issues are also endemic.⁶

Most importantly, states often see capitated managed care primarily as a mechanism to reduce (and regularize) expenses, instead of a means to improve efficient access to services. In the context of LTSS—where people with disabilities and special health care needs by definition have higher health care costs than other populations—the importance of establishing adequate rate setting mechanisms to ensure that managed care companies have the resources to cover needed services cannot be overstated. And because capitated entities have a built in financial incentive to simply refuse to cover needed services, effective oversight and transparency to

³ See e.g. Centers for Medicare & Medicaid Services, Letter to Kansas Medicaid Director (Jan. 17, 2017), (denying a waiver extension request because “CMS received a significant number of complaints and concerns from beneficiaries, providers, and advocates regarding the operation of the KanCare demonstration that were substantiated during a CMS onsite review in October 2016”).

⁴ MACPAC, *supra* note 2, at 59 (“Unlike managed care for medical services, for which providers may be used to dealing with Medicaid plans and commercial insurance plans for people with employer-sponsored insurance, few payers other than Medicaid cover LTSS. Thus, transitioning to managed care may mean that, for example, instead of submitting claims to the Medicaid agency, LTSS providers must learn to contract with plans for rates—something they may have never done before—and adjust to new billing systems. This might be particularly challenging in circumstances where several managed care companies operate in the same region or state, each with its own processes and interfaces for payment and billing”).

⁵ *Id.* at 48 (“As states gain MLTSS experience, attention is turning to program outcomes. Although there is modest evidence of some successes, there are many unanswered questions. Limited baseline data and insufficient targeted quality measures have made evaluation difficult. Efforts to implement new quality measures and collect better encounter data may improve monitoring and oversight of MLTSS in the future”).

⁶ *Id.* at 51 (“In addition, high turnover and shortages among the personal care workforce present a challenge to all states, particularly as demand for HCBS grows with an aging population (Stone and Harahan 2010”).

prevent such abuses – through quality measurement and effective appeals – must be in place.⁷ States’ failure to acknowledge these potential problems and to involve stakeholders in planning for the transition to managed care has led to deaths and serious, life-threatening impacts on people with disabilities and has decimated decades old community-support networks for people with disabilities in several states. Transparency and public access to and input on RFIs, applications, contracts, rates, and other aspects of the managed care contracting process is crucial to ensure adequate rate setting and robust accountability for the spending of public funds.

While we do not oppose the changes that CMS proposes in these sections, we urge CMS to take a more active role in enforcing statutory requirements for adequate rates that ensure equal access. Oversight in the area of LTSS is particularly weak, leaving people with disabilities even more at risk of facing budget-driven cuts to services that they need. This can result in worse health outcomes as well as unnecessary institutionalization, costing States and taxpayers more in the end. In addition, as we recommend further below, CMS should focus on ensuring there is national, mandated, comparable, quality data related to LTSS that will enable better rate setting and contracting.

2. § 438.10: Information Requirements

We oppose CMS’s proposal at § 438.109(d)(2) and (3) to eliminate the requirement to include taglines in large print and prevalent non-English languages on “all written materials” and instead require these taglines only on materials that “are critical for obtaining services.” Taglines are absolutely essential for people with vision disabilities to obtain the information they need regarding Medicaid coverage and services. Permitting states to include taglines only on documents they deem essential for “obtaining services,” opens the door for inconsistent, subjective, and possibly discriminatory policies. As a result, some people with vision disabilities will miss out on information they need to make informed decisions about their care.

We also oppose CMS’s proposal at § 438.109(d)(2) and (3) to change the definition of “large print” from “no smaller than 18 point font” to “conspicuously visible.” This subjective standard provides no clarity on what may be “conspicuously visible” for vision-impaired individuals who would be at risk of losing access to critical consumer information vital to their healthcare needs. CMS’s argument that eliminating the 18 point font standard will lead to shorter and more user friendly materials ignores the needs of people with disabilities who deserve equal access to information about Medicaid coverage and services.

⁷ Watchdog.org, Michael Carroll, Virginia facing unexpected \$462 million in additional Medicaid expenses (Nov 14, 2018), https://www.watchdog.org/virginia/virginia-facing-unexpected-million-in-additional-medicaid-expenses/article_2afcef2a-e74c-11e8-9910-8fc4254970f2.html (“About \$260 million of the total stemmed from the state’s projected 3.5 percent cost saving from moving to a managed-care system, according to Gray, who said that no states have reaped such savings during the first three years of managed care. “Rates have to be actuarially sound under federal law,” he said. “These I don’t think were.”)

We also oppose CMS's proposal at § 438.10(f)(1)) to give individuals less notice of a provider's termination. People with disabilities rely heavily on specialists, require access to limited physically and programmatically accessible providers, and often face provider workforce shortages as discussed above. For some specialties, such as behavioral health, it could take months to find and see a new provider. People with disabilities living in rural areas face even higher hurdles. Delays or breaks in coverage can be a matter of life, death, and independence for millions of Americans with disabilities, and their families and friends. The current requirement of 15 days to post notice of termination is arguably too long to provide people with disabilities the time they need to identify alternative providers. Delaying the notice requirement more is unacceptable. Even if the plan and provider continue to negotiate and the situation becomes moot, it is extremely irresponsible to not give people, especially those with disabilities or chronic conditions, as much time as possible to locate new providers.

Likewise, the requirement that provider directories indicate a provider's cultural competence training is crucially important for people with disabilities. We oppose the proposal at § 438.10(h)(1)(vii)) to eliminate such information from the provider directory. Disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, and does not occur uniformly among racial and ethnic groups. Cultural competency is extremely important to our populations and should continue to be indicated in the provider directory to facilitate enrollees decision-making about which providers can best serve their particular needs.

We also oppose the proposed reduction in access to print directories at § 438.10(h)(3). CMS admits in the discussion that this change would particularly affect enrollees with disabilities, but it will also impact rural and older adults disproportionately as well. Access to online information is uneven across states and populations. Nationwide, half of households with incomes under \$25,000 have either no computer or no broadband at home.⁸ We urge CMS to maintain the current standard, which is simpler than creating and monitoring special exceptions for disproportionately impacted populations.

3. § 438.68: Network Adequacy Standards

We oppose the proposal to eliminate the required time and distance standards. As we previously commented, mandatory network adequacy standards ensure that consumers can actually get needed care from their Medicaid plans and help to guide states and Medicaid plans in developing their networks.⁹ If states find other criteria, such as provider-to-enrollee ratios to

⁸Camille Ryan & Jamie Lewis, American Community Survey Reports, *Computer and Internet Use in the United States: 2015* 9 (2017), <https://www.census.gov/content/dam/Census/library/publications/2017/acs/acs-37.pdf>; Rachel Garfield et al., Kaiser Family Found., *Implications of Work Requirements in Medicaid: What Does the Data Say?* (Jun. 12, 2018), <http://files.kff.org/attachment/Issue-Brief-Implications-of-Work-Requirements-in-Medicaid-What-Does-the-Data-Say>.

⁹ CCD 2015 Comments, *supra* note 1.

be useful, CMS should add those factors to the list of mandatory criteria. States currently set their own standards for network adequacy without any national guidelines. Loosening of the minimal federal standards in the current rule represents an unnecessary step backwards that will decrease accountability.

CMS's justification for this change actually supports the addition of more criteria, not the elimination of the current criteria. Telehealth services could easily be incorporated into time and distance standards—in some locations, as a matter of state law, a telehealth services must be provided in an office setting, which would include travel time for individuals utilizing the service. We also point out that telehealth, while particularly useful in rural areas, is also limited by access to broadband and other technology issues. Some populations, including older adults and people living outside metropolitan areas have lower access to the internet and computers that could affect their use of telehealth.¹⁰ Nor can or should services be limited to telehealth for certain geographic areas. Instead, we urge CMS to maintain the time and distance standards and add provider-to-enrollee ratios to these required standards. We reiterate our recommendation from our comments on the 2015 NPRM that CMS adopt specific minimum standards in all of these areas and create a federal minimum standard that allows states flexibility to implement additional standards but ensures comprehensive oversight by CMS. The other quantitative standards suggested by CMS in this proposed rule could also be incorporated into these minimum federal standards.

While we appreciate CMS's recognition that LTSS programs have "often very limited supply of providers" and that people who utilize LTSS have "potential functional limitations," this is not a reason to provide states with more flexibility, it is a reason to do *more* to ensure minimum standards are in place and enforced. We also are extremely disappointed that CMS did not convene a group of experts to help create national network adequacy standards for LTSS, subject to a robust stakeholder notice and comment process. This would allow CMS to ensure consistent standards for all provider types without weakening the standards currently in place.

We also strongly oppose CMS's decision to repeal the federal definition of specialist at § 438.68(b)(1)(iv). For people with disabilities, access to specialists can be a matter of life, death, and independence. We urge CMS to provide federal guidance to remedy any confusion, not to defer this decision to the states and eliminate an important federal baseline.

If CMS goes forward with this harmful proposal to eliminate even the basic federal standards required now, CMS should require that all state standards include standards addressing geographic distance, timeliness, and number of providers and enrollees.¹¹ Simply "encouraging" states to consider multiple standards in combination is totally insufficient. In addition, CMS

¹⁰ See Ryan and Lewis, *supra* note 8.

¹¹ See *e.g.* Community Living Policy Center, Ari Ne'eman, Managed Long-Term Services and Supports: Assessing Provider Network Adequacy (December 2018), <https://clpc.ucsf.edu/publications/managed-long-term-services-and-supports-assessing-provider-network-adequacy>.

cannot simply encourage states to solicit stakeholder input, it must mandate that states engage and incorporate feedback from stakeholders on their proposed network adequacy standards.

4. § 438.242(c): Enrollee Encounter Data

We concur with CMS’s analysis that this information is already publicly available and should be shared. We would urge additional transparency to enhance appropriate access to de-identified encounter data within the scope of what is appropriate under HIPAA and other relevant statutes for advocates and researchers. We would also urge CMS to do more to ensure the reliability of encounter data, including implementing the recommendation outlined in the recent Government Accountability Office report, including issuing sub-regulatory guidance about the circumstances under which CMS will withhold FFP for non-compliance.¹² Encounter data is extremely important, as CMS points out, for the “proper monitoring and administration of the Medicaid program, particularly for capitation rate setting and review, financial management, and encounter data analysis.”¹³

5. § 438.334: Medicaid Managed Care Quality Rating System (QRS)

We oppose these changes and urge CMS to maintain the current rules. By changing the requirement that state alternatives must be “substantially comparable” to the federal standards “to the extent feasible,” CMS is compromising data comparability and the effectiveness of a QRS in deference to state flexibility. The proposed replacement mandatory measures can never be as comprehensive as a complete and universal set of measures and will only open the door to data of limited comparability that will not allow individuals using services to accurately assess their state’s system. In addition, the proposed elimination of pre-authorization of these plans in addition to the modified public comment process create a serious concern that there will be little to no oversight of these alternative measures.

We believe that CMS should maintain and implement the current rule. We would also like to point out that the QRS must adequately account for the quality of LTSS care provided by managed care entities. Unfortunately, neither the Marketplace nor Medicare cover home and community-based services or other LTSS beyond short term stays. CMS acknowledges in the preamble that a Medicaid QRS must go beyond aligning with the Marketplace QRS or Medicare Star Rating systems, but the rule makes no specific mention of the need to incorporate LTSS measures into the Medicaid QRS. We recommend that CMS add language to the rule ensuring that any Medicaid Managed Care QRS must include performance measures related to plans’ LTSS coverage, including measures in at a minimum the three required domains listed in § 438.330(c)(1) on quality of life, rebalancing, and community integration.

6. § 438.340: Managed Care State Quality Strategy

¹² United States Government Accountability Office, MEDICAID MANAGED CARE: Additional CMS Actions Needed to Help Ensure Data Reliability (October 2018) <https://www.gao.gov/assets/700/695069.pdf/>.

¹³ 83 Fed. Reg. 57279 (Nov. 14, 2018).

We completely concur with CMS that the current definition of disability status is too narrow. However, we must point out that allowing state discretion in determining what demographic data is relevant and what should be shared will likely lead to data that cannot be compared across states or used for national analysis on health disparities. CMS should thus require States to include in their quality strategy information about how they define disability and the sources of information the state uses to share data with MCEs. We also urge CMS to issue clearer guidance and technical assistance on how states can best collect and share data on disability status in their application process or through claims data. The clear aim here is to improve consistency between states so we can obtain more comparable and complete data on how to identify and reduce health disparities people with disabilities experience. We again encourage CMS to develop national measures, which would assist with this process.

7. § 457.126: Grievance System

We oppose the change to the rules regarding continuation of benefits while an appeal is pending. Access to benefits during a pending appeal is often a matter of life and death to children with disabilities and special health care needs, in addition to being required as a matter of due process, and CMS should not finalize this proposal that puts access to benefits at risk until an appeal is finalized.

Thank you for the opportunity to comment. If you have any questions please contact Bethany Lilly (bethanyl@bazelon.org) or David Machledt (machledt@healthlaw.org), co-chairs of the CCD Health Task Force.

Sincerely,

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