



July 6, 2021

Shalanda Young
Acting Director
Office of Management and Budget
725 17th Street, NW
Washington, DC 20503

Re: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government

Dear Acting Director Young:

Thank you for the opportunity to comment on the Office of Management and Budget's (OMB) Request for Information (RFI) entitled, "Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government."

Our organizations represent millions of patients facing serious, acute and chronic health conditions across the country. Our organizations have a unique perspective on what patients need to prevent disease, cure illness and manage chronic health conditions. Our breadth enables us to draw upon a wealth of knowledge and expertise that can be an invaluable resource in this discussion. We urge the federal government to make the best use of the knowledge and experience our patients and organizations offer in response to this RFI.

Our organizations applaud recent executive orders and the RFI's broad reach across all government agencies, programs and funding. Our organizations are committed to working with you to advance

equity and support for populations that have been marginalized based on race, ethnicity, gender identity, sexual orientation, disability status, and country of origin.

In March of 2017, our organizations agreed upon three overarching principles¹ to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need, including all the services in the essential health benefit (EHB) package. While our comments below will focus on health coverage, we acknowledge that the patients we represent are impacted by the effects of systemic racism in housing, finance, environment, criminal justice and judicial systems, and other federal program and policy areas. There is evidence that systemic racism in these areas adversely impacts health in multiple ways.

E.O. 13985 calls for the Federal Government to “pursue a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality.” The Centers for Medicare and Medicaid Services (CMS) must be an essential element of that approach. For example, Medicaid covers health and long-term care services for over 73 million Americans who are disproportionately people of color.

Our organizations offer the following comments on three areas of the RFI in which the Administration can take action to advance equity in federal healthcare programs, particularly Medicaid and the Affordable Care Act (ACA) Marketplace: Equity Assessments, Barrier and Burden Reduction, and Stakeholder and Community Engagement.

Equity Assessments and Strategies

Using Data to Inform Equitable Public Policy

Data are crucial for identifying disparities and where policy interventions are needed to address inequities. Data should be consistent across federal agencies and programs, to the extent possible, and reflect the full range of demographic characteristics of populations that have been marginalized.

As OMB examines data collection efforts across the federal government, our organizations urge you to strengthen current standards for reporting federal data on race and ethnicity. The current OMB categories for race and ethnicity are not homogenous. The U.S. population has continued to become more racially and ethnically diverse since OMB's last revision of the Standards for the Classification of Federal Data on Race and Ethnicity. Aggregating heterogeneous racial and ethnic subpopulations in the collection of public health data can obscure health disparities. Ensuring detailed race and ethnicity data are available, as well as accurate, objective, and impartial, is critical to evidence-based health equity work. Adding subgroups to the required minimum reporting categories can provide opportunities for improved reporting of information pertaining to the health of the nation's diverse population.

Within CMS, the agency should first evaluate data currently collected and the process for its collection. Where it is not already being done and where it is possible, state and federal entities should strive to collect self-reported data on race, ethnicity, gender, disability and sexual orientation. When collecting

¹ Consensus Health Reform Principles. Available at: <https://www.lung.org/getmedia/a80ca017-c045-4415-87d9-97a952ff399c/020121-healthcare-principles43logos.pdf>.

these data though, it should be made clear why data are being collected and how the data will be used. Individuals collecting this information should undergo cultural competency and skilled communication training to regain trust and minimize the trauma and stigma that underserved communities may experience when interacting with government entities.

The existing data show that there is a need for more and better data, but the agency certainly has enough already to recognize there is a fundamental equity problem that requires action. In addition, while data collection is essential, it is not sufficient. These data must be used to inform policy and efforts to eliminate disparities and promote equity.

Barrier and Burden Reduction

Ensuring that CMS Does Not Approve State Medicaid Policies that Undermine Equity

States have broad discretion to administer their Medicaid programs subject to federal requirements. CMS has responsibility for ensuring state compliance with these requirements. CMS issues regulations and sub-regulatory guidance, including State Medicaid Director (SMD) and State Health Official (SHO) letters, to explain and implement these requirements. CMS's primary tool for ensuring compliance with these requirements is review and approval of State Plan Amendments (SPAs). In addition, CMS, acting on behalf of the Secretary, has the authority under section 1115 of the Social Security Act to waive federal requirements to enable states to conduct demonstrations that are "likely to promote the objectives of" Medicaid.

In issuing regulations and sub-regulatory guidance, CMS should, to the extent the Medicaid statute allows, ensure that the policies set forth in regulations and SMDs and SHOs advance equity. At a minimum, CMS should not issue any regulation or SMD or SHO that would be likely to undermine equity or lead to further inequities. As an example of sub-regulatory guidance that would not meet the criteria, in January 2018, CMS issued a SMD that encouraged states to submit proposals for work and community engagement requirements in their Medicaid programs, requirements that disproportionality impact Black women and families.²

In reviewing SPAs and applications for new section 1115 demonstrations (or extensions), CMS should assess whether proposed state Medicaid policies would be likely to undermine equity. Specifically:

- CMS should require that when a state submits a SPA that would reduce eligibility or benefits, or increase cost-sharing, the state must provide an assessment of the likely impact of the proposed SPA on equity, including a stratification of the beneficiaries that would be affected by race/ethnicity. CMS should post the proposed SPA and accompanying explanation on Medicaid.gov when received. If federal law permits, CMS should deny approval of a SPA that would likely undermine equity.
- CMS should require that when a state applies for a new section 1115 demonstration, or an extension of an existing demonstration, the state provide the information necessary for CMS to assess the likely impact of the proposed demonstration or extension on equity. If CMS determines that the proposed demonstration or extension would undermine equity, it should disapprove the proposal. For example, Indiana's "Healthy Indiana Plan (HIP) 2.0" section 1115 demonstration evaluation found that black HIP members "had a higher likelihood of disenrolling

² <https://ccf.georgetown.edu/2020/06/02/racial-health-inequities-and-work-requirements/>

due to non-payment of premiums” and of moving to the lower tiered benefit package where individuals are subject to copayments for most services.³ Moving forward, Indiana’s demonstration, and others like it, should not be allowed. Policies that would likely undermine equity are not “likely to promote the objectives of” Medicaid.

Additionally, CMS should promptly take action that will help states implement expansions of coverage for groups that have been historically marginalized. For example, this could include releasing guidance required under the Substance Use Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities (SUPPORT) Act regarding Section 1115 demonstration requests to facilitate Medicaid enrollment and provide healthcare services to individuals within 30 days of release from incarceration. CMS should also issue guidance on the implementation of the state plan option to extend postpartum coverage that was passed through the American Rescue Plan Act, to include clarification on the eligibility categories that can receive extended coverage. In this guidance, CMS should also highlight pathways by which Medicaid and/or the Children’s Health Insurance Program (CHIP) could provide extended postpartum coverage to otherwise ineligible pregnant and postpartum individuals outside traditional eligibility pathways (i.e. through a Section 1115 demonstration, a CHIP Health Services Initiative, or other options).

Adjust Timeframes for the End of the Public Health Emergency to Support Uninterrupted Coverage for Underserved Populations

During the COVID-19 Public Health Emergency (PHE), Medicaid enrollment has increased significantly due in part to the maintenance of effort requirement in the Families First Coronavirus Response Act. Once the PHE ends, states will need to redetermine eligibility for millions of beneficiaries. CMS needs to update previous guidance, or issue new guidance, on the unwinding of the PHE that protects people of color and other underserved populations against erroneous terminations of coverage.

CMS should provide a full year for state Medicaid agencies to fully return to normal eligibility and enrollment operations following the end of the PHE. This will ensure that state systems, call centers, and eligibility workers are not overwhelmed and are able to be responsive to the needs of beneficiaries in a timely manner. It will also ensure that future workloads are more evenly distributed over the course of the year. By allowing states additional time to resume normal operations, underserved populations are more likely to get the necessary assistance to stay enrolled in coverage. States should be notified that CMS will consider racially disparate outcomes as it monitors state resumption of normal eligibility and enrollment requirements.

CMS should also require states to review eligibility for all individuals prior to disenrollment, or minimally shorten the look-back period from six to three months. Current guidance allows states to maintain a pending adverse action list of individuals who did not respond to a request for information following a renewal or change in circumstances in the final six months of the PHE. While in some cases, the disenrollment is appropriate (e.g., the individual aged out of coverage), pending adverse actions based on income or returned mail should be reexamined in general and specifically with an eye to racially disparate impacts. In many cases, the data used to trigger the request for information will be older than six months and may not reflect the individual’s current situation. Unstable housing, which was exacerbated during the pandemic among low-income enrollees, may result in lost or misplaced mail,

³ The Lewin Group, “Healthy Indiana Plan Interim Evaluation Report,” December 18, 2019, <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/in-healthy-indiana-plan-support-20-pa8.pdf>.

particularly given that most states send a single notice/request for information. Conducting a fresh review of eligibility will help protect eligible individuals, especially those in underserved populations, from a gap in, or worse, a loss of coverage while reducing the administrative inefficiency and costs associated with churn.

Improvements to Outreach and Enrollment Efforts for Underserved Communities, Especially Related to the ACA

Since its enactment in 2010, the ACA has brought about significant coverage gains, bringing the uninsured rate down to an historic low over the past decade, and the expansion of Medicaid eligibility was particularly helpful in reducing uninsurance.⁴ These overall declines also led to significant reductions in racial and ethnic disparities in health insurance coverage rates.⁵

However, since 2017, the number of uninsured individuals has risen including the number of uninsured children – particularly Latino children.⁶ This has largely been due to federal policy changes made to coverage options available under the ACA and Medicaid, reduced funding for outreach and enrollment assistance in the ACA marketplaces, barriers to enrollment and retention in state Medicaid programs, and immigration policies that have depressed immigrant families' engagement with public coverage programs. Thirty million U.S. residents lacked health insurance in 2020 and disparities among uninsured remain, with most non-white groups more likely to be uninsured than whites.⁷ Of the 10.9 million people currently eligible for ACA marketplace coverage subsidies but unenrolled, 30 percent are Hispanic, 59 percent have a high school diploma or less, 42 percent are young adults, 16 percent live in rural areas, and 11 percent do not have internet access at home.⁸

These unequal rates in access to coverage indicate a need to prioritize ramping up outreach and enrollment assistance programs for those who are eligible for coverage but not yet enrolled in both the marketplace and Medicaid. Studies have shown the success of consumer assistance in getting people enrolled in coverage.⁹ Increased investments in outreach for trusted, culturally competent partners in populations of focus will also help draw in more uninsured to evaluate their coverage options and eligibility for financial assistance. In 2019, a significant share of the population was unaware that the ACA provided subsidies for coverage and expanded Medicaid.¹⁰ Because a significant share of the eligible but unenrolled are from groups that have been marginalized, greater investments in outreach and consumer assistance will go a long way in improving health equity by reducing disparities that impose barriers to coverage.

⁴ [Affordable Care Act Coverage Gains Drove Uninsured Rate to New Low](#), Center on Budget and Policy Priorities, March 23, 2020.

⁵ Ajay Chaudry et al. [Did the Affordable Care Act Reduce Racial and Ethnic Disparities in Health Insurance Coverage?](#), The Commonwealth Fund, Aug. 21, 2019.

⁶ Kelly Whitener and Alexandra Corcoran [Getting Back on Track: A Detailed Look at Health Coverage Trends for Latino Children](#), Georgetown University Center for Children and Families, June 2021.

⁷ Kenneth Finegold et al., [Trends in the U.S. Uninsured Population, 2010-2020](#), U.S. Department of Health & Human Services' Office of the Assistant Secretary for Planning & Evaluation (ASPE), Feb. 11, 2021.

⁸ Daniel McDermott and Cynthia Cox, [A Closer Look at the Uninsured Marketplace Eligible Population Following the American Rescue Plan Act](#), KFF, May 27, 2021.

⁹ Karen Pollitz et al. ["Consumer Assistance in Health Insurance: Evidence of Impact and Unmet Need,"](#) Kaiser Family Foundation, Aug. 7, 2020; Karen Pollitz et al., ["2016 Survey of Health Insurance Marketplace Assister Programs and Brokers,"](#) Kaiser Family Foundation, Jun. 8, 2016.

¹⁰ Mollyann Brodie et al., ["The Past, Present and Possible Future of Public Opinion on the ACA,"](#) Health Affairs, Feb. 19, 2020.

ACA Section 1557

Section 1557 of the ACA established an expansive prohibition on discrimination on the basis of race, color, national origin, sex, age, or disability by any health program or activity that receives federal funding. This statutory protection took effect at the time of the ACA's enactment in March 2010 and received implementing regulations, promulgated by HHS, in 2016. Among its provisions, the 2016 rule: (1) made clear the broad applicability of the nondiscrimination protection to a wide range of health programs and entities, including benefit design in private health plans; (2) defined prohibited sex discrimination to include discrimination based on gender identity and sex stereotyping; (3) established minimum notice and language access requirements to inform the public of, among other things, ways to seek redress from prohibited discrimination and how to obtain language assistance; (4) set forth protections to prevent discrimination against persons with limited English proficiency (LEP); and (5) codified robust enforcement procedures that recognized the right of individuals to bring a private lawsuit in response to a violation of Section 1557.

In 2020, the Trump Administration issued a new regulation purporting to reinterpret Section 1557. That rulemaking substantially undermined, and in some cases flat-out eliminated the key protections noted above, based on legally dubious justifications and policy preferences dismissive of the burdens and barriers to care faced by millions of Americans. The former administration published the rule immediately following, and in disregard of, a Supreme Court decision, *Bostock vs. Clayton County*, that rendered a major element of its regulation legally untenable.¹¹

In May 2021, this Administration provided notice that, in light of *Bostock*, it will interpret and enforce Section 1557's prohibition on discrimination on the basis of sex as barring discrimination on the basis of sexual orientation and gender identity.¹² We applaud this approach, as we applaud the President's January 20, 2021 Executive Order directing all agencies to take steps to combat discrimination based on sexual orientation and gender identity and to review all agency actions to ensure consistency with *Bostock*.¹³ These efforts will make a difference in the lives of LGBTQ patients who, in the case of the new Section 1557 guidance, will again have a federal forum for the redress of discrimination in healthcare by covered entities.

But as the Administration well recognizes, far more steps are needed to stamp out discrimination in healthcare and to reduce burdens to care persistently faced by many. We therefore urge the Administration to issue new implementing regulations for Section 1557 that are consistent with the statute and the Administration's stated commitment to nondiscrimination, coverage access, and health equity. In accordance with federal law and the Administration's recent *Bostock* notice, this rulemaking should codify Section 1557's applicability to discrimination on the basis of gender identity and sexual orientation. A new rule should also revisit many of the other protections erroneously stripped from the books by the prior Administration's action. First, the rule must recognize the broad reach of the statute to a range of healthcare programs and activities previously covered under the 2016 rule but inexplicably excused from compliance by the prior Administration. This includes reinstating the protections against benefit designs that discriminate against people with disabilities by discouraging enrollment among people with disabilities. Such a rule should also reinstate notice and language access requirements,

¹¹ https://www.supremecourt.gov/opinions/19pdf/17-1618_hfci.pdf

¹² <https://www.hhs.gov/sites/default/files/ocr-bostock-notification.pdf>

¹³ <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-preventing-and-combating-discrimination-on-basis-of-gender-identity-or-sexual-orientation/>

strengthen protections for people with LEP, and ensure the government and private individuals have sufficient tools to address violations of Section 1557, including through a private right of action.

Provide Robust Federal Funding to Assist Consumers with Appeals

Data from marketplace issuers show about 17 percent of in-network claims are denied for marketplace enrollees, though rates by issuer vary from less than 1 percent to more than 50 percent.¹⁴ However, marketplace issuer data also show that enrollees appeal less than 1 percent of all denied in-network claims and very few of those will request an external review.¹⁵ Requesting an appeal requires time, resources, and an understanding of insurance terms that few consumers have, particularly those of lower socioeconomic status, who have limited English proficiency, or for whom the information and process is otherwise inaccessible. Consumer assistance programs can help consumers overcome these barriers and successfully appeal denied claims.¹⁶ However, these programs have not received federal funding since 2012. Robust funding for consumer assistance programs in each territory, state and DC would make available assistance with appeals across coverage types, including marketplace plans and employer-sponsored coverage.

Network Adequacy and Health Plan Provider Directories

Federal law requires qualified health plans (QHPs) sold through the ACA marketplaces to maintain an adequate network of providers and, beginning in 2022, will obligate all group health plans and all health insurance issuers offering individual or group health coverage to maintain accurate and up-to-date online provider directories. These critical federal protections are designed to ensure that marketplace enrollees have timely, meaningful access to the care and services they need, as well as accurate information sufficient to enable them to understand plans' networks and identify the plans and providers most likely to meet their needs.

It is vital for all patients to ensure that plans' provider networks are of sufficient size and composition, and that provider directories are accurate, informative, and clear. Yet for patients from underserved communities, who have experienced discrimination in healthcare settings and systemically worse health outcomes, this mission is especially important, and the consequences of an inadequate or non-transparent network are likely greater.

We urge the Administration to use its authorities to the full extent for which they were adopted. At a minimum, we suggest that QHP provider networks should be evaluated on their ability to provide culturally- and linguistically-competent care as well as care accessible to people with disabilities. This means, among other things, a rigorous assessment of whether a network includes sufficient providers and/or provides sufficient access to appropriate language services to ensure LEP individuals can obtain timely care in their preferred language, as well as assessment of physical, language, and other accessibility. It also means networks must ensure access to culturally appropriate care reflecting the diversity of enrollees' backgrounds and attuned to traditionally underserved communities, including

¹⁴ Karen Pollitz and Daniel McDermott, "[Claims Denials and Appeal in ACA Marketplace Plans](#)," Kaiser Family Foundation," Jan. 20, 2021.

¹⁵ Pollitz, "Claims Denials and Appeals in ACA Marketplace Plans."

¹⁶ See, for example, Health Education Assistance Unit, Maryland Office of the Attorney General, *Annual Report on the Health Insurance Carrier Appeals and Grievances Process*, Fiscal Year 2020, available at: <https://www.marylandattorneygeneral.gov/CPD%20Documents/HEAU/Annual%20Reports/HEAUannrpt20.pdf>; and Community Health Advocates, *2020 Annual Report*, New York, available at: https://smhttp-ssl-58547.nexcesscdn.net/nycss/images/uploads/pubs/CHA_Report_2020_V61.pdf

people of color, immigrants, people with disabilities, and LGBTQ individuals. Further, to enable consumers to identify the plans and providers likely to meet their needs, all health plans must be required to indicate in their provider directories the languages other than English spoken by a provider and/or their staff.

Stakeholder and Community Engagement

Utilize Existing Opportunities to Engage Diverse Participants on Equity in Medicaid

CMS has multiple stakeholder groups that can be utilized to engage diverse participants on administering the Medicaid program. For example, CMS has created and enlists the advice of “technical advisory groups” (TAGs) for tribes (TTAG), eligibility (ETAG), and Medicaid systems (S-TAG), among others. CMS could add equity to the portfolio of all of the existing groups. Additionally, states are required to establish Medical Care Advisory Committees (MCACs), including representation from Medicaid beneficiaries and consumer organizations, to advise the Medicaid agency on policy development and program administration. CMS could also assess the extent to which MCACs currently enable such participation and whether MCACs are advising their Medicaid agencies on advancing equity.

Encourage Participation of Diverse Stakeholders in Marketplace Policy Development and Implementation

It’s essential that diverse stakeholders be afforded a full opportunity – and encouraged – to engage throughout the process for policy development and program implementation in the Marketplace as well. This should include early engagement (for example, considering whether a formal consultation process as is required for states submitting Section 1332 waivers should be broadened to other stakeholder communities or additional federal programs) as well as continued engagement throughout program implementation and evaluation (for example, soliciting feedback from consumer assistance programs, Navigators and other groups working with consumers in under-resourced communities). Stakeholder outreach and engagement should recognize any potential barriers to participation, such as the need to have information translated into multiple languages and be accessible to individuals with disabilities, and to allow for in-person or virtual participation.

Conclusion

We appreciate the opportunity to comment on the request for information. Please contact Hannah Green with the American Lung Association if you have any questions or if we can be of further assistance.

Sincerely,

American Cancer Society Cancer Action Network
American Heart Association
American Lung Association
American Liver Foundation
American Kidney Fund
Arthritis Foundation
Asthma and Allergy Foundation of America
Cancer Support Community
Cystic Fibrosis Foundation

Epilepsy Foundation
Family Voices
Hemophilia Federation of America
Immune Deficiency Foundation
Muscular Dystrophy Association
National Alliance on Mental Illness
National Eczema Association
National Health Council
National Hemophilia Foundation
National Kidney Foundation
National MS Society
National Organization for Rare Disorders
National Patient Advocate Foundation
Pulmonary Hypertension Association
Susan G. Komen
The AIDS Institute
The Leukemia & Lymphoma Society
WomenHeart: The National Coalition for Women with Heart Disease