Office of Management and Budget, Executive Office of the President

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

July 6, 2021

The Honorable Shalanda Young, Acting Director
725 17th St., NW
Washington, DC 20503

Re: RIN #: OMB-2021-0005-0001

Submitted electronically via regulations.gov

Dear Acting Director Young:

Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all. We seek to make concrete and tangible improvements to the health and health care of the nation – improvements that make a real difference in people's lives. In all of our work, we strive to elevate the interests of children and families in public policy to ensure that their health and well-being is foremost on the minds of policymakers.

Families USA appreciates the opportunity to provide additional comment on *Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government.* Several organizations have joined Families USA in the submission of our recommendations, including Whitman-Walker Health, Whitman-Walker Institute, California Pan-Ethnic Health Network, National Urban League, and the Prevention Institute. Our collective feedback addresses areas 1, 2, and 5.

Thank you for the opportunity to submit these comments. If you have any questions, please contact Eliot Fishman at EFishman@familiesusa.org.

Respectfully submitted,

Mackenzie Marshall
Federal Relations Associate

Dear Acting Director Young,

The Biden Administration faces a historic opportunity, and a historic responsibility, to pursue racial equity and social justice. We at Families USA are committed to the equitable, affordable, and accessible distribution and availability of health care for every consumer and family in the United States. We therefore appreciate the opportunity to respond to the Office of Management and Budget's (OMB) request for information (RFI) to help address our nation's health equity crisis. The stark racial and ethnic disparities in the ongoing COVID-19 pandemic and response have proven that health equity remains a critical unsolved problem. To this end, we are grateful for your efforts to understand the administrative factors contributing to inequitable health outcomes in the United States, and develop policies based on the specific, evidence-based recommendations submitted for consideration. We respectfully submit our comments below.

Background

The United States is now in the middle of the vaccination phase of recovery from the COVID-19 pandemic, and America's families are struggling to recover from the devastating toll the virus claimed. This past year has laid bare the hard reality that our health care system is failing families across the nation. Those who have been hardest hit from the pandemic are members of communities that have long faced inequities and injustices through the systematic repetition and implementation of regressive policies that do not equitably distribute the resources that taxpayers fund. Across the nation, Black individuals have died from COVID-19 at 1.4 times the rate of white individuals.[i] Throughout the pandemic, essential and frontline workers were tasked with continuing to work in order to enable the rest of the nation to follow public health guidance and remain at home. Racial and ethnic minority populations are overrepresented in these lines of work, many of whom also live in communities that have been disproportionately affected by the COVID-19 virus.[ii] Because of the nature of their work, essential workers are more likely to be exposed to and infected by the COVID-19 virus. Overall, those who belong to underrepresented and minority groups in the nation were hardest hit by this public health crisis. People of color also continue to be more likely to be uninsured, a major pandemic risk factor not just for uninsured individuals but also to the communities in which they live.[iii]

The COVID-19 pandemic was a sentinel event, calling attention to the true breadth of inequities in the health outcomes faced by underserved communities across the nation. Before the virus swept across the globe, the United States was struggling under the burden of inequitable health disparities. In 2019, American Indian and Alaska Native populations experienced the highest rate of uninsurance of any Americans, followed by Hispanic or Latinos, Native Hawaiian and Pacific Islanders, and Black or African Americans.[iv] Maternal and infant mortality in the country reflect shocking and unacceptable racial and ethnic disparities in health outcomes: Black and American Indian and Alaska Native mothers experience rates of maternal mortality that are two to three times higher than their White counterparts.[v] Geographic disparities also play a role in poor health outcomes with rural Americans experiencing a higher risk of death from heart disease, cancer, unintentional injury, chronic lower respiratory disease, and stroke, than their urban and suburban counterparts.[vi]

Both the Biden-Harris administration and the 117th Congress have a possible—and likely time-limited—political opportunity to make substantial federal investments across multiple agencies of the US government to root out systemic racism that directly affects Black, Indigenous, and people of color, as well as advance meaningful equity reforms for LGBTQ communities, people with disabilities, and other populations who are most often marginalized.

The Biden Administration has recognized these long-standing systemic issues, and President Biden issued executive order 13985 “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government”, which calls for a long-overdue examination and implementation of policies that will further equity for all families in America. The need for a long-term set of policies that address the root causes of systemic inequities and injustices is clear. Families USA respectfully submits these policy recommendations and associated evidence-base for your consideration.

Topic 1: Equity Assessments and Strategies. Approaches and methods for holistic and program-or policy-specific assessments of equity for public sector entities, including but not limited to the development of public policy strategies that advance equity and the use of data to inform equitable public policy strategies

Studies have shown that improving quality of care also has a positive impact on reducing health care disparities.[vii] However, efforts to improve quality without correctly acknowledging and engaging in efforts to include the voices of those who are underrepresented or disenfranchised, actually leads to an increase in health disparities.[viii] The following recommendations address how quality improvement can and should be pursued, with a clear focus on how equity should be explicitly accounted for in these types of reform.

Recommendation 1: The Department of Health and Human Services (HHS) should undergo a multi-stakeholder process to develop a core health equity measure set, and require all payers and providers to report on those measures through Medicare and Medicaid (Consumers First Admin Agenda).
In order to be able to “Pay for Equity”, **HHS should firstly develop a core health equity measure set**. This core equity set should be determined by a wide variety of stakeholders, including those with lived experience and individuals that identify as a part of underrepresented, marginalized, and/or disenfranchised communities that experience those health disparities that we are working to eliminate. The Office of the Assistance Secretary for Planning and Evaluation (ASPE), in conjunction with RAND Health Care, recently submitted a report to HHS/the Centers for Medicare and Medicaid Services (CMS) that defines a health equity measurement approach. This approach was developed in response to Executive Order 13985, issued by President Biden.

Recommendation 2: CMS should incorporate health equity into quality measurements and performance-based payments, including paying providers for reducing disparities in health outcomes: “Pay for Equity”.
Major health organizations have realized that exploring new payment systems is a key factor in improving health equity and reducing disparities.[ix] In 2016, HHS recommended developing health equity measures and adjusting payment to reward the improvement of equitable care.[x] As charged in statute, ASPE wrote two reports to Congress in 2014, making the recommendation that CMS include measures of health equity in public reporting and value-based payment (VBP) programs.[xi] This is not a novel recommendation, but it has yet to be implemented, and as such, stands as one of our top recommendations.

In conjunction with this recommendation, we also suggest **Medicare and Medicaid pay-for-performance programs for providers, ACOs and plans should stratify measures by race, ethnicity, and primary language, at minimum, and move to incentivize the reduction of disparities across these measures**. The stratification of data “is necessary to measure and publicly report—in a standardized and systematic way—the nature and extent of health care disparities.”[xii] As part of building stratified data into Pay for Performance, **CMS should direct Medicare's Quality Payment Program, Medicare Advantage programs, and Hospital Quality programs, to report all quality and outcomes data stratified by race, ethnicity, primary language, geographic location, socioeconomic status, gender identity, sexual orientation, age, and disability status.** The reporting of such data should follow the Office of the National Coordinator for Health Information Technology's (ONC) 2015 Edition Health Information Technology Certification Criteria Final Rule which establishes HIT certification requirements that include full disaggregation of race and ethnicity, language, sexual orientation, gender identity and social and behavioral risk factors.[xiii] The goal of stratifying quality measures by race, ethnicity and other sociodemographic factors is to enable providers, policymakers, researchers and other stakeholders to drill down to individual level quality information that illustrates where disparities are occurring in health care delivery.

Recommendation 3: In addition to Recommendation 2, the Administration should build new infrastructure for stratified health data.

The collection and reporting of data are important as they allow for transparent analysis of trends and relationships that are essential to informing policymakers and the public. However, without significant federal involvement, data reporting can be used to hinder equity and deepen disparities.[xiv,xv] Furthermore, lack of representation in datasets have marginalized whole groups of people in data-informed decision-making.[xvi] In order to be able to effectively strategy quality and performance measures to hold the health care system accountable for reducing inequities, there needs to be standardized data collection and reporting across all payers and providers. Families USA calls on federal agencies to collect and report data in a stratified manner, allowing for a transparent understanding of how historically marginalized groups may experience different outcomes than their counterparts.

Data Collection

- **HHS should establish a national all-payer claims database (APCD):** Such a database would require both public and private payers to report health care utilization and claims data to the national APCD according to federally established standards across the following categories: medical and clinical, prescription drug, dental, behavioral health, available social services data, as well as prices charged for health care services. Data would be required to be collected and reported across all data categories stratified by race, ethnicity, primary language, geographic location, socioeconomic status, gender identity, sexual orientation, age, and disability status. HHS already has the regulatory authority and is collecting much of this data, so this would be a natural next step in being able to sue sophisticated data analysis to make improvements in the cost, quality, and equitable distribution of health care.
- **The Office of Management and Budget and the Census Bureau should develop protocols, in consultation with community members, data users and researchers, for using data disaggregation consistently throughout the collection, analysis, and reporting of racial and ethnic subgroup data.** It is important to ensure that these protocols are applicable to data policy leaders at every agency, such as the Departments of Health and Human Services, Housing and Urban Development, Transportation, and Labor.
- Similarly, **CMS should require and incentivize collection of self-reported standardized equity data sets, including patient social and behavioral risk data, disaggregated by race, ethnicity, primary language, geographic location, socioeconomic status, gender identity, sexual orientation, age and ability status, across all payers and providers.** Self-reported collection of data is the gold standard for collecting disaggregated data.[xvii, xviii,xix] To mitigate patient concerns that race and ethnicity or other demographic data may be used in a discriminatory way,

providers should explain that the data will be used to improve the quality of care.[xx] There are two key approaches providers should consider in operationalizing self-reported data methods:

- Planned Procedures: Conduct surveys with patients prior to admission as part of the pre-contact, check-in process where patients are asked to complete and verify demographic information, medical history and insurance status;
- Emergency Visits: Conduct surveys with patients when patient is stable during the time of insurance verification.

Provider Reporting: Quality and CLAS Data.

- The ONC 2015 Edition Health Information Technology Certification Criteria Final Rule, the “2015 Edition” establishes HIT certification requirements that include full disaggregation of race and ethnicity, language, sexual orientation, gender identify and social and behavioral risk factors.[xxi] **CMS should immediately require and incentivize ONC’s 2015 Edition standards for collecting disaggregated data for all payers, providers, and all CMS quality programs, including all hospital payment reform programs.**[xxii]
- The Office of Minority Health at the US Department of Health and Human Services developed the National Culturally and Linguistically Appropriate Services (CLAS) Standards. The CLAS Standards are intended to advance health equity, improve quality and help eliminate health care disparities by establishing a blueprint for health and health care organizations. There are 15 standards across governance, leadership and workforce; communication and language assistance; and engagement, continuous improvement and accountability. The National CLAS standards were revised in 2013 to account for the increasing diversity of the U.S. population, the growth in cultural and linguistic competency fields, and the changing policy and legislative landscape, including the Affordable Care Act. **In the near term, CMS should require all payers and providers to demonstrate how they are implementing the National Culturally and Linguistically Appropriate Services (CLAS) standards and report publicly on their CLAS implementation score, with the long-term goal of reporting on a core health equity measure set, which needs to still be determined by HHS (see recommendation 2).**

Recommendation 4: Refocus the Center for Medicare and Medicaid Innovation on health equity:
Both the new Director of CMMI and the new Administrator of CMS have placed health equity as a high strategic priority. CMMI will need to operate quite differently in order to make substantial progress on health equity. Close collaboration with other parts of CMS and with IHS—which in the aggregate provide health coverage to most people of color in the United States—will be a necessity in every step of CMMI model development and implementation.

More fundamentally, CMMI’s ability to advance payment models that center equity will be limited if all CMMI models are considered failures if they do not reduce costs. Multiple pieces of legislation were introduced in the last congress that would mend the Center for Medicare and Medicaid Innovation’s (CMMI) statutory language to include a focus on improving health equity, in addition to reducing program expenditures.

Families USA also recommends that CMMI, state-level Medicaid, or multi-payer payment reform initiatives be required to collect input from a diverse group of consumer advocates, community providers, and other key stakeholders. In order to fully integrate the consumer voice and experience into administrative work, agencies should pursue a multi-pronged approach. Firstly, when developing new value-based payment models, such as during the RFI and early design phase, the Technical Expert Panel application phase, and the evaluation design phase, programs and initiatives should be required to collect input from a diverse group of stakeholders, as described above. Additionally, CMS should integrate patient reported outcomes measures across all value-based payment and delivery programs in order to collect patient-level data that surfaces more accurate insights into how patients feel and perceive their health and health care as it relates to their health outcomes. Furthermore, CMS should develop payment and delivery models that invest in community-driven approaches designed to meet peoples' health needs by creating community-stakeholder tables where community and consumer representatives have a decision-making seat at the policymaking table, along with payors, providers and other sectors that influence health, to drive decision-making about how health care resources are distributed and redistributed to meet the specific needs of that community. These approaches should be implemented simultaneously to ensure the needs of consumers and patients are at the center of health care payment and delivery system reforms and that those reforms are driving reductions in disparities.

Recommendation 5: Require CMMI to design and test one or more new delivery and payment models exclusively focused on early intervention and prevention using evidence-based interventions for at-risk children.

Up to this point, health insurers and other payers have focused payment and delivery reform models on adults.[xxiii] Only one model from the Center for Medicare & Medicaid Innovation, Integrated Care for Kids (InCK), targets children. Children as a group tend to be much less costly than adults; therefore, there are fewer opportunities to drive immediate savings through transformed care delivery. The few efforts to incorporate the needs of children into delivery reform, including from the Center for Medicare & Medicaid Innovation (CMMI), have been small in scale and on lengthy timelines relative to similar efforts targeting adults.

While CMMI launched a small child-focused initiative in 2020, the Integrated Care for Kids (InCK) program, the bulk of CMMI's efforts focus on adult and senior populations. CMMI currently oversees some of the most promising models, including accountable care organizations (ACOs), bundled payments, and patient-centered medical homes (PCMH). Evaluation of these models shows encouraging results on cost savings and improved quality, and there has been wide adoption of these models across public and private payers. Many believe these models also have significant potential to improve the care and health of children and their families. Integrated Care for Kids (InCK), which was initiated in early 2019, is an important, albeit modest, step taken by CMMI to include children in payment reform. This model aims to reduce expenditures and improve the quality of care for children under 21 years old who are covered by Medicaid and the Children's Health Insurance Program (CHIP) through the prevention, early identification, and treatment of behavioral and physical health needs. Compared to the considerable scale CMMI and the MSSP program have achieved in developing payment reforms for adults, the InCK initiative does not make a large enough investment to drive delivery system reform efforts at scale for children, nor does it establish medium-term timelines for widespread adoption of a specific model or set of models.

CMMI is testing various medical home models, including the Comprehensive Primary Care Plus (CPC+) initiative and the Primary Care First model. However, both are largely focused on adult populations. A common primary care medical home model for children is focused on children with medical complexity (CMC) and integrates a primary care medical home with tertiary care.[xxiv] This integrated model for CMC is the exception that proves the rule. By focusing on short-term avoidable costs, it perpetuates the existing model and framework, and keeps the vast majority of children from being meaningfully included in payment reform. CMC are a small subgroup of children who consume about one-third of all child health expenditures and account for more than 40% of all child hospital deaths. These factors align

CMC-focused models with existing health care transformation efforts focused on reducing health care costs and improving health care quality, <u>but not on health equity</u>. Unfortunately, broader pediatric medical homes have largely not been incorporated into PCMH frameworks for the Centers for Medicare & Medicaid Services (CMS) and commercial insurers. For example, some of the most effective pediatric models for managing and preventing ACEs, such as DULCE (Developmental Understanding and Legal Collaboration for Everyone) and HealthySteps, include basing an interdisciplinary team in a pediatric medical home. The PCMH model and other primary care medical home models are ready to expand their provision of services beyond CMC and CSHCN to provide comprehensive, team-based, coordinated health care to all children.

OMB should work to establish payment and delivery models with CMMI authority that support and incentivize a focus on the social, emotional, behavioral and relational health of children, ideally as part of a high-performing pediatric medical home. These models must prioritize equitable health outcomes, particularly for BIPOC children and families, and address inequities in reimbursement for community based providers such as peer providers and community health workers (CHWs).

We recommend the following clinical elements of a child-focused CMMI model:

- Integrating Primary Care and Behavioral Health
- Addressing the Symptoms of Trauma of Parents and Caregivers
- Connecting Community Health Workers for Care Coordination to Pediatric Practices and Home Visiting.
- Identifying and Responding to adverse Childhood Experiences
- Building Home visiting into Care Delivery

These recommendations are detailed in our publication with Futures Without Violence, "Health Care Payment and Delivery System Reform for Children as a Tool to Improve the Health of Vulnerable Communities".[xxv]

Recommendation 6**: CMS should leverage the Medicaid program to address the Social Determinants of Health**

The Administration has clearly signaled its intention to support continued innovation in the use of Medicaid funds to address the social determinants of health. To support the success of these potential new Medicaid demonstrations, the Administration should:

- Build robust operational collaboration between CMMI and federal and state Medicaid programs regarding Medicaid payment and delivery systems that emphasize SDOH.
- Develop health equity-focused Medicaid demonstration opportunities in collaboration between CMMI and CMCS that:
  - Incorporate "pay for equity" principles;
  - Stratified measurement of access to physical, behavioral and oral health care,
  - Investments in provider capacity to operationalize Alternative Payment Methodologies,
  - Broader restructuring of health care delivery and payment in Medicaid or on a multi-payer basis, giving more financial and operational authority to primary care and formally linking physical and behavioral health with social and human services;
  - Robust measures of network adequacy in Medicaid.
- Leverage Medicaid waiver authorities to improve Medicaid coverage for people re-entering the community from incarceration, in parallel to support of legislative efforts with the same goal.

- Leverage Medicaid and Marketplace waiver authorities to support access to care and/or coverage for all people regardless of immigration status.

CMS should also build on existing CMMI pilots and Medicaid demonstrations to scale up investments in social determinants of health in traditional Medicare, Medicare Advantage, and under Medicaid managed care and demonstration authorities.

Recommendation 7: Create strong and explicit federal Medicaid network adequacy standards, at a minimum for behavioral health and for pediatric subspecialists

The Supreme Court ruled in 2015 that providers cannot sue in court to enforce the statutory requirement that Medicaid provide a level of access "available at least to the extent that comparable care and services are available to the general population." This decision explicitly placed the responsibility on the federal Centers for Medicare and Medicaid Services to enforce standards to give Medicaid beneficiaries access to "care and services comparable" to other insurance products. The Obama administration Medicaid managed care regulation, however, merely required states to have some "time and distance" measure of access to physicians and other providers, and also to have specialist-specific federal review.

The Trump Administration turned what were already limited federal standards for how states measure the adequacy of plan networks into a completely open-ended requirement to essentially just file some description of a standard.

Specialists are a long standing issue for Medicaid but some states have excellent specialist standards. Both of these were removed by the Trump administration. These were the only specific requirements of states regarding network adequacy in the previous rule so this was a significant weakening of what was already a highly flexible federal oversight framework. The current rule leaves CMS oversight of managed care networks as at best incredibly vague and more likely a legal fiction. The Biden administration should put in place specific enforceable standards for Medicaid networks in both managed care and fee-for-service Medicaid.

Recommendation 8: Bring Medicaid benefits up to the standard of care by incorporating community-based providers for at risk parents and children

Comprehensive medical benefits for children and pregnant women should now include community-based providers who can conduct home visits, tied to a robust medical home. Families USA is advocating for these benefits to be added to the Medicaid benefit as delineated in statute. But given the substantial evidence base supporting the clinical benefit of these services, CMS can and should act via regulation to clarify that these benefits are part of pregnancy-related services and mandatory under the children's Medicaid benefit (EPSDT), respectively:

- Services provided by community-based doulas, perinatal community health workers, and other peer support service providers:
- MCH home visiting programs such as the Nurse-Family Partnership or others in the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program.
- Child-parent supports, including evidence-based parenting support programs, home visiting services by licensed practitioners, whole person care and community integration services, and dyadic therapy treatment for children and adolescents at risk for or with an attachment disorder, or as a diagnostic tool to determine an attachment disorder.

These recommendations are elaborated here: MCH Priorities Fact Sheet

Topic 2: Barrier and Burden Reduction. Approaches and methods for assessing and remedying barriers, burden, and inequities in public service delivery and access. Barriers that underserved communities and individuals may face to enrollment in and access to benefits and services in Federal programs.

Requiring people to take multiple steps (even minor ones) to obtain benefits substantially reduces participation in benefit programs; and such procedural requirements take a particularly heavy toll on people in historically disadvantaged communities, where economic stresses often impose cognitive demands that limit the "bandwidth" available to learn about benefit programs and to complete the paperwork needed to obtain or retain assistance. Paradoxically, the same challenging life circumstances that qualify people for assistance also interfere with their ability to overcome the procedural challenges typically required to obtain that assistance. In program after program, those with the greatest need are often the least likely to enroll.

The Affordable Care Act's (ACA) drafters took these lessons into account by including provisions that sought to prevent eligible people from being denied health coverage because of failure to complete needless paperwork. Sections 1413 and 2201 thus required the use of a single, streamlined form for all insurance affordability programs; mandated data matches, whenever possible, to establish eligibility for both initial and renewed coverage, rather than deny health coverage unless consumers provide documents; forbade state inquiries that were not essential to determining eligibility; and required initial eligibility for all insurance affordability programs (IAPs) to be determined at the point of application – no matter where the application was filed (with Medicaid or the exchange) or how it was filed (telephonically, electronically, in-person, or by mail).

After the ACA's 2010 passage, states faced enormous challenges in rapidly modernizing obsolete state Medicaid systems and creating new health insurance exchanges from scratch. Those challenges limited how far and how fast the Obama administration could go, but officials nevertheless made remarkable progress streamlining eligibility, enrollment, and renewal. More than a decade after the ACA's enactment, it is now time for the Biden/Harris administration to fully implement sections 1413 and 2201 of the ACA so that historically marginalized and disadvantaged communities can finally obtain equitable access to health benefits.

Recommendation 9: Fully implement the "no wrong door" enrollment approach required by the ACA. Contrary to the ACA's explicit "no wrong door" requirement, eligible people who apply for the "wrong" program in most states –Medicaid-eligible people who file applications with an exchange, or people eligible for exchange premium tax credits who submit an application to the Medicaid agency – must remain uninsured while their files are transferred to another agency and the latter agency completes its processing of the files. Coverage gains have been an order of magnitude lower in states with such bifurcated eligibility systems. Interviews with consumer advocates show that state Medicaid programs typically deny coverage until families submit the same information they already provided to the health insurance exchange – often via a redundant, second application form. Illustrating the "glitches" that can result from bifurcated eligibility, when the Texas Medicaid computer systems received file transfers, children were misclassified as adults. Rather than grant children health coverage if family income was at or below the applicable standard of 205% of the federal poverty level (FPL), children were denied health care unless their family income fell below the 17%-FPL standard Texas used for adult parents. This glitch began in 2014 and was not discovered until 2019; no one knows how many eligible children were denied health care as a result.[xxvi]

Current policies have the effect of singling out children of color for disproportionate risk. In states like Texas that have maximally bifurcated eligibility systems, where exchanges merely "assess" rather than determine eligibility for Medicaid and CHIP, children of color comprise 14% of all non-elderly state residents, but fully 32% of all uninsured residents who qualify for Medicaid and CHIP[xxvii] and so would be at risk of not receiving coverage if their families apply to the exchange. It is past time to require the agencies that receive applications to ensure an immediate determination of eligibility for all IAPs, drawing on all available data sources, as required by the ACA.

Recommendation 10: Require state Medicaid and CHIP programs to tap into all reliable and relevant data sources in qualifying eligible families for health coverage.
ACA §1413(c)(3) requires states to determine eligibility "on the basis of reliable, third party data,"[xxviii] except for data sources where HHS affirmatively finds that data use costs outweighs the "expected gains in accuracy, efficiency, and program participation." This provision has never been enforced. Instead, the Centers for Medicare & Medicaid Services (CMS) let each state's Medicaid and CHIP programs choose the data sources they tap into. As a result, many states are ignoring sources of data that could prove essential in preventing major losses of coverage, including when current Medicaid maintenance-of-effort requirements expire at the end of the public health emergency. For example:

- At the start of this year, only 19 states planned to link to U.S.-Postal-Service change-of-address data. Without that data, many who move will lose coverage as a result, because their state's notices will be sent to the wrong address. Disadvantaged populations tend to move more frequently than other people, so this preventable and foreseeable loss of coverage will further exacerbate existing inequities.
- Very few states use income tax data to renew eligibility, even though 72% of all Medicaid beneficiaries are in households that file tax returns, including 81% of children.[xxix] As we explain in our next recommendation, such data could be used to renew eligibility for a large segment of the Medicaid-eligible population.

Recommendation 11: Require state Medicaid and CHIP programs to use evidence-based business rules to renew eligibility administratively based on reliable sources of data.
When Medicaid and CHIP eligibility is redetermined, the state sends the beneficiary a notice that explains the basis of the state's decision and asks the beneficiary to provide additional information. We know that many if not most people will fail to respond, especially when economic challenges stress time and other resources. The key policy choice is thus the following: *when the beneficiary fails to respond, does coverage continue, or does the beneficiary become uninsured? When is the default, in case of inaction, health coverage, and when is it denial of health coverage?*

Federal regulations provide that, whenever "reliable information" demonstrates continued eligibility, beneficiaries should continue receiving coverage unless they respond to the state's notice with information indicating potential ineligibility. Without clear CMS standards for state implementation, the help that low-income families receive from this important safeguard has come to depend on where they happen to live. In January 2020, nearly a decade after ACA's enactment, only nine states used administrative renewal for 75% or more of their beneficiaries. Among the other states, 21 renewed fewer than half of beneficiaries administratively, and four admitted that they were still not renewing anyone administratively. Five other states did not say what they did.

To prevent disadvantaged and marginalized communities from losing coverage due to their states' failure to perform at the level achieved by leading states, CMS should identify factual circumstances where continued eligibility is sufficiently likely that states should not be allowed to make coverage termination the default. In such cases, unless the beneficiary provides a report indicating ineligibility or other specific evidence shows that the family no longer qualifies, coverage should continue. Examples of such factual circumstances include receipt of benefits under the Supplemental Nutritional Assistance Program, which establishes more than a 95% likelihood of continued Medicaid eligibility; and combinations of income-tax and quarterly-wage data that establish an 85% or greater likelihood of continued Medicaid eligibility,. Urban Institute analysis suggests that, for populations known to have an 85% or greater likelihood of continued eligibility, administrative renewal greatly increases the accuracy of overall eligibility outcomes.

Recommendation 12: Forbid states from prematurely terminating Medicaid and CHIP eligibility unless clear evidence demonstrates that beneficiaries no longer qualify.

From 2017 to 2019, the number of non-elderly Medicaid beneficiaries with incomes at or below 200% of the federal poverty level fell by 2.9 million, even as the number of uninsured rose in that same income range.[xxx] Proportionate Medicaid losses were literally three times as great for people of color, compared to White people. One important driver of this change was the practice of "periodic income checks." Even though ACA regulations call for 12-month eligibility periods, states implementing periodic income checks routinely match their Medicaid beneficiary records to past quarterly wage data. If those records showed wages above applicable income thresholds, beneficiaries are terminated unless they come forward (typically within 10 days of the state mailing out a notice) to document continued eligibility.

This practice ignores the extraordinary income fluctuations that affect low-wage workers in the contemporary economy. According to one recent study, nearly half of all low-income, working-age adults experience, each year, at least one month's spike in income that exceeds average monthly income by 25% or more. According to another study, the average low and moderate-income household experiences an average of 2.6 months per year in which income exceeds the family's annual income by 25% or more. Income fluctuation has by far the greatest impact on lower-income households who did not attend college. Periodic income checks thus take health insurance away from people based on unstable circumstances that are most likely for the very families who actually qualify for coverage, disproportionately harming people of color.

CMS should bar states from using evidence of income fluctuation, without more, as the basis of terminating coverage before a beneficiary's 12-month eligibility period has run its course. Instead, CMS should use longitudinal survey data to develop, validate, and publish business rules (available both in words and model code) for states' use, building on examples already developed by researchers. Such rules would distinguish income changes that signify likely ineligibility from those consistent with continued eligibility – taking into account not just a single quarter's income spike, but also other relevant indicators, such as patterns over multiple quarters of wage records, the extent to which quarterly wages exceed applicable eligibility thresholds, prior-year tax information that supplements more recent quarterly wage records, etc. Only in cases where evidence demonstrates probable ineligibility should states be allowed to end coverage based on wage spikes if a beneficiary fails to respond to the state's notice. Such policy clarifications would address the devastating effects disproportionately visited on communities of color when people "churn" on and off Medicaid and CHIP, as documented in a recent issue brief published by the Assistant Secretary for Planning and Evaluation.

Recommendation 13: Raise user fees for healthcare.gov, to fund increased application assistance and improved website operations.

Much evidence shows a substantial impact on enrollment when low-income people receive assistance learning about health programs and completing necessary forms. To provide funding needed for a robust level of such assistance, as well as to improve the operation of the healthcare.gov website to lower barriers to enrollment, CMS should raise the user fees charged to health insurers that offer coverage on the federally-facilitated marketplace and use the resulting revenue for these important services.

Topic 5: Stakeholder and Community Engagement. Approaches and methods for accessible and meaningful agency engagement with underserved communities

To ensure those voices most impacted by policies being made, it is critical to build community power among members of these groups, especially historically underserved communities, to drive policy decisions that impact their communities. Establishing community-stakeholder tables that include community and consumer leaders as decision-makers, as mentioned in Recommendation 4, is a critical approach to empower community and consumer leaders with the ability to determine how resources are allocated to meet the health needs of their communities.

Recommendation 14: Provide ongoing funding both to navigator entities and certified assisters that help with enrollment; and to consumer assistance programs that help with post-enrollment problems with access to care, billing, and appeals. Ensure that both types of programs have reach into communities of color and provide assistance in multiple languages.

Consumer assistance programs can serve the role of bridging the gap between technical policy recommendations and the voice of community members. Consumer assistance programs have helped millions of underserved or disadvantaged consumers, understand, buy, and keep their health insurance, and 90% of individuals who used consumer assistance programs to help them enroll in coverage, rated them very highly.[xxxi] Hispanic consumers are more likely to seek assistance then their White counterparts[xxxii], and account for almost 40% of uninsured individuals in the nation (while only making up 18.9% of the population)[xxxiii]. Providing ongoing funding to these programs will meet a massive unmet need. An estimated 5 million consumers sought help in the enrollment process, but were unable to get it.[xxxiv] 66% of these individuals stated that they would seek consumer assistance if available to them.[xxxv] With millions having lost their employer-sponsored insurance due to the pandemic, many will likely be eligible for marketplace or Medicaid coverage. However, without the guidance of navigator entities or consumer assistance programs, many of these eligible individuals and families face the risk of poor or no coverage.

Furthermore, **Consumer assistance programs can be helpful in flagging problems arising in underserved communities and should be invited to comment early in the process of rules development.** By allowing consumer assistance programs to comment early in the process of rules development, agencies will ensure that the consumer experience is at the front and center of a federal response to critical policy implementation.

On behalf of Families USA, we appreciate the opportunity to provide the above recommendations and feedback. Please contact Eliot Fishman, Senior Director of Health Policy, at EFishman@FamiliesUSA.org for further information.

Sincerely,

Families USA
Whitman-Walker Health/Whitman-Walker Institute
California Pan-Ethnic Health Network (CPEHN)
National Urban League
Prevention Institute

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