

October 21, 2022

VIA ELECTRONIC TRANSMISSION

Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services (CMS)
200 Independence Avenue, SW
Washington, D.C. 20201

Re: RIN0938-AU52 – Mandatory Medicaid and Children’s Health Insurance Program (CHIP) Core Set Reporting

Dear Administrator Brooks-LaSure:

The undersigned organizations support efforts to strengthen data collection and quality reporting in Medicaid and CHIP, including mandatory state reporting of outcomes measures important to individuals using the services. It is essential to include policy changes that identify health disparities and improve health equity in these vital programs.

Generally, we represent the interests of people with disabilities of all ages, older adults, people with substance use disorders and/or mental illness, and low-income individuals and families who use Medicaid. We are members of the Disability & Aging Collaborative (DAC) and/or the Health Task Force of the Consortium for Constituents with Disabilities (CCD). The DAC is a coalition of approximately 40 national organizations that work together to advance long-term services and supports (LTSS) policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability and aging organizations and is committed to ensuring older adults and people with disabilities are able to access the support and services, including health care, they need to live in the community. 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 a society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. Together, we appreciate the opportunity to comment on the Centers for Medicare and Medicaid Services’ (CMS’s) proposed rule to implement required standardized quality reporting in the Medicaid and CHIP programs. We support robust, quality improvement practices and performance oversight in these programs, and recognize the urgent need to improve the identification and tracking of health disparities as a necessary first step to building a more equitable health system.

The COVID-19 pandemic revealed the woeful inadequacy of our health care data infrastructure to measure the disparate impact of the disease, as well as the disparate access to health care for certain marginalized groups. President Biden's administration has prioritized improving that infrastructure to inform policies that aim to lessen those inequities. While many gaps persist in the core measure sets, we appreciate that CMS has also for the first time proposed to phase-in required reporting of a group of core measures by key demographic characteristics, such as race and ethnicity, age, sex, and disability. We hope this represents the beginning of a paradigm shift that would both establish such stratified reporting as an expected standard across these programs and elevate the perspectives of beneficiaries in making decisions about what measures go into these core sets.

We expect that as CMS requires more state reporting, it will also work to develop a public-facing, easy-to-understand quality measures system for use by beneficiaries and family members so that they can quickly evaluate state, plan, and provider performance on key metrics, where they need improvement, along with opportunities for how they can participate in advocacy to accelerate progress. This would be especially useful in helping consumers choose providers and plans, though we understand the complexities of interpreting comparative performance.

Our recommendations for this proposed rule track with five general points:

- Standardized reporting of required measures should be a mandatory floor for quality measurement, and expectations for reporting should increase over time;
- Equity should be a central goal and priority of quality improvement programs. CMS should act with greater urgency to require reporting of quality measures separated by key demographics and then design interventions that hold providers, health plans, and states accountable to its equity goals;
- CMS should improve and standardize data collection to identify beneficiaries with disabilities. A methodology based on disability questions from the American Community Survey with added questions for speech-related disabilities would improve current procedures that rely on eligibility groups to define this population. Quality reporting should reflect the whole range of beneficiaries with disabilities, including the millions of people with disabilities who become eligible through other categories, such as the adult expansion or parents and caretakers;
- The process for updating and defining core measures must include meaningful representation from beneficiaries of all ages and their advocates, including people with disabilities and behavioral health disorders; and

- CMS should continue to improve quality reporting for groups that have historically been more challenging to measure, such as the 12.3 million dually eligible individuals, people who use long-term services and supports, people with substance use disorders, and people in FFS Medicaid in states that cover most people through managed care.

Section-by-Section Recommendations

§ 437.1(c) – Purpose

We find that the proposed purpose for the Child and Adult Core Sets does not accurately capture the aims embedded in the statutory language. Specifically, we believe the purpose should reference and prioritize the identification and reduction of health disparities, consistent with the statute, and emphasize that the core measure set must encourage comparative analysis at the national, state, program, and provider levels.

Section 1139A of the Social Security Act defines the Child Core measure set as “a group of valid, reliable, and evidence-based quality measures.”¹ It further clarifies that an evidence-based quality measure “shall, at a minimum, be designed to identify and eliminate racial and ethnic disparities in child health and the provision of health care” and “ensure that the data required for such measures is collected and reported in a standard format that permits comparison of quality and data at a State, plan, and provider level.”²

The statute again highlights health disparities and comparative analysis in its requirement that the initial Child Core Set, “taken together, can be used to estimate the overall national quality of health care for children, including children with special needs, and to perform comparative analyses of pediatric health care quality and racial, ethnic, and socioeconomic disparities in child health and health care for children.”³

These explicit references to health equity and multi-level comparative analysis should be reflected in the regulations defining the purpose for both Child and Adult core sets.⁴ As written, the purpose can be construed as limited to national and state-level analysis, which does not reflect the importance of quality measures for measuring specific populations, evaluating program and plan performance, and ensuring that individual providers are also delivering high quality care.

¹ 42 U.S.C. § 1320b-9a(a)(8).

² 42 U.S.C. § 1320b-9a(b)(2).

³ 42 C.F.R. § 438.330(a)(3)(D).

⁴ The statute directs the Secretary to develop the Adult Core Set “in the same manner” as the Child Core Set. 42 U.S.C. § 1320b-9b(a), (b)(5).

Recommendation: Amend § 437.1(c) as follows:

(c) *Purpose.* (1) The purpose of the Medicaid and CHIP Child Core Set and the Medicaid Adult Core Set is to measure the overall national quality of care for beneficiaries; monitor performance **and promote comparative analysis at multiple levels, including the State, program, plan and provider levels; the State-level, identify and eliminate health disparities across populations;** and improve the quality of health care.

§ 437.5 Definitions

We recommend revising the definition of behavioral health to include recovery services and name substance use disorders separately from mental health disorders. This would reflect the discussion in the preamble.

Recommendation: Insert the following additions into the definition of behavioral health at § 437.5:

Behavioral health means a beneficiary's whole emotional and mental well-being, which includes, but is not limited to, the prevention, treatment **and recovery** from mental disorders **and** substance use disorders.

§ 437.10. Child, Adult, and Health Home Core Sets

A. Consultation with Stakeholders

In § 437.10(a), CMS lays out the stakeholder process for updating the Adult and Child Core Sets and defines the parties of interest. We cannot stress enough the importance of elevating the perspectives of beneficiaries and beneficiary advocacy groups in this critical consensus-based process. One component of the definition of the core measure sets is to “allow purchasers, families, and health care providers to understand the quality of care.”⁵ Part of that understanding may come from creating reports and comparative tools that let people compare plans and providers based on quality outcomes. But another side of understanding quality of care lies in the selection and reporting process itself. This means providing beneficiaries, their families, and advocacy groups the support necessary to actively and productively engage with the technical side of quality measurement, and also ensuring that problems and shortcomings they identify receive equal consideration.

In our experience, while mandated a seat at the table, these stakeholders often get overwhelmed by providers, plan representatives, State officials, and expert measure

⁵ 42 U.S.C. § 1320b-9a(a)(8)(C).

developers in the process of developing recommendations for measure updates. This effect has been particularly salient in the disability and aging communities' long efforts to get some HCBS measures endorsed by the National Quality Forum, which is an important factor for inclusion into one of these Core Measure Sets.

While most of the tasks listed in this paragraph adhere closely to the statute, we have concerns that one of the criteria for including measures listed in subparagraph (iv) privileges State interests in a manner we feel is not reflected in the statute. Specifically, we have concerns that requiring stakeholders to choose measures that “represent minimal additional burden to States” would create substantial barriers to adding new measures to the set or requiring states to report measures by specific populations or demographic characteristics. We could not find this language reflected anywhere in the statute, which describes a “consensus” process among various stakeholders, and we feel including it in the regulation would upset the balance of stakeholder voices by privileging State interests.⁶ While the “burden” of reporting will always be a consideration, beneficiaries face serious negative outcomes if measures do not reflect their priorities and needs, especially if there is not adequate oversight to monitor care quality across the system. It is due to such repeated complaints about “administrative burden” that we do not yet have regular reporting of health disparities in our Medicaid quality system. We urge CMS to delete this unjustified language in § 437.10(a)(2) and add a cross-reference to the Core Set purpose to emphasize that consideration of health equity remains a priority in the ongoing development and advancement of core measures.

Recommendations:

Amend § 437.10(a)(2)(i) as follows:

- (i) Establish priorities for the development and advancement of the Core Sets ***consistent with 437.1(c) [as amended in above comments]***

Amend § 437.10(a)(iv) as follows:

- (iv) Ensure that all measures included in the Core Sets reflect an evidence-based process including testing, validation, and consensus among interested parties; are meaningful for States; ***and*** are feasible for State-level and/or Health Home program level reporting as appropriate.; ~~and represent minimal additional burden to States.~~

⁶ 42 U.S.C. § 1320b-9a(b)(5).

We also identified what appears to be an oversight in the types of “interested parties” that CMS must consult as it updates each core measure set.⁷ The proposed regulation requires consultation with pediatricians, children’s hospitals, national consumer groups representing children and national organizations representing purchasers of children’s health care, among others.⁸ This parallels language from § 1139A(b)(3), but is specific to the Child Core Set.⁹

However, proposed § 437.10 creates standards for the Adult and Health Home Core Sets in addition to the Child Core Measure Set. Logically, the “interested parties” the Secretary must consult for the Adult Core Set should reflect organizations and providers appropriate for the adult Medicaid population similar to how interested parties for the Child Core Set reflect organizations appropriate for children and adolescents. The statute establishing the process for the Adult Core Set instructs the Secretary to create an Adult Medicaid Quality Measurement Program “in the same manner as the Secretary did for the pediatric quality measures program under section 1139A(b).”¹⁰ This does not mean the stakeholder lists must be identical but rather that the process must be parallel.

As written, the proposed regulation does not require the Secretary to consult with national organizations representing adults as part of the process to update the Adult Core Set. But it does require consultation with national organizations representing children for updates to the Adult Core Set. We do not believe this was CMS’s intent. The Supreme Court has found that “No rule of [statutory] construction necessitates our acceptance of an interpretation resulting in patently absurd consequences.”¹¹

The proposed regulation must be amended to require consultation with interested parties as appropriate for the populations covered by each measure set. For the Adult and Health Home measure sets, the list of required interested parties in the regulation must include national organizations that represent adults, including adults with disabilities and adults with chronic conditions and behavioral health conditions, and organizations representing the populations covered by the health home state plan option, respectively.

B. Population-Level Reporting

Standardized quality measures across the Medicaid program are critical to ensuring high-quality care for recipients. To accomplish this goal, this proposed rule mandates the inclusion in Core Set measures of specific populations historically excluded from

⁷ 87 Fed. Reg. 51328 [proposed 42 CFR §437.10(e)].

⁸ *Id.*

⁹ 42 U.S.C. § 1320b-9a(b)(3).

¹⁰ *Id.*

¹¹ *United States v. Brown*, 333 U.S. 18, 27 (1948).

reporting, such as persons dually eligible for Medicare and Medicaid. Specifically, the rule would require the Secretary to annually define measures that states must report for specific populations, including at least the population dually enrolled in Medicare and Medicaid, people receiving services through specific delivery systems, and people receiving services in different types of healthcare settings or provider-types, such as Federally Qualified Health Centers and other safety-net providers. We strongly support this proposed provision as it could greatly enhance the specificity and comprehensiveness of Medicaid quality reporting.

Including the 12.3 million persons eligible for both Medicare and Medicaid in Core Set reporting will advance state-based efforts to identify beneficiaries' needs and develop complementary strategies to improve their health outcomes.¹² This group accounts for a much larger share of Medicaid spending than its share of the Medicaid population and generally has significantly higher health needs. More granular analysis of quality measures is especially important for the dually eligible population, as unique needs stemming from the demographic diversity of dually eligible beneficiaries and poor coordination between the Medicare and Medicaid programs puts them at increased risk of poor health and utilization of high-cost services.

In a September 2021 analysis of HEDIS measures for persons enrolled in Medicare Advantage (MA) Plans, persons dually eligible for Medicare and Medicaid faced substantial, "widespread" disparities in clinical care with "worse results," and they "often received worse clinical care" than Medicare-only MA enrollees.¹³ The largest disparities were in the HEDIS measures of follow-up after hospitalization for mental illness and potentially harmful drug disease interactions. Better reporting of the Medicaid Core sets will help reveal the full scope of these disparities and inform better care coordination for people who are dually eligible.

We strongly support the analysis of quality measures inclusive of dually eligible individuals by key demographic factors, such as race and ethnicity, as well as by delivery systems and provider types to allow for the deployment of targeted strategies that better account for the needs of these beneficiaries. Compared to Medicare-only recipients, persons dually eligible are more likely to be female, Black or Latinx, experience higher rates of chronic disease, utilize high-cost emergency services, and

¹² CMS, MMCO, *Data Analysis Brief: Medicare-Medicaid Dual Enrollment 2006 through 2019* (2020), <https://www.cms.gov/files/document/medicaremedicaidualenrollmenteverenrolledtrendsdatabrief.pdf>.

¹³ CMS Off. of Minority Health, *Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility or Eligibility for a Low-Income Subsidy*, vii-viii (Sept. 2021), <https://www.cms.gov/files/document/2021-delis-national-disparities-stratified-report.pdf>.

be limited in English proficiency.¹⁴ We also suggest expanded data disaggregation, beyond the scope of this proposed rule, of Medicare and Medicaid data by demographic characteristics and delivery systems to better understand utilization, access, and quality for beneficiaries.

As the proposed rule indicates, states face barriers such as “additional work to obtain and analyze Medicare utilization data” that can hinder reporting compliance.¹⁵ Ongoing challenges surrounding states’ ability to link and analyze Medicare and Medicaid data currently prevent robust analysis of service quality. Insufficient data coordination makes designing appropriate services for beneficiaries harder, often resulting in poorer quality of care. States must develop the capacity to link Medicare and Medicaid data, not solely for the core measures outlined in this proposed rule, but to further integration efforts for dually eligible individuals. But they cannot do this alone. CMS should encourage states to develop the data infrastructure needed to link Medicare and Medicaid datasets promptly.

States need CMS to provide technical assistance to help states develop the data infrastructure needed to link Medicare and Medicaid datasets. The suggestions outlined in the proposed rule, including one-on-one sessions, written guidance, measure specification, coding assistance, site visits, webinars, learning collaboratives, and shared best practices from states, can help ensure state compliance with reporting requirements. We also encourage CMS to explore technological interventions, such as open-source tools, that could be implemented at the federal and state levels to facilitate the integration of Medicare and Medicaid databases.

We also support improved and expanded collection of data on people with disabilities. This diverse population faces many barriers to accessing care and merit better tracking of health disparities in Core measures that may differ from the rest of the Medicaid population. Current procedures that rely on eligibility groups or on medical diagnoses in patient record to define this population fall short of recognizing the scope and diversity of beneficiaries with disabilities. We know, for example, that millions of people with disabilities become Medicaid eligible through categories that are not specific to disability, such as expansion adults and parents and caretaker groups, and so may be left out from disability-specific quality reporting.¹⁶

¹⁴ ATI Advisory and Arnold Ventures, *A Profile of Medicare-Medicaid Dual Beneficiaries* (2022), <https://atiadvisory.com/wp-content/uploads/2022/06/A-Profile-of-Medicare-Medicaid-Dual-Beneficiaries.pdf>.

¹⁵ 87 Fed. Reg 51317 [proposed 42 C.F.R. §437.10(b)].

¹⁶ David Machledt, Nat. Health Law Prog., *The Faces of Medicaid Expansion: Filling Gaps in Coverage* (2017), <https://healthlaw.org/resource/the-faces-of-medicare-expansion-filling-gaps-in-coverage/>.

We recommend that CMS shift to a methodology based on disability questions from the American Community Survey with added questions for people with speech-related or other communication disabilities who cannot rely on speech to be understood on all Medicaid applications, redeterminations, beneficiary surveys, or grievance attempts.¹⁷ These changes would allow for a more robust reporting of disparities related to the diverse array of people with disabilities and prepare the way for meeting the specific accommodation needs of this diverse group so they can enjoy equally effective healthcare.

C. Length of Phase-in for Reporting by Population Groups

This proposed rule allows 5 years for states to build their capacity to report measures separately for key populations and demographic characteristics, and grants considerable discretion to the Secretary to define the scope of those required measures. We realize that it will take time to implement some of these changes and bring states up to speed, but we also recognize the urgency of the ongoing disproportionate and frankly discriminatory impacts of our health care system. It has been more than 12 years since the passage of the ACA § 4302 that – had it been funded – would have required collecting and reporting of demographic data in Medicaid to analyze health disparities at the federal and state level.¹⁸ In the intervening years, progress has come in baby steps.

Given the general 90% federal match for upgrading computer systems to do this kind of reporting, it would not be overly burdensome to establish a tighter window for phasing in reporting on health disparities. NCQA, which is also implementing required demographic level reporting for HEDIS measures, plans on a 3-year phase-in for 15 measures.¹⁹ We think a comparable period would appropriately match the technical challenges with the urgent need to use valid health disparities data to inform interventions that strengthen health equity.

¹⁷ There is currently no way to know how many Medicaid recipients are being denied access to effective communication. When they are denied access to effective communication, people cannot effectively communicate abuse, pain, discomfort, a desire to live elsewhere, a desire to spend their days doing something else, or any type of self-determination.

¹⁸ Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, 124 Stat. 119, § 4302 [amending 42 U.S.C. § 300k(b) & (c)].

¹⁹ Margaret E. O’Kane et al., *The Future of HEDIS*[®], 26 (June 22, 2021), <https://www.ncqa.org/wp-content/uploads/2021/06/2021-0622-Future-of-HEDIS.pdf>.

§ 437.15. Annual Reporting on the Child, Adult, and Health Home Core Sets

We strongly support frequent public reporting of core measures, at least annually. We encourage the Secretary to publish standardized core measures with appropriate national benchmarks that permit comparisons across states and over time. While the child and adult Medicaid populations differ substantially across states due to varying eligibility thresholds, it is important to establish expected standards. Better demographic reporting may also make it easier to make cross-state comparisons that account for coverage differences.

As CMS improves demographic data collection through T-MSIS and its ability to report some of the Core measures for the states, we also encourage focused reports that highlight population disparities, including analysis of disparities for beneficiaries with intersectional identities who may face increased health inequities, such as people of color with disabilities. Most current reporting on disparities is limited to single factors that do not account for compound discrimination. Understanding how multiple identities affect access to and quality of health care is necessary to inform better ways to direct resources to improve Medicaid and CHIP programs.

Over the longer term, our advocacy seeks to advance whole-person health and wellness for all Medicaid beneficiaries. This requires communication, sharing, coordination, and ultimately integration of health and wellness practices and measures with specialized Medicaid programs (such as HCBS, programs serving persons dually eligible for Medicare and Medicaid, persons served in the behavioral health systems, and persons with a variety of co-occurring conditions and diagnoses). The development and reporting of Medicaid and CHIP Core measure sets should prioritize measures that provide data on how well state programs fulfill the goals to provide more seamless and integrated health care.

We also urge CMS to reconsider its policy to limit public reporting of voluntary Core measures to measures reported by at least 25 states.²⁰ This arbitrary threshold reduces transparency and may also create barriers to more widespread adoption of some quality measures. We recommend a much lower threshold for public reporting, perhaps 10 states. The statute only requires that core measures are “in use,” not that a majority of states use them.²¹

Finally, we recommend that CMS streamline the language in § 437.15(a). The statute refers to voluntary reporting on the initial adult core set and requires reporting on

²⁰ 87 Fed. Reg. 51308.

²¹ 42 U.S.C. § 1320b-9a(a)(2).

behavioral health measures in the Adult Core Set by 2024.²² It does not, however, preclude CMS from using its authority under § 1902(a)(4) to require reporting on other adult core measures or other quality measures generally. For example, we believe that at a future date, CMS could and should require reporting on specific measures in the HCBS Core Measure Set or on adult vaccinations and preventive care using its authority under § 1902(a)(4) and (6).

Recommendation: Delete the following phrase from 437.15(a)(i):

(i) Must report annually, by December 31st, on all measures ~~on the Child Core Set and the behavioral health measures in the Adult Core Set~~ that are identified by the Secretary pursuant to § 437.10(b)(1)(iii) of this subpart.

§ 437.20 State Plan Requirements

While this section requires attestations that generally authorize CMS to withhold Medicaid funding from states that do not comply with quality reporting requirements, CMS should develop more explicit guidance outlining specific, graduated enforcement mechanisms for states that remain out of compliance.²³ In other areas of oversight, compliance has been delayed due to a lack of clear consequences for States and other entities that fail to comply, and the urgency of these needed oversight mechanisms demands prompt State action.

Conclusion

Older adults, persons dually eligible for Medicare and Medicaid, and people with disabilities of all ages face unique challenges accessing quality care and have been largely left out of quality measure reporting. With this proposed rule, CMS has taken important steps to renew focus on identifying and tracking health disparities and to expand the scope of quality measurement to encompass some of these smaller, often overlooked groups. A strong push for more focused quality measurement that can identify disparities for specific populations will inform future targeted interventions. Still, even more urgency is needed.

As quality measurement grows increasingly important with ongoing shifts toward capitated managed care and value-based payment initiatives linked to performance metrics, CMS must ensure that care quality and access for marginalized groups are fairly represented in core measures. In future guidance and implementation, we urge

²² 42 U.S.C. § 1320b-9b(b)(3).

²³ 87 Fed. Reg. 51319 [Discussion explaining CMS's authority to withhold Medicaid funding for noncompliance].

CMS to continue to develop – or commission development of – more outcomes measures that matter to beneficiaries, including measures that support whole-person health and wellness.

In the meantime, we hope CMS accepts our recommendations to implement these changes in Medicaid and CHIP quality reporting. If you have any questions, please contact David Machledt, National Health Law Program (machledt@healthlaw.org).

Sincerely,

Access Ready

American Association on Health and Disability

American Association of People with Disabilities

American Physical Therapy Association

The Arc of the United States

Association of Assistive Technology Act Program

Autism Society of America

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

The Bazelon Center for Mental Health Law

Caring Across Generations

CommunicationFIRST

Community Catalyst

Disability Policy Consortium

Disability Rights Education and Defense Fund (DREDF)

Epilepsy Foundation

Family Voices

Justice in Aging

Lakeshore Foundation

Medicare Rights Center

Muscular Dystrophy Association

National Association of Councils on Developmental Disabilities

National Center for Parent Leadership, Advocacy, and Community Empowerment
(National PLACE)

National Disability Institute

National Disability Rights Network (NDRN)

National Health Law Program

National Association of State Head Injury Administrators

Spina Bifida Association

TASH