THE 100 DAYS AGENDA:

A Patient-First Blueprint

Leukemia & Lymphoma Society
American Lung Association
Cancer Action Network
Epilepsy Foundation
MDA Muscular Dystrophy Association
Cystic Fibrosis Foundation
National Multiple Sclerosis Society

National Psoriasis Foundation
American Heart Association
NPAF National Patient Advocate Foundation
National Health Council
Arthritis Foundation
United Way

Chronic Disease Coalition
Lutheran Services in America
NAMI National Alliance on Mental Illness
American Liver Foundation
NORD
HFA Hemophilia Federation of America
Mended Hearts

Cancer Support Community
American Kidney Fund
ALS Association
The AIDS Institute
WomenHeart
National Kidney Foundation

Susan G. Komen
National Hemophilia Foundation
PHA Pulmonary Hypertension Association
aafa Asthma and Allergy Foundation of America
Family Voices
March of Dimes
Crohn's & Colitis Foundation

The Leukemia & Lymphoma Society
American Lung Association
Epilepsy Foundation
American Cancer Society Cancer Action Network
Muscular Dystrophy Association
Cystic Fibrosis Foundation
National Multiple Sclerosis Society
National Psoriasis Foundation
American Heart Association
National Patient Advocate Foundation
National Health Council
Arthritis Foundation
United Way Worldwide
Chronic Disease Coalition
Lutheran Services in America
National Alliance on Mental Illness
American Liver Foundation
National Organization for Rare Disorders
Hemophilia Federation of America
Mended Hearts & Mended Little Hearts
American Kidney Fund
Cancer Support Community
ALS Association
The AIDS Institute
WomenHeart: The National Coalition for Women with Heart Disease
National Kidney Foundation
Susan G. Komen
National Hemophilia Foundation
Pulmonary Hypertension Association
Asthma and Allergy Foundation of America
Family Voices
March of Dimes
Crohn's & Colitis Foundation

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EXECUTIVE SUMMARY

Our organizations represent millions of patients and consumers across the country who live with serious, acute, and chronic health conditions. These individuals need access to comprehensive, affordable health coverage to meet their medical needs. In March 2017, we adopted a core set of principles to guide and measure any work to reform, change, or improve our nation's health insurance system. Our core principles are that **health care *must* be adequate, affordable, and accessible.**

The first 100 days of any Administration represent a rare opportunity for both the President and Congress to jumpstart their policy agendas and advance their priorities, including changes to the rules and laws that impact people with pre-existing conditions we represent. Together, our organizations identified key priorities that we expect elected officials to pursue in the first 100 days of their terms in 2021. The health and wellbeing of both the individuals we represent, and the nation as a whole, depend on the Administration and Congress acting quickly to secure these changes.

REDUCE ADMINISTRATIVE BARRIERS TO CARE

The enactment of the ACA introduced a new era for the patients we represent, many of whom live with pre-existing medical conditions, allowing them to newly obtain affordable and comprehensive health coverage. Since that time, pivotal guardrails that protect patients and their families have been eroded while insurance practices that disproportionately discriminate against patients with pre-existing conditions have proliferated. Recent administrative changes governing Medicaid, the individual and small group insurance markets, and employer-sponsored health coverage create barriers to care and resurrect discriminatory policies that threaten the health and wellbeing of patients and their families. Our organizations are concerned that such changes diminish access to affordable and adequate health coverage for all patients coping with serious and chronic conditions, particularly those in low-income and underserved communities.

STAND UP FOR PATIENTS IN THE COURTS

Since passage of the ACA, the contours of our health system have increasingly been shaped by the courts. Even today, through cases such as *California v. Texas*, the future of our health care system hangs in the balance. Our organizations often weigh in on legal matters, joining together to file as *amici* in legal cases like *California v. Texas*, to provide data and perspective on behalf of pro-patient policies. Our engagement in the courts is grounded in our firm belief that patients are best served by insurance coverage that is accessible, affordable and comprehensive.

ADVANCE A ROBUST, PRO-PATIENT LEGISLATIVE AGENDA

Administrative action is not enough to achieve the changes necessary to secure patients access to the coverage and care they need. Therefore, we strongly urge the Administration and Congress to champion and prioritize legislative changes like reining in noncompliant and "alternative" insurance products that leave unwitting consumers exposed to grave financial and medical risk; addressing ongoing issues of affordability, such as surprise medical billing, the family glitch, high-deductible health plans, and growing deductibles and out-of-pocket costs in employer-sponsored plans; expanding the generosity of subsidies for individual market coverage and opening new avenues for patients and their families to access those plans; and bolstering federal assistance to states for Medicaid costs. We also offer principles for consideration in the development of a public option, to make sure that any such program meets the needs of patients with serious health conditions.

For questions or comments regarding the content of this report, please contact Katie Berge, Director of Federal Government Affairs at The Leukemia & Lymphoma Society at katie.berge@lls.org.

RECOMMENDATIONS AT A GLANCE

Unwind Administrative Changes that Create Barriers to Care

MEDICAID

#1: Eliminate Policies in Sec. 1115 Waivers that Create Barriers to Care: Our organizations urge the Administration to reject any Section 1115 demonstration applications that include policies that create unnecessary barriers to care. This includes excessive premiums, cost-sharing for emergency care, and the removal of retroactive eligibility and non-emergency medical transportation, as well as proposals that reduce EPSDT benefits for young adults. We also ask that the Administration only approve demonstrations that improve access to coverage and have valid experimental design.

#2: Eliminate Work and Community Engagement Requirements: We strongly oppose work and community engagement requirements. CMS must rescind the guidances, deny all current or pending waivers in this area, and explicitly communicate to states that the January 2018 State Medicaid Director letter encouraging states to apply for such waivers is no longer reflective of the Centers for Medicare and Medicaid Services' (CMS's) position.

#3: Rescind the Block Grant Guidance: Block grants and per capita caps will reduce access to quality and affordable health care for patients with serious and chronic health conditions; like work and community engagement requirements, they are therefore not allowable in the Medicaid program. We urge the Administration to immediately rescind the January 2020 guidance.

#4: Stop Changes to the Medicaid Managed Care rules: CMS must withdraw the 2018 Medicaid managed care proposed rule. Instead, CMS should increase and strengthen monitoring and oversight requirements for Medicaid managed care, including in the areas of network adequacy (including for long-term services and supports), civil rights protections, rate review and actuarial soundness of capitation rates, data reporting, quality oversight, and grievance and appeal procedures.

#5: Establish Standards that Ensure Patient Access to Care in Medicaid: In tandem with enforcing strong network adequacy requirements in managed care, CMS should implement a system of monitoring, oversight, and enforcement of provider payment rates in Medicaid that ensures sufficient access to services, including waiver services. In building this system, CMS should start with the numerous comments provided in the 2011 notice of proposed rulemaking (NPRM), 2015 final rule with comment period, and 2019 proposed rescission-many of which include proposed frameworks for access measurement-as well as soliciting new input through a request for information (RFI).

#6: Stop the Proposed Medicaid Fiscal Accountability Rule (MFAR): If CMS considers additional work on Medicaid financing should focus on transparency and the reporting of accurate and reliable data about the operations and financing of the Medicaid program.

#7: Withdraw Proposed Changes to the Official Poverty Measure: We urge the withdrawal of the proposed changes to the statistical index put forward by OMB in May 2019. Instead, the Administration should update OPM's current formula to accurately reflect the needs of low-income individuals and families. Today, the current formula's calculations for basic household expenses for families underestimates child care and housing expenses. Instead of revising down the OPM formula to make benefits less generous over time, it should be revised and updated such that the calculation more accurately reflects the needs and expenses of low-income individuals and families.

THE AFFORDABLE CARE ACT (ACA)

#8: Limit Short-Term, Limited-Duration (STLD) Insurance Products: STLD plans pose a significant threat to our patient populations. The Administration should immediately limit the harm of these plans by restoring the 3-month duration limit, limiting renewability and stacking, banning sales during Open Enrollment, limiting internet and phone sales, establishing a prohibition on plan rescissions, improving disclosures, and working with Congress to codify these regulations in law.

#9: Restrict Multiple Employer Welfare Arrangements (MEWAs) & Association Health Plans (AHPs): The Administration should direct DOL to reverse the 2018 rule and reinstate the previous regulations governing these plans while also including new provisions that help protect patients and consumers. These include codifying the "look through" doctrine and working with

Congress to clarify the term "issuer" such that MEWAs and AHPs that are regulated by a state are subject to federal insurance requirements.

#10: Withdraw the Grandfathered Insurance Plan Rule: We urge the Departments of HHS, Labor, and Treasury Departments to withdraw the proposed rule published in July 2020 which weakens existing regulations and further degrades patient protections. Any future changes to the rules impacting health plans with grandfathered plans should encourage those plans to come into compliance with the ACA.

#11: Rescind the 1332 Guidance: Our organizations ask CMS to immediately withdraw this guidance. Halting the implementation of this guidance will protect people with pre-existing conditions from the repercussions of these market destabilizing actions. Additionally, CMS should codify and strengthen the previous 2015 guidance on Section 1332 of the Affordable Care through the rulemaking process.

#12: Reinstate Robust Open Enrollment Periods: We urge HHS to immediately reinstate a full 90-day open enrollment period to ensure patients and consumers have adequate time to shop for and compare plans. We also urge the legislative codification of a minimum open enrollment period such that it may not be manipulated by future administrations.

#13: Fund Education & Outreach Activities: Funding must immediately be restored for outreach and enrollment activities for the 2020 Open Enrollment period. Funding should include support for activities that reach underserved populations, including racial and ethnic minorities and those with limited English proficiency. We also ask that the Administration work with Congress to pursue legislation that would require HHS to use allocated funds exclusively for these purposes. HHS should also be mandated to provide biweekly public reports that include state-by-state information for the duration of the open enrollment period.

#14: Fully Fund Navigator Services: Navigators are a critical bridge to accessing and understanding health care information and coverage for patients and consumers. The Administration should fully restore funding and support for navigators and restore community and consumer-focused navigator requirements and navigator training requirements.

#15: Strengthen Web Brokers & Insurance Agent Standards: We urge the Administration to reverse recent regulatory changes that have relaxed regulatory standards for web-brokers, and to layer on additional consumer protections. For example, HHS can require brokers to sell only qualified health plans (QHPs) during open enrollment, require "best-interest" conduct standards akin to fiduciary standards for brokers selling health plans, require brokers and agents to provide clear disclosures about plans that are not ACA-compliant, screen consumers for Medicare and Medicaid eligibility, and disclose the amount of their commissions.

#16: Website Management & Patient Accessibility: We urge the Administration to direct HHS and CMS to schedule any routine maintenance to HealthCare.gov to minimize reduction in access for consumers and take steps to minimize the impact these outages will have on consumers. We also recommend that CMS be required to 1) provide a public explanation for any required outage or emergency maintenance and 2) explain its plan(s) for how to provide information and follow-up to consumers who may try to access HealthCare.gov during these times.

#17: Reverse Anti-patient Policies that were Included in NBPP rules since 2017: Our organizations request that the Administration reverse numerous anti-patient policies included in NBPP rules since 2017, including changes to the essential health benefits (EHB), adjustments to actuarial value (AV), and others. The Administration should also move to immediately strengthen network adequacy requirements and improve its appeals processes such that they are more consumer friendly, consider implementing standardized plan options, and increase CMS oversight of issuer compliance.

EMPLOYER-SPONSORED COVERAGE

#18: Reverse the Excepted Benefit Health Reimbursement Account Rules: Our organizations ask that the Administration reverse the excepted benefit HRA rule which promotes with federal tax benefits substandard coverage that fails to provide adequate financial protection.

Address Challenges in the Courts

#19: Defend the ACA in *California v Texas:* Our organizations are gravely concerned by the Administration's failure to fully and robustly defend the constitutionality of the ACA and the consumer protections it offers to those we represent. We strongly encourage the federal government to fully defend the Affordable Care Act, and to acknowledge and support the evidentiary record that has been created with regard to the benefits of the law for our patient population.

#20: Discontinue Support for Work & Community Engagement Requirements: Our organizations agree with the court rulings that have invalidated work and community engagement requirements within the Medicaid program, and we urge HHS to discontinue its support of 1115 waiver applications which include such requirements.

#21: Other Administrative Rules in Litigation: Our organizations do not support the expansion of subpar insurance plans, such as AHPs and STLD insurance that do not comply with the ACA's patient protections and that undermine the effectiveness of the law, nor do we support efforts to limit non-discrimination in health care settings. Insurance plans that lack the protections offered by the ACA should be strictly regulated and, in some circumstances, eliminated altogether. We therefore urge HHS to rescind rules allowing for these approaches.

Enact a Comprehensive Pro-Patient Legislative Agenda

#22: Codify Limits & Bans on the Sale of Non-Compliant Insurance Plans: Prohibit the Department of Health and Human Services, the Department of Treasury, and the Department of Labor from implementing, enforcing, or in any way giving effect to final rules that expanded availability of short-term limited-duration or association health plans. For those individuals who are already covered by these plans, ensure that any people who lose this subpar coverage due to rescission of the rule have options to purchase comprehensive, affordable coverage that meets their needs. Additionally, Congress should move to enshrine patient protections into law by codifying the suite of patient and consumer-focused protections outlined in the above section on STLD plans and AHPs. It is critical to note, however, that such policies are interdependent. As such any individual policy enacted alone will fail to offer the type of comprehensive protection consumers require.

#23: Rein in Insurance-Like Products: Revise the federal definition of "insurance" to curtail the inappropriate sale, marketing, and development of insurance-like-products which jeopardize patient health and safety. This should include any products that are marketed to consumers as—or resembling—health insurance, such as farm bureau plans, health care sharing ministries, and some limited-indemnity plans.

#24: Immediately Ban Surprise Medical Billing: We urge the Administration and Congress to work together to immediately pass bicameral, bipartisan legislation that meets our coalition principles.

#25: Increase the FMAP for Remaining States that Have Not Yet Expanded Medicaid: Congress should provide 100 percent FMAP for the first three years that states expand their Medicaid programs, a financial incentive that was available to states that expanded their programs in 2013.

#26: Expand Subsidies for Marketplace Coverage: Our organizations strongly support increasing financial support for individuals and families, and we urge policymakers in the Administration and Congress to increase the number of people eligible for, and the generosity of, advanced premium tax credits (APTCs). Congress should also consider increasing affordability by changing the APTC benchmark from the current silver plan to a higher-level plan, such as gold.

#27: Fix the Family Glitch: Immediately fix the family glitch through regulation or legislation to ensure that families with unaffordable employer-based coverage can access the ACA's advance premium tax credits. Ensure that families can immediately access coverage by implementing a special enrollment period.

#28: Ensure Genuine Affordability: Update federal employer-sponsored coverage affordability standards to allow employees to access subsidized individual market coverage in cases in which their only employer-sponsored insurance option fails to provide comprehensive coverage. Update the cost inputs to federal ESI affordability standards to capture both premium and deductible costs in comparison with employee income. Policymakers should consider applying additional patient protections to HDHPs, including potential options for consumer off-ramps to more affordable coverage through the ACA marketplaces and Medicaid when employer-sponsored HDHPs fail to meet basic affordability tests.

#29: Key Considerations for Developing a Public Option: The Administration and Congress should, at a minimum, account for the following considerations should a public option be developed:

- **Adequate: A public option should be at least as comprehensive as ACA marketplace plans.** We recommend that the public option be a robust benefit. At a minimum, a public option should cover preventive services without cost-sharing, cover the essential health benefits, and ensure that plans meet a minimum actuarial value. This includes ensuring patients have access to prescription medications, preventive and emergency services, and reproductive and maternity care.
- **Affordable: A public option must improve affordability of coverage.** A public option must include caps on out-of-pocket costs and other protections that reduce consumer costs. Affordability should not be measured on premiums alone, but should also take into account deductibles and other out-of-pocket costs. Any attempt to craft a federal public option should be designed thoughtfully; the program must enable more individuals to access high-quality, affordable care while preserving or improving affordability for existing individual market enrollees. Proposals should also be paired with increases in eligibility for and the generosity of the ACA's subsidies in order to expand high-quality coverage to more individuals and families.
- **Accessible: A public option must increase the number of insured individuals and ensure patients have access to the services and providers that they need**. A public option that is broadly available to people in a variety of coverage situations is likely to generate a much bigger increase in coverage than a program with relatively narrow eligibility criteria. Additionally, patients must have access to adequate and robust provider networks. Policymakers must ensure that patients have timely access to providers and specialty services.

PREAMBLE

Our 33 organizations represent the interests of the millions of patients and consumers in the United States who live with serious, acute, and chronic conditions. In March 2017, we worked to identify three overarching principles to guide and measure any work to further reform and improve the nation's health insurance system. Our core principles are that health care must be **adequate, affordable, and accessible**.[1] Together, we work to ensure that voices and priorities of our patients are represented in Congress, states, the Administration, and the courts to ensure that access to high-quality health coverage is always available to Americans and their families.

Prior to the Affordable Care Act (ACA), individuals who were in the most need of health insurance coverage—including older and sicker Americans and people living with pre-existing conditions—often found it difficult, if not impossible, to obtain and retain health insurance that provided the coverage they needed at an affordable cost. Many individuals were denied coverage due to their pre-existing conditions, were charged outrageous premiums, and/or were left with inadequate benefit packages.

Now more than ever, millions of Americans, including many who are low-income or live with pre-existing health conditions, rely on health care coverage received through the ACA. In fact, the number of uninsured nonelderly Americans decreased from over 46.5 million in 2010 (the year the ACA was enacted) to just below 27 million in 2016.[2] Prior to the law's implementation, millions of patients had difficulty affording medication, routine care, preventive screenings, and other services that are essential for maintaining and improving their health. Indeed, many patients with serious and chronic conditions were often forced to delay or forego necessary health care. While our organizations recognize that the ACA is far from perfect, it has increased the number of Americans with health insurance, improved health outcomes, and decreased health disparities more than any other single piece of legislation within recent memory. Yet this progress is imperiled; policy changes since 2017 have attempted to undo many of the ACA's gains, and it is clear that additional steps must be taken to improve and expand our system of care. These include:

- Reversing policies that restrict access to Medicaid, including work and community engagement requirements, block grant guidances, and changes to the underlying structures that limit the quality or generosity of Medicaid benefits.
- Reversing administrative actions that create barriers to high-quality individual and small group health insurance coverage for patients, including funding cuts for navigator services, revisions to the 1332 guidance, loosening the regulation of non-compliant plans, and expanding the sale of non-compliant plans that put patients and consumers at risk.
- Standing up for patients and vigorously defending the ACA in the courts.
- Advancing a comprehensive pro-patient legislative agenda that strengthens and improves upon coverage gains resulting from the ACA.

The COVID-19 pandemic has further complicated the health insurance landscape for our patients. Recent reports indicate that approximately 5.4 million people have lost access to employer-sponsored coverage in the first two months of the pandemic alone.[3] This poses a significant threat to individuals with pre-existing conditions who are at increased risk of infection and adverse health outcomes from COVID-19.

1 Health care reform principles. American Heart Association website. http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_495416.pdf.

2 Tolbert, J., Orgera, K., Singer, N., & Damico, A. (2019, December). *Key Facts about the Uninsured Population*. Kaiser Family Foundation. http://files.kff.org/attachment/Issue-Brief-Key-Facts-about-the-Uninsured-Population

3 Dorn, S. (2020, July). *The COVID-19 Pandemic and Resulting Economic Crash Have Caused the Greatest Health Insurance Losses in American History*. The National Center for Coverage Innovation at Families USA. https://familiesusa.org/wp-content/uploads/2020/07/COV-254_Coverage-Loss_Report_7-17-20.pdf

Furthermore, the pandemic's disproportionate impact on communities of color makes it clear that more needs to be done to support our system of care so that all Americans receive the testing, treatment, and care they need—not only to maintain their health, but also to limit the spread of this dangerous disease. Longstanding racial and ethnic health disparities have resulted in disproportionately higher rates of certain chronic conditions and poorer health outcomes for minority populations. Half of the 30 million Americans without insurance are people of color.[4] As our nation moves forward to eliminate health disparities and address the impact of systemic racism on the health of communities of color, improving access to quality and affordable health care coverage will be essential. Our organizations are committed to making the elimination of health disparities central to all of the work that we do to improve access to quality and affordable health care for patients with serious and chronic health conditions.

Our organizations supported some of the temporary policies enacted during the COVID-19 pandemic to improve patients' access to care. While we believe that tools such as telehealth can rise to meet some needs of patients, they must be accompanied by policies that support robust access to comprehensive coverage. As policymakers further shape what telehealth looks like, it is important that patient perspectives be considered to ensure that policymakers fully account for the needs of all Americans, including those with pre-existing conditions.[5]

Together, our organizations understand what individuals and families need to prevent disease, manage health, and treat illness. We urge you to consider the needs of the communities we represent as you develop your legislative and administrative priorities intended to preserve coverage for individuals who are currently covered, extend coverage to those who remain uninsured, protect those who are under-insured, and lower costs and improve quality of care for all. With this in mind, we make the following recommendations.

4 Young, C. L. (2020, February 20). *There are clear, race-based inequalities in health insurance and health outcomes*. Brookings. https://www.brookings.edu/blog/usc-brookings-schaeffer-on-health-policy/2020/02/19/there-are-clear-race-based-inequalities-in-health-insurance-and-health-outcomes/

5 *Coalition Principles for Telehealth Policy.* (2020, August). https://prismic-io.s3.amazonaws.com/npf-website/12ec08fb-7bc8-4663-9f91-c1583be66c01_FINAL+Principles+for+Telehealth+Policy+_8_27_2020.pdf

UNWIND ADMINISTRATIVE CHANGES THAT CREATE BARRIERS TO CARE

Our organizations are deeply troubled by policies that restrict or place burdensome barriers to accessing care, particularly for low-income and underserved communities. To ensure all patients can seek and receive the services they need, we ask that the Administration utilize its authorities to remove these barriers and implement policies that would streamline enrollment and ensure that every patient has equitable access to comprehensive health care at an affordable cost.

Medicaid

Medicaid plays a crucial role in the health care of low-income and disabled individuals and families across the United States by providing access to preventive services, treatment, disease management, and care coordination. For example, Medicaid provides health insurance coverage for nearly one half of children and one third of adults with cystic fibrosis,[6] nearly half of children with asthma,[7] one-third of adults with epilepsy,[8] and disproportionately covers adults living with diabetes.[9] Furthermore, almost a third of the adult population with Medicaid coverage has a history of cardiovascular disease.[10] It is clear that the Medicaid program is a critical access point for disease management and care. The importance of the Medicaid program for our patients has only grown over the past few months as Medicaid enrollment continues to increase as a result of the COVID-19 pandemic and its economic impact.

The Medicaid program has faced a number of threats over the past three years, including: legislative efforts to repeal Medicaid expansion and restructure the program's funding; proposed rules that jeopardize patients' access to treatments and services in fee-for-service and Medicaid managed care; and Section 1115 waivers that created new and serious barriers to care for patients. We therefore make the following comments and recommendations regarding our organizations' priorities for the Medicaid program in hopes that the Administration will swiftly remove unnecessary or burdensome barriers to care and implement policies that will strengthen and improve the overall function of the program for the individuals and families we represent.

#1: Eliminate Policies in Section 1115 Waivers that Create Barriers to Care

Medicaid's core mission, as defined in Section 1901 of the Social Security Act (SSA), is to provide health care coverage for low-income individuals and families. The intent of the 1115 Demonstration Waiver program is to increase access and test innovative approaches to delivering care to further the objectives of the Medicaid program.[11] As a result, Section 1115 waivers have historically been used to leverage the Medicaid program's flexibilities to extend coverage and services to additional populations. However, since 2016, states have begun to use Section 1115 waivers to restrict—instead of expand—access to care. Frequently, applications lack sufficient evidence, complete impact data, and requisite budgetary information. Some of the financial policy and administrative barriers to coverage requested and approved in recent years include:

- **Premiums:**
  Multiple states have established or raised premiums for

6 Cystic Fibrosis Foundation. (2017, August). *2016 Patient Registry: Annual Data Report*. https://www.cff.org/research/researcher-resources/patient-registry/2016-patient-registry-annual-data-report.pdf

7 Centers for Disease Control and Prevention. (2016). *Health Care Coverage among Children | CDC*. Cdc.Gov. https://www.cdc.gov/asthma/asthma_stats/Health_Care_Coverage_among_Children.htm

8 Thurman, D. J., Kobau, R., Luo, Y. H., Helmers, S. L., & Zack, M. M. (2016). Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013. *Epilepsy & behavior : E&B*, *55*, 184–188. https://doi.org/10.1016/j.yebeh.2015.10.028

9 Garfield, S. S., Xenakis, J. J., Bastian, A., & McBride, M. (2015). Experiences of People with Diabetes by Payer Type: An Analysis of the Roper Diabetes Data Set. *Diabetes Therapy*, *6*(2), 113–125. https://doi.org/10.1007/s13300-015-0109-z

10 Kaiser Family Foundation. (2012, November). *The Role of Medicaid for People with Cardiovascular Diseases*. https://www.kff.org/wp-content/uploads/2013/01/8383_cd.pdf

11 Centers for Medicare and Medicaid Services. (2020). *Section 1115 Demonstrations, Medicaid*. https://www.medicaid.gov/medicaid/section-1115-demonstrations/index.html

beneficiaries, increasing the number of enrollees who lose Medicaid coverage and discouraging eligible people from enrolling in the program. Research has shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary health care services.[12]

- **Short-sighted cost-sharing for emergency care:** Charging co-pays for treatment in the emergency department deters patients from seeking emergency care when needed. For example, a study of enrollees in Oregon's Medicaid program demonstrated that implementation of a co-pay on emergency services resulted in decreased utilization of such services but did not produce the intended cost savings because of subsequent use of more intensive and expensive services, suggesting the policy is associated with inappropriate delays in needed care.[13]
- **Delayed coverage for eligible patients:** Retroactive eligibility in Medicaid is a beneficial policy that prevents gaps in coverage by covering eligible individuals for up to 90 days prior to the month of application, assuming the individual had been eligible for Medicaid coverage during that time frame. Recent waivers have removed this protection, meaning that uninsured patients who have been in an accident or diagnosed with a serious illness and are eligible for Medicaid might have to delay treatment or take on significant medical debt. Eliminating this patient protection has also weakened the safety net by putting in doubt provider reimbursements for patients who are eligible for but new to Medicaid.
- **Patient lockouts:** Some states have imposed lockouts for failure to pay monthly premiums or for failure to comply with other criteria such as work and community engagement requirements. Regardless of the reason, it is never appropriate to withhold care by locking patients out of coverage. For individuals with chronic health conditions, maintaining access to comprehensive coverage is vital to ensuring they continue to maintain access to their physicians, medications, and other treatments and services they need.
- **Reduced benefits for young adults:** The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit ensures children and young adults can access certain screenings, services, or treatments that are medically necessary, even if they are not normally covered under a state's Medicaid program for adults. Limiting the benefit to 19- and 20-year-olds, as recent waivers have proposed, reduces patients' ability to access needed health care services at a critical time in their development.
- **Elimination of non-emergency transportation (NEMT):** NEMT helps Medicaid enrollees get transportation to their medical appointments so they can manage their conditions and stay healthy. Without this benefit, enrollees may be unable to afford transportation to appointments and as a result delay needed care, possibly resulting in patients needing more expensive treatments in the future.

Recommendation #1: Our organizations urge the Administration to reject any Section 1115 demonstration applications that include these and other financial and administrative barriers that jeopardize patients' access to care while adding needless complexity to the program. We also request that the Administration only approve demonstrations that improve access to coverage and have a valid experimental design.

#2: Eliminate Work & Community Engagement Requirements

In January 2018, CMS issued a state Medicaid director letter inviting state Medicaid directors to submit waiver applications involving work and community engagement requirements, and since 2016, 21 states have submitted waivers that would implement work and community engagement requirements on some or all of their Medicaid eligible populations.[14] Such requirements eliminate Medicaid access for eligible people who fail to successfully navigate the rules and paperwork necessary to demonstrate to their state that they met stringent requirements for working, studying, or volunteering a set number of hours over a short period of time.

These requirements have been shown to significantly harm patients by reducing their access to health care services both in the short and long term.[15,16] Indeed, implementing work and community engagement requirements in Medicaid programs creates unnecessary barriers to care and has already negatively impacted vulnerable populations, including leading to coverage losses among individuals already working that harmed their

12 Artiga, S., Ubri, P., & Zur, J. (2017, June). **The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings**. Kaiser Family Foundation. https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

13 Wallace, N. T., McConnell, K. J., Gallia, C. A., & Smith, J. A. (2008). How effective are copayments in reducing expenditures for low-income adult Medicaid beneficiaries? Experience from the Oregon health plan. **Health services research**, **43**(2), 515–530. https://doi.org/10.1111/j.1475-6773.2007.00824.x

14 Centers for Medicare and Medicaid Services. (2018, January 11). *CMS announces new policy guidance for states to test community engagement for able-bodied adults | CMS* [Press release]. https://www.cms.gov/newsroom/press-releases/cms-announces-new-policy-guidance-states-test-community-engagement-able-bodied-adults

15 Hill, I., & Burroughs, E. (2019, October). *Lessons from Launching Medicaid Work Requirements in Arkansas*. Urban Institute. https://www.urban.org/research/publication/lessons-launching-medicaid-work-requirements-arkansas/view/full_report

16 Sommers, B. D., Chen, L., Blendon, R. J., Orav, E. J., & Epstein, A. M. (2020). Medicaid Work Requirements In Arkansas: Two-Year Impacts On Coverage, Employment, And Affordability Of Care. *Health Affairs*, *39*(9), 1522–1530. https://doi.org/10.1377/hlthaff.2020.00538

health.[17] For example, in 2018 Arkansas implemented a work reporting requirement where Medicaid enrollees had to report their hours worked or file for an exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals.[18,19] Despite a large undertaking by the state to inform residents, surveys found that a lack of awareness or confusion about the new requirement were common. This confusion may have contributed to the significant loss of coverage. More than 95 percent of Arkansans subject to the reporting requirements appeared to already meet required hours of work or qualify for an exemption (further confirming that most Medicaid beneficiaries are working if they are able to do so).[20] Furthermore, this significant loss of Medicaid coverage was not associated with a corresponding increase in employment.[21]

These requirements are not only harmful to patients and ineffective at increasing actual work and community engagement; they are also in direct opposition to the statutory intent of the Medicaid program. The Medicaid statute defines the factors states can consider in determining eligibility for Medicaid, such as income, citizenship and immigration status, and state residence. The statute does *not* include beneficiaries' employment status or ability to work, if they are seeking work, or their ability to engage in work-related activities as a permissible factor in determining Medicaid eligibility.[22] As a result, these polices fall outside statutory authority for the Medicaid program. Prior determinations by the U.S. District Court for the District of Columbia invalidated work requirement waivers submitted by Michigan, Kentucky, New Hampshire, and Arkansas for similar reasons.[23,24,25,26]

Recommendation #2: Our organizations strongly oppose work and community engagement requirements. CMS must rescind the guidance, deny all current or pending waivers in this area, and explicitly communicate to states that the January 2018 State Medicaid Director letter encouraging states to apply for such waivers is no longer reflective of the Centers for Medicare and Medicaid Services' (CMS's) position.

#3: Rescind Block Grant Guidance

On January 30, 2020, CMS issued guidance that would allow states to apply for a waiver to impose a block grant or per capita cap on their Medicaid programs.[27] This guidance is deeply troubling to our organizations and the communities we serve. These policies are designed to reduce federal funding for Medicaid and force states to either make up the difference with their own funds or cut their programs by reducing the number of people they serve and the benefits they provide. Per capita caps and block grants would cut Medicaid most deeply precisely when the need is greatest, because funding would no longer increase automatically in response to changing demographics or emerging public health threats such as COVID-19.

In addition to changing the financial structure of state Medicaid programs, the guidance also invites states to make a variety of changes that would be detrimental to patients including: waiving retroactive and presumptive eligibility, asset testing, limiting or restricting core benefits by allowing states to select another state's benchmark package, waiving EPSDT, and limiting prescription drug coverage, amongst others. While each of these policies is concerning on its own, the broad flexibility afforded to states by CMS to utilize one or more of these in combination with per capita cap or block grant financing structure poses major threats to patients' ability to access care through the Medicaid program.

Recommendation #3: Block grants and per capita caps will reduce access to quality and affordable health care for patients with serious and chronic health conditions and—like work and community engagement requirements—are therefore not allowable in the Medicaid program. The Administration must immediately rescind the January 2020 guidance.

17 Thousands in Arkansas lose Medicaid due to new work requirement. (2018, November 19). [Video]. PBS NewsHour. https://www.pbs.org/newshour/show/with-new-work-requirement-thousands-lose-medicaid-coverage-in-arkansas

18 Rudowitz, R., Musumeci, M., & Hall, C. (2019, March). *February State Data for Medicaid Work Requirements in Arkansas*. Kaiser Family Foundation. https://www.kff.org/medicaid/issue-brief/state-data-for-medicaid-work-requirements-in-arkansas/

19 Arkansas Department of Human Services. (2018, December). *Arkansas Works Program December 2018 Report*. http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

20 Sommers, B. D., Goldman, A. L., Blendon, R. J., Orav, E. J., & Epstein, A. M. (2019). Medicaid Work Requirements—Results from the First Year in Arkansas. *New England Journal of Medicine*, *381*(11), 1073–1082. https://doi.org/10.1056/nejmsr1901772

21 Ibid.

22 Perkins, Jane. "Medicaid Work Requirements: Legally Suspect," National Health Law Program, (March 2017). https://healthlaw.org/resource/medicaid-work-requirements-legally-suspect/

23 Boasberg, J. (2020, November 18). *Docket for YOUNG v. AZAR, 1:19-cv-03526—CourtListener.com*. CourtListener. https://www.courtlistener.com/docket/16504777/young-v-azar/

24 *Docket for Ronnie Stewart v. Alex Azar, II, 19-5095—CourtListener.com*. (2019, July 30). CourtListener. https://www.courtlistener.com/docket/9684/ronnie-stewart-v-alex-azar-ii/

25 *Docket for Charles Gresham v. Alex Azar II—CourtListener.com*. (2019, March 27). CourtListener. https://www.courtlistener.com/opinion/4604323/gresham-v-azar/

26 *Docket for Samuel Philbrick v. Alex Azar II, 1:19-cv-00773—CourtListener.com*. (2020, September 20). CourtListener. https://www.courtlistener.com/docket/14756647/philbrick-v-azar-ii/

27 Centers for Medicare and Medicaid Services. (2020b, January 30). *State Medicaid Director Letter Re: Healthy Adult Opportunity*. https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf

#4: Stop Changes to Medicaid Managed Care Rules

Contracted managed care plans now serve nearly 70% of Medicaid enrollees.[28] Regulation and oversight of managed care is crucial to a well-functioning Medicaid program, but under the current system, many access challenges remain for the patients we represent. For example, patient struggles to access care through managed care organizations have been well-documented in several states, including Iowa, Kansas, and Texas.[29, 30, 31] In 2016, CMS issued a final rule that included substantial updates to managed care requirements. In 2018, CMS issued a proposed rule that pulled back several of these requirements.

Recommendation #4: CMS should withdraw the 2018 Medicaid managed care proposed rule. Instead, CMS should increase and strengthen monitoring, oversight, and requirements for Medicaid managed care, including in the areas of network adequacy (including for long-term services and supports), civil rights protections, rate review and actuarial soundness of capitation rates, data reporting, quality oversight, and grievance and appeal procedures.

#5: Establish Sufficient Standards to Ensure Access to Care

Section 1902(a)(30)(A) of the Social Security Act requires that state Medicaid programs "assure that payments are consistent with efficiency, economy and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area." As a result, CMS has a duty to monitor provider rates to ensure beneficiaries have adequate access to services. In 2015, CMS issued a final rule that included steps for states to show that they were ensuring access to services, but the final rule excluded services provided under a waiver. This excluded the nearly 70% of enrollees served through managed care[32] and the majority of home and community-based services (HCBS) provided through 1915(c) waivers. In 2019, CMS proposed to withdraw the 2015 rule entirely. After the U.S. Supreme Court ruled in *Armstrong v. Exceptional Child Center, Inc.* that providers do not have standing to challenge Medicaid payment rates, CMS must provide oversight of state payment rates to ensure they comply with the law and do not threaten patients' access to services.

Recommendation #5: In tandem with enforcing strong network adequacy requirements in managed care, CMS should withdraw the 2019 proposed rule and implement a system of monitoring, oversight, and enforcement of provider payment rates in Medicaid that ensures sufficient access to services, including waiver services. In building this system, CMS should start with the numerous comments provided in the 2011 NPRM, 2015 final rule with comment period, and 2019 proposed rescission, many of which include proposed frameworks for access measurement, as well as soliciting new input through an RFI.

#6: Stop the Proposed Medicaid Fiscal Accountability Rule

Medicaid is a federal-state matching program; the federal government only matches state expenditures for covered services for eligible individuals. States rely on a variety of funding sources, including provider taxes, intergovernmental transfers (IGTs), and certified public expenditures (CPEs), to pay for their share of the program. Reliance on these funding sources is widespread; in state fiscal year 2019, almost all states raised revenues from assessments on hospitals, intermediate care facilities, and/or nursing facilities[33], and some states have assessments on managed care plans as well. In fact, some states established or increased provider taxes to help finance the state cost of the Medicaid expansion, which has helped patients in these states receive earlier stage cancer diagnoses, decreased maternal and infant deaths[34],

28 *Total Medicaid MCO Enrollment.* (2020, August 21). KFF. https://www.kff.org/other/state-indicator/total-medicaid-mco-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D

29 Leys, T., & Gruber-Miller, S. (2019, July 10). Iowa agrees to 8.6% raises for Medicaid management companies. *The DesMoines Register*. https://eu.desmoinesregister.com/story/news/health/2019/07/10/iowa-medicaid-privatization-managed-care-companies-amerigroup-centene-iowa-total-care-mcos-increase/1691928001/

30 Hall, J. P., Kurth, N. K., & LaPierre, T. (2017, May). *Kansas Medicaid: Evaluating Program Satisfaction, Access to Care, and Unmet Needs of Adults with Serious Mental Illness*. Health Forward Foundation—University of Kansas Institute for Health and Disability Policy Studies. https://healthforward.org/research/kansas-medicaid-evaluating-program-satisfaction-access-care-unmet-needs-adults-serious-mental-illness/

31 McSwane, J. D., & Chavez, A. (2018, June 3). Pain & Profit: An investigation into the way Texas treats its most fragile citizens—Managed-care companies overstated the number of physicians available to treat the state's sickest patients. *Dallas Morning News*. https://johndhancock.github.io/projects/pain-and-profit/

32 Kaiser Family Foundation. (2020, August 21). *Total Medicaid MCO Enrollment*. KFF. https://www.kff.org/other/state-indicator/total-medicaid-mco-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D

33 Kaiser Family Foundation. (2019, October). *Tables Report: A View from the States Key medicaid Policy Changes*. http://files.kff.org/attachment/Tables-Report-A-View-from-the-States-Key-Medicaid-Policy-Changes

34 Searing, A., & Cohen Ross, D. (2019, May). *Medicaid Expansion Fills Gaps in Maternal Health Coverage Leading to Healthier Mothers and Babies*. Georgetown University Health Policy Institute Center for Children and Families. https://ccf.georgetown.edu/2019/05/09/medicaid-expansion-fills-gaps-in-maternal-health-coverage-leading-to-healthier-mothers-and-babies/

reduced deaths from opioid overdoses[35], and reduced racial disparities in timely treatment for cancer patients[36], among numerous other beneficial health outcomes.[37] Most states use IGTs and/or CPEs as well.[38] In 2019, CMS issued a proposed rule that could have resulted in large-scale disallowance of these financing mechanisms based on broad, loosely defined standards. This would force states to raise taxes or cut benefits, a significant risk to the people with serious chronic conditions who rely on the program. Our organizations were very pleased that CMS responded to widespread stakeholder concerns and withdrew this rule in September 2020.

Recommendation #6: If CMS considers additional work on this topic, it should focus on transparency and the reporting of accurate and reliable data about the operations and financing of the Medicaid program.

#7: Withdraw the Proposed Changes to the Official Poverty Measure

On May 7, 2019, the Office of Management and Budget (OMB) released a proposal to change the Official Poverty Measure (OPM). The proposed changes to the OPM's inflation calculation would reduce the annual adjustments to the poverty measure and therefore may exacerbate existing weaknesses, putting vulnerable Americans—including those with serious and chronic diseases—at great risk of losing health coverage and other benefits. Further lowering the poverty line would also give policymakers and the public less credible information about the number and characteristics of Americans living in poverty.

The changes put forward by OMB would have a direct and significant impact on programs operated by the Department of Health and Human Services (HHS), the Department responsible for issuing poverty guidelines that are used across many government programs. If these changes were to be implemented, they would impact a great number of programs, including those that serve patients such as the Medicare Part D low-income subsidy (LIS), the Children's Health Insurance Program (CHIP), Advance Premium Tax Credits (APTCs), nutrition programs, and others. If finalized, the cumulative impact of such a change may seriously disrupt access to health care and cause further distressing financial hardships for the people already struggling with serious and chronic illness.

Recommendation #7: We urge that the proposed changes to the statistical index put forward by OMB in May 2019 be withdrawn. Instead, the Administration should update OPM's current formula to accurately reflect the needs of low-income individuals and families. Today, the current formula's calculations for basic household expenses for families underestimates child care and housing expenses.[39] Instead of revising down the OPM formula to make benefits less generous over time, it should be revised and updated such that the calculation more accurately reflects the needs and expenses of low-income individuals and families.

The Affordable Care Act

Prior to the enactment of the patient protections included in the ACA, it was difficult—and often impossible—for people with serious illnesses to get or keep affordable and adequate health insurance. The ACA has radically changed our patients' experience with the health insurance market for the better. Today, issuers are required to provide comprehensive coverage and prohibited from unfair coverage restrictions that discriminate against people with serious or chronic illnesses on the basis of their pre-existing condition.

However, over the past several years, steps to deregulate the insurance industry have allowed issuers to again employ practices that were once used to discriminate against people with pre-existing conditions. In addition to resurrecting discriminatory practices, these deregulatory actions have led to an increase in the number of unregulated insurance-like products being marketed to consumers as health insurance. Other administrative actions have decreased funding for outreach and education resources, making it more difficult for patients to make informed decisions about the type of insurance that best meets their medical needs. The cumulative result of weakening the overall effectiveness of the ACA, segmenting the individual market risk pool, and increasing the market for sub-par products that attract but fail to protect younger, healthier individuals is artificially inflated insurance premiums for people who rely on comprehensive coverage. We therefore urge the Administration to restore protections and resources that help patients get high-quality insurance coverage that meets their needs. To that end, we make the following recommendations:

35 Kravitz-Wirtz, N., Davis, C. S., Ponicki, W. R., Rivera-Aguirre, A., Marshall, B. D. L., Martins, S. S., & Cerdá, M. (2020). Association of Medicaid Expansion With Opioid Overdose Mortality in the United States. *JAMA Network Open*, *3*(1), e1919066. https://doi.org/10.1001/jamanetworkopen.2019.19066

36 *Racial Disparities in Access to Timely Cancer Treatment Nearly*. (2019, June 2). [Press release]. https://www.asco.org/about-asco/press-center/news-releases/racial-disparities-access-timely-cancer-treatment-nearly

37 Soni, A., Simon, K., Cawley, J., & Sabik, L. (2018). Effect of Medicaid Expansions of 2014 on Overall and Early-Stage Cancer Diagnoses. *American Journal of Public Health*, *108*(2), 216–218. https://doi.org/10.2105/ajph.2017.304166

38 Government Accountability Office. (2015, December). *GAP Analysis of State-Reported Data*. https://www.gao.gov/special.pubs/gao-15-227sp/sectionb212.html

39 National Research Council. (1995). *Measuring Poverty: A New Approach*. The National Academies Press. https://doi.org/10.17226/4759

#8: Limit Short-Term, Limited-Duration (STLD) Insurance

We are deeply concerned that STLD (or short-term) plans have disproportionately harmed patients with pre-existing conditions. While STLD plans can offer cheaper premiums for some consumers, they are not required to adhere to important standards, including prohibitions on discrimination against people with pre-existing conditions, coverage for the 10 essential health benefit categories, limitation on age rating of premiums, annual out of pocket maximums, prohibitions on gender rating, annual benefit limits, and lifetime coverage limits, and many other critical patient and consumer protections. In fact, two separate studies of plans being sold in 2019 found that a majority do not cover all of the essential health benefits—particularly prescription drugs and mental health.[40, 41]

STLD plans are allowed to charge higher premiums or refuse to sell coverage altogether to individuals with pre-existing conditions. Plans can also exclude specific services based on an individual's health status and medical history, include deductibles that are many times higher than ACA compliant plans, and do not need to meet basic network adequacy requirements. Therefore, many of the individuals represented by our organizations would be both unable to purchase short-term plans due to a pre-existing condition and unwilling to do so when confronted with the lack of patient protections—or find themselves seriously underinsured if they unwittingly purchased such a plan.

Expanding access to these policies has artificially inflated premiums in the marketplace by siphoning younger and healthier individuals away from the ACA-compliant market risk pool.[42] Indeed, consumers who continue to require comprehensive ACA-compliant health plans have seen their premiums go up, contributing to existing affordability problems. A study conducted by the Urban Institute projected that the 2018 proposed rule would lead over 2.5 million younger and healthier consumers across the country to move out of minimum essential coverage plans into short-term plans, increasing premiums for those consumers who remain in the nongroup insurance market by an average of 18.3%.[43] A February 2020 report commissioned by The Leukemia & Lymphoma Society bolsters that finding. In states where STLD availability has not been regulated, insurer rate filings show premiums that are an average of 5% higher, compared to rates filed in states that banned or significantly restricted STLD policies. Insurers attribute those rates to regulatory actions (including STLD policy expansion and the repeal of the individual mandate). As a result of the STLD plan expansion and the elimination of the individual mandate, the ACA individual market in states that lack STLD restrictions is expected to lose up to 6% of members to non-ACA-compliant coverage, such as STLD policies, or become uninsured by 2021.[44]

Recommendation #8: STLD plans pose a significant threat to our patient populations and anyone who enrolls and may become sick. The Administration should immediately limit the harm of these plans by:

- **Restoring 3-month Duration:** Prohibiting STLD plans from extending beyond 3 months would help ensure that these products were used for their original purpose, providing a short-term option intended only to bridge a gap in coverage between comprehensive health plans.
- **Limiting Renewability and Closing the "Stacking" Loophole**: STLD plans should not be renewable or allowed to continue for more than three months because of the significant risk posed to consumers by their combination of extraordinary deductibles and limited catastrophic financial protection. The renewability of plans should be reserved for health insurance that meets the definition of minimum essential coverage (MEC), which short-term plans do not meet. Allowing short-term plans to be renewed or purchased consecutively from different issuers (a loophole in the duration limit protections known as "stacking") contributes to increased premiums and financial risk for consumers. We therefore recommend that plans not be allowed to renew, and that consumers not be allowed to purchase consecutive STLD plans from different issuers.
- **Banning Sales During Open Enrollment:** Studies indicate that STLD plans have been aggressively and deceptively marketed to consumers, especially during the ACA's annual Open Enrollment period.[45] We therefore urgethe Administration to impose a ban on sales during federal and state open enrollment periods in order to decrease consumer confusion.

40 Hansen, D., & Dieguez, G. (2020, February). *The impact of short-term limited-duration policy expansion on patients and the ACA individual market*. Milliman Actuarial. https://www.lls.org/sites/default/files/National/USA/Pdf/STLD-Impact-Report-Final-Public.pdf

41 U.S. House of Representatives Committee on Energy and Commerce. (2020, June). *Shortchanged: How the Trump Administration's Expansion of Junk Short-Term Health Insurance Plans is Putting Americans at Risk*. Subcommittee on Health and Subcommittee on Oversight and Investigations—Democratic Staff Report https://degette.house.gov/sites/degette.house.gov/files/STLDI%20Report%2006%2025%2020%20FINAL_.pdf

42 Ibid.

43 Blumberg, L., Buettgens, M., & Wang, R. (2018, March). *Updated: The Potential Impact of Short-Term Limited-Duration Policies on Insurance Coverage, Premiums, and Federal Spending*. Urban Institute. https://www.urban.org/research/publication/updated-potential-impact-short-term-limited-duration-policies-insurance-coverage-premiums-and-federal-spending

44 Ibid.

45 Findlay, S. (2019, January 31). **Ads For Short-Term Plans Lacking ACA Protections Swamped Consumers' Online Searches**. Kaiser Health News. https://khn.org/news/ads-for-short-term-plans-lacking-aca-protections-swamped-consumers-online-searches/

- **Limiting Sales via the Internet & Phone:** Sales of STLD plans via the internet and phone have also increased since they were deregulated in 2018.[46] The increased availability of these plans, combined with deceptive marketing practices, leave consumers at increased risk of purchasing a plan that does not meet their medical needs. As a result, we ask HHS to restrict sales of non-compliant plans to in-person encounters In compliance with COVID restrictions.
- **Establishing a Prohibition on Rescissions:** Unlike comprehensive insurance plans sold on the individual market, short-term plans are able to rescind a patient's coverage following a process called post-claims underwriting. There is evidence that plans have utilized this process to initiate retroactive coverage rescissions, leaving patients who thought they were covered without any financial or medical protection whatsoever. This practice leaves patients without access to necessary services and at significant financial risk.[47] As such, we urge HHS to place strong prohibitions on the practice of rescissions within this market.
- **Improving Disclosures:** Disclosure alone is not an adequate solution to the risks posed by the proliferation of STLD plans. However, providing consumer information in a clear and comprehensive way is critical to reducing the risk that consumers are misled into purchasing inadequate coverage. Consumer disclosure should be provided in writing and verbally; be of sufficient font size using bold and boxes to aid consumers in identifying critical information and ensure readability; must explicitly say that a STLD plan is not comprehensive, including a list of MEC services that are not provided; and, when applicable, provide a clear explanation that the plan does not have a network of providers and/or offer protection against being balance billed by participating providers following a service.
- **Codifying These Regulations into Law:** Leaders and members of both parties have repeatedly committed to protecting patients from discriminatory practices, such as those utilized by STLD plans. We urge Congress to codify the protections above into law in order to robustly protect patients and consumers.

46 Ibid.

47 Palanker, D., & Goe, C. (2020, March 27). **States Don't Know What's Happening in Their Short-Term Health Plan Markets and That's a Problem | Commonwealth Fund**. Commonwealth Fund. https://www.commonwealthfund.org/blog/2020/states-dont-know-whats-happening-their-short-term-health-plan-markets-and-thats-problem

#9: Restrict Multiple Employer Welfare Arrangements (MEWAs) & Association Health Plans (AHPs)

In 2018, the Department of Labor (DOL) significantly altered the standards and regulatory structures governing Multiple Employer Welfare Arrangements (MEWAs) (which include Association Health Plans [AHPs]) to offer less regulated coverage to small businesses and sole proprietors. These changes weakened standards related to benefit structure, cost, and oversight of these plans. Our organizations continue to share our concerns about these changes and their impact on the on the communities we serve.

Most AHPs are not required to comply with EHB coverage requirements created under the ACA. The rule finalized by DOL on June 2018 that makes it easier for AHPs to qualify for regulation as Employee Retirement Income Security Act (ERISA)-governed large-group health plans (sometimes referred to as single multi-employer plans) that do not have to comply with many of the ACA's coverage and adequacy requirements. The rule was challenged, and in March 2019 the District Court for the U.S. District of Columbia held the expansion of the definition of a "bona fide association" in the rule was an unreasonable interpretation of ERISA.[48] The court struck down the provisions of the rule that allowed employers that lacked common interests as well as sole proprietors to form AHPs (the decision does not touch existing plans but prevents sales or marketing of new AHPs under the rule). The Department appealed to the U.S. Court of Appeals for the District of Columbia, and the case was argued in November 2019. No decision has been issued on the appeal.

As the case works its way through the appeals process, our organizations continue to be deeply concerned about the implications of this rule on the individuals we represent. Our patients rely on the ACA's coverage requirements for access to medically necessary care.

AHPs are concerning, in part, because they are allowed to charge high premiums to consumers based on a range of factors that, in practice, facilitate discrimination against the patients we represent. Though AHPs may not vary plan premiums based upon health factors, these arrangements may hike premiums for groups of enrollees for reasons such as gender, age, employee classifications, locations, or any other non-health criteria that could stratify the plan beneficiary population. This wide discretion enables AHPs to offer products that effectively exclude entire classes of beneficiaries with higher rates of illness and disease.

Furthermore, AHPs have broad flexibility to structure their benefit designs in ways that could harm patients with certain health and pre-existing conditions. Consequently, AHPs can

48 *State of New York v. United States Department of Labor* (March 28, 2019), https://www.courtlistener.com/opinion/4604772/state-of-new-york-v-united-states-department-of-labor/

design plans that exclude coverage for medically necessary prescription drugs, certain specialists who treat particularly expensive conditions, or other medically necessary care for individuals with chronic conditions. AHPs are also not subject to network adequacy requirements. These limitations are particularly concerning for our organizations as we represent the individuals who are most in need of access to emergency services, outpatient care, and specialty physicians. Without regulation and oversight of network adequacy within AHPs, the physicians and services patients rely on could be excluded from AHP provider networks altogether or only include facilities or specialists in the network that are far too distant from beneficiaries to be accessible. Such tactics allow AHPs to provide coverage-in-name-only for people with pre-existing conditions.

Recommendation #9: Direct DOL to reverse the 2018 rule and reinstate to the previous regulations governing these plans while also including new provisions that would help protect patients and consumers. They include:

- **Codifying the "Look Through" Doctrine:** CMS should codify the "look-through" doctrine[49] in regulation. The doctrine holds that, except in "rare instances," regulators must "look through" an association (effectively disregard it) and regulate the health coverage that the association issues based on the type of entity that actually receives it. For example, an individual who buys coverage through an association must receive a plan that complies with federal laws applicable to the individual health insurance market; a small employer must receive coverage that complies with federal small group market rules.
- **Clarifying the Term "Issuer":** Second, CMS could clarify through guidance or regulation that a self-funded MEWA that is regulated by a state is an "issuer" for purposes of federal law, and therefore subject to federal insurance requirements applicable to issuers.[50] This would mean clarifying "issuer" to ensure that it is sufficiently broad to include entities that (1) must obtain state authorization to engage in what is the business of insurance; and (2) are subject to at least some state insurance law standards.

#10: Withdraw the Grandfathered Plans Rule

Grandfathered group health plans can provide fewer consumer protections than ACA-compliant plans. For example, grandfathered plans are not required to cover preventive services without cost-sharing, including co-pays, co-insurance and deductibles, as ACA-compliant plans are required to do. They also may not include services like cancer screenings, preventive treatments for cardiovascular disease, screenings for pregnant women, tobacco cessation, or coverage for patients who are eligible to participate in clinical trials.

They are also not required to provide coverage for essential health benefits. Prior to the creation of the 10 EHB categories, patients and consumers frequently found themselves enrolled in plans that failed to provide coverage for the care they routinely relied upon to maintain their health or treat illnesses. Patients with serious illnesses would discover they were not covered for new and innovative treatments, some individuals could not get coverage for emergency room services, and patients with chronic illnesses were often denied coverage for life-improving, sometimes even life-saving, medication. Many of these individuals did not realize at the time of their enrollment that they had selected a plan that did not meet their health care needs, let alone provide adequate coverage for a new diagnosis.

In July of 2020, the Departments of HHS, Labor, and Treasury released a proposed rule that would further relax cost sharing requirements for some grandfathered plans. Our organizations are concerned that allowing grandfathered plans to make significant changes to their benefit designs is contrary to the intent of the ACA and could cause further harm to patients and consumers, given the many important standards that do not apply to these plans.[51] By allowing grandfathered plans, including grandfathered high-deductible health plans (HDHPs) to increase plan cost-sharing requirements, the proposed rule would further limit health care access for enrollees. Together, we continue to strongly oppose attempts to further weaken regulatory standards for grandfathered plans.

Recommendation #10: We urge the Departments of HHS, Labor, and Treasury withdraw the proposed rule published in July 2020, which weakens existing regulations and further degrades patient protections. Any future changes to the rules impacting health plans with grandfathered plans should encourage those plans to come into compliance with the ACA.

49 Please see https://www.cms.gov/CCIIO/Resources/Files/Downlxoads/association_coverage_9_1_2011.pdf for most recent interpretation of the "look through" doctrine.

50 This means clarifying "issuer" to ensure that it is sufficiently broad to include entities that (1) must obtain state authorization to engage in what is the business of insurance; and (2) are subject to at least some state insurance law standards.

51 Comments on CMS-9923-NC: Request for Information Regarding Grandfathered Group Health Plans and Grandfathered Group Health Insurance Coverage, March 27, 2019. https://www.lung.org/getmedia/2149f755-55b0-4bf5-826a-69d16d1c0030/health-partner-comments-re-5.pdf.

#11: Rescind 1332 Guidance

Our organizations are also deeply concerned about the guidance interpreting the guardrails of Section 1332 of the ACA promulgated by CMS in October 2018. States that choose to pursue some of the policies allowed under this guidance, including those that use federal taxpayer dollars to promote short-term plans and other substandard coverage, pose a significant threat not only to the function of the exchanges, but also to individual consumers and patients.

The 1332 guidance substantially erodes the guardrails governing coverage that people with pre-existing conditions such as cystic fibrosis, lung disease, cancer, cardiovascular disease, diabetes, rare disorders, pregnancy, and many others rely on in the individual marketplace. Of particular concern, the guidance allows states to let individuals use advanced premium tax credits to purchase non-compliant short-term, limited duration insurance plans—which could further draw younger, healthier people out of the risk pool for comprehensive insurance and drive up premiums for those who need comprehensive coverage. The guidance also eliminates protections for vulnerable populations, such as individuals with low incomes and those with chronic and serious health issues, by removing the requirement to safeguard those populations under any waiver. We are deeply concerned by this guidance as these changes contravene the plain reading of the statutory requirements for Section 1332 waiver program, fundamentally altering the nature of the program and jeopardizing adequate, affordable coverage for people with pre-existing conditions in the individual market.

Recommendation #11: Our organizations ask CMS to immediately withdraw this guidance. Halting the implementation of this guidance will protect people with pre-existing conditions from the repercussions of these market destabilizing actions. Additionally, CMS should improve and codify the previous 2015 guidance on Section 1332 of the Affordable Care Act through the rulemaking process.

#12: Reinstate Robust Open Enrollment Periods

The ACA included a number of policies that encouraged patients to enroll in high-quality coverage via the exchanges, including a sufficiently long open enrollment period. Until 2018, HHS' annual open enrollment period for federally facilitated exchanges (FFE) ran for 90 days, from November 1st to January 31st. However, in 2017, HHS promulgated rules that would allow the department to truncate open enrollment by half, reducing the number of days consumers and patients could enroll in coverage down to just 45 days.[52]

Shortening the enrollment period greatly reduced the amount of time consumers had to shop, compare plans, and ultimately complete the enrollment process. The reduced open enrollment period also overlays several prominent holidays when individuals and families, especially those who are low-income, experience financial stress and may have less time to devote to researching the best insurance options for themselves or their families. Data from the states that facilitate their own exchanges and therefore have the option to extend their open enrollment periods show that longer open enrollment periods correlate with increased enrollment.[53]

Recommendation #12: We urge HHS to immediately reinstate a full 90-day open enrollment period to ensure patients and consumers have adequate time to shop and compare plans. We also urge legislative codification of a minimum open enrollment period such that it may not be manipulated in future administrations.

#13: Fund Education & Outreach

People with pre-existing conditions need access to adequate, affordable health insurance. In order for insurance to be accessible, potential enrollees need to understand and be aware of the annual open enrollment period.

Over the last four years, CMS funding for open enrollment education and outreach programs has been cut by 90 percent.[54] These critical programs are necessary to ensure individuals are aware of the open enrollment period and their health care coverage options. Research has shown that states that de-

52 *Patient Protection and Affordable Care Act: Market Stabilization*. (2017, February). U.S. Department of Health and Human Services. https://s3.amazonaws.com/public-inspection.federalregister.gov/2017-03027.pdf

53 Peck, J. (2018, May 17). *Why Marketing Matters for HealthCare.gov—Get America Covered*. Medium. https://medium.com/get-america-covered/why-marketing-matters-for-healthcare-gov-46d19534a287

54 Jost, T. (2017, August 31). *CMS Cuts ACA Advertising By 90 Percent Amid Other Cuts To Enrollment Outreach*. Health Affairs Blog. https://www.healthaffairs.org/do/10.1377/hblog20170901.061790/full/

vote robust resources to marketing, outreach, and enrollment assistance programs experience higher rates of enrollment compared to those who do not.

An analysis by Covered California released in September 2017 estimated that the potential impact of reduced federal marketing investment in the exchanges could mean one million fewer Americans enrolled in health insurance and a 2.6% average increase in premiums for the 2019 plan year due to the smaller consumer pool and less healthy risk profile. If the reduced spending were to lead to a 20% decline in enrollment, 2.1 million fewer insured Americans would be covered and premiums could increase by 5.3%.[55] Making consumers aware of their coverage options can help promote broader participation of healthy individuals to help offset the costs of older, sicker patients—lowering costs for everyone in the marketplace.

Recommendation #13: Funding must immediately be restored for outreach and enrollment activities for the 2021 Open Enrollment period. Funding should include support for activities that reach underserved populations, including racial and ethnic minorities and those with limited English proficiency. We also ask that the Administration work with Congress to pursue legislation that would require HHS to use allocated funds exclusively for these purposes. HHS should also be mandated to provide biweekly public reports, providing state-by-state information for the duration of the open enrollment period.

#14: Fully Fund Navigators

Resources that help consumers understand and select health care coverage are an essential component of any health care system. Navigators offer a critically important and unparalleled service for enrollees by helping people who need health insurance obtain free, unbiased help to enroll through their state Exchange while also educating consumers about their coverage options, including Medicaid and Medicare.

Our organizations have been concerned by HHS' systematic disinvestment from these critical services since 2017. HHS has cut funding for outreach and enrollment activities by more than 90 percent since 2016 leaving advocates and private partners to attempt to fill the gap.[56] It is frustrating and disappointing that CMS continues to assert that the need for these services has decreased as the number of uninsured or underinsured Americans has continued to grow during the COVID-19 pandemic.[57,58]

Marketing, education, and outreach conducted by Navigators are essential to promoting a healthier, balanced risk pool, which benefits the entire market by bringing down the cost of insurance and stabilizing the markets.[59] Patients and their families rely on Navigators as unbiased, free resources to find and attain adequate and affordable health care coverage through the most appropriate program and to obtain post-enrollment help understanding how to use their coverage. Many Navigators also provide in-person help to low-income and rural communities, consumers with limited English proficiency, people with disabilities, and other populations for whom such assistance is not often available.

Recommendation #14: Navigators are a critical bridge to accessing and understanding health care information and coverage for patients and consumers. The Administration should take the following steps:

- **Fully Restore Funding and Support for Navigator Services:**
  Funding dedicated to Navigator services should be fully restored so that states and communities have access to sufficient services throughout the year, including but not limited to, open enrollment.
- **Restore Community & Consumer Focused Navigator Requirements:**
  Under the ACA, Navigators assist consumers by providing information regarding enrollment in Qualified Health Plans (QHPs) as well as post-enrollment activities, such as increasing health literacy, assisting with renewals, and educating consumers on how to avoid disenrollment for non-payment. The 2019 Notice of Benefit and Payment Parameters (NBPP) eliminated these requirements as well as critical criteria that ensured patients and consumers had adequate access to enrollment services where they live. The NBPP thus eliminated the requirement that each

55 Lee, P., Pegany, V., Scullary, J., & Stevens, C. (2017, November). *Marketing Matters: How Marketing and Outreach Builds Stable Marketplaces and Pays Off for the Federal Government*. Covered California. https://hbex.coveredca.com/data-research/library/CoveredCA_Marketing_Matters_Issue_Brief.pdf

56 Pear, R. (2018, July 11). Trump Officials Slash Grants That Help Consumers Get Obamacare. *Https://Www.Nytimes.Com/#publisher*. https://www.nytimes.com/2018/07/10/us/politics/trump-affordable-care-act.html

57 Wishner, J., Hill, I., Benatar, S., Gadsden, S., & Upadhyay, D. (2015, October). *Factors That Contributed to High Marketplace Enrollment Rates in Five States in 2015*. Robert Wood Johnson Foundation & Urban Institute. http://www.urban.org/sites/default/files/publication/72431/2000486-Factors-That-Contributed-To-High-Marketplace-Enrollment-Rates-In-Five-States-In-2015.pdf

58 FamiliesUSA. (2020, August). *America's Coverage Crisis Deepens: New Survey Data Show Millions of Adults Became Uninsured, Starting in Late June*. Familiesusa.Org. https://familiesusa.org/wp-content/uploads/2020/08/COV-312_Pulse-Fact-Sheet.pdf

59 Livingston, S. (2017, August 31). *CMS slashes ACA marketplace education and outreach funds*. Modern Healthcare. https://www.modernhealthcare.com/article/20170831/NEWS/170839969/cms-slashes-aca-marketplace-education-and-outreach-funds

exchange must have **at least** two Navigator entities, that at least one must be community-based and consumer-focused, and that at least one must have a physical presence in the community it serves. These requirements should be immediately restored. Exchanges should also be required to use Navigators to reach underserved communities, including racial and ethnic minorities and people with disabilities.

- **Restoring Navigator Training Requirements:** Prior to 2019, Navigators who used the federally facilitated exchange (FFE) to enroll consumers were required to receive training on 20 topics, including cultural sensitivity, Section 1557 non-discrimination requirements, post-enrollment responsibilities and others. Training for these 20 categories should be reinstated immediately.

#15: Strengthen Web Brokers & Insurance Agent Standards

We are concerned that HHS has taken steps to allow web brokers and insurance agents to facilitate marketplace enrollment through the websites of third-party "direct enrollment entities," including issuers. In 2018, HHS debuted the "Help on Demand" referral system, which connected consumers using the "find local help" tool on healthcare.gov with available agents or brokers. While web brokers have been allowed for some time, HHS has allowed web brokers to shift focus away from high-quality QHP products sold via healthcare.gov and allowed brokers to market and sell plans with less than adequate coverage that can discriminate based on health status, such as short-term or association health plans. Web brokers and agents also have financial incentives to sell certain products to consumers, with non-compliant plans typically providing higher commissions than ACA compliant plans.[60,61] Furthermore, there is no mandate that brokers provide patients and consumers useful information needed to make informed choices.

Recommendation #15: Our organizations urge the Administration to reverse recent regulatory changes that have relaxed regulatory standards for web-brokers in addition to layering on additional consumer protections. For example, HHS can require brokers to sell only QHPs during open enrollment, require "best-interest" conduct standards akin to fiduciary standards for brokers selling health plans, require brokers and agents to provide clear disclosures about plans that are not ACA-compliant, screen consumers for Medicare and Medicaid eligibility, and disclose the amount of their commissions.

#16: Website Management & Patient Accessibility

As organizations working to ensure that patients and consumers understand their health insurance options and are able to enroll, we have been disappointed with HHS's administration of healthcare.gov. Healthcare.gov is the primary portal for millions of consumers who shop for, enroll, and re-enroll in Marketplace health insurance during open enrollment.

During the 2017, 2018, and 2019 open enrollment periods, HHS inappropriately scheduled extended website maintenance and service outages, frequently at high-traffic times like weekends and weeknights. While healthcare.gov underwent periodic and short shutdowns for maintenance in previous open enrollment periods, the plans announced by HHS for the 2018 open enrollment period were unprecedented. By shutting down for 12 hours during every Sunday except one, in addition to the first night of open enrollment, HHS impeded numerous consumers from researching and enrolling in coverage.

Recommendation #16: We urge the Administration to direct HHS and CMS to schedule any routine maintenance to minimize reduction in access for consumers and take steps to minimize the impact these outages will have on consumers. We also recommend that CMS be required to: 1) provide a public explanation for any required outages and 2) explain its plan(s) for how to provide information and follow-up to consumers who may try to access healthcare.gov during these times.

60 Straw, T. (2019, June 6). *"Direct Enrollment" in Marketplace Coverage Lacks Protections for*. Center on Budget and Policy Priorities. https://www.cbpp.org/research/health/direct-enrollment-in-marketplace-coverage-lacks-protections-for-consumers-exposes

61 Lucia, K., Corlette, S., Palanker, D., & Hoppe, O. (2018, August). *Views From the Market: Insurance Brokers' Perspectives on Changes to Individual Health Insurance*. Robert Wood Johnson Foundation. https://www.rwjf.org/content/dam/farm/reports/issue_briefs/2018/rwjf447745

#17: Reverse Anti-Patient Policies Advanced in NBPP Rules

The annual Notice of Benefit and Payment Parameters (NBPP) rule governs key functions of the ACA including the operation of the insurance marketplaces, plan standards, factors impacting affordability of coverage, and other elements of the law that help ensure the efficient and smooth operation of the ACA. Since 2017, however, HHS and CMS have made significant changes to the structure and function of the ACA via the NBPP. In general, these changes have served to undermine the affordability, adequacy, and accessibility of coverage offered through the exchanges.

Together, our organizations have offered robust comments on each of the NBPP's published since 2017 and have repeatedly shared with HHS our concerns about how these changes will impact the patients we represent.[62, 63, 64]

In the 2020 NBPP, CMS changed the **premium adjustment factor** formula used to calculate changes to subsidies, out-of-pocket caps, and other costs. While CMS previously calculated the premium adjustment factor based on employer-sponsored insurance premiums, CMS now uses average private health insurance premiums in the formula, raising the premium adjustment factor by 3.6% from 2019. In its proposed rule, CMS anticipated that this action alone would increase premiums by up to $220[65] for 7.3 million subsidy-eligible individuals and families, resulting in approximately 100,000 consumers losing their health insurance coverage in 2020 alone. This action also contributed to faster growth of the net premiums paid by consumers on the Marketplaces and a faster growth in the maximum out of pocket (MOOP) limit paid by all Americans, including those with large group employer coverage.

Our organizations also strongly opposed the Departments' changes to the **Essential Health Benefit (EHB) requirements** in the 2019 NBPP. This action undermined the core patient protections enshrined in the EHB requirements by allowing states to mix and match benefit structures in a way that could harm patients and consumers by reducing the generosity of benefits.

Today, states have the flexibility to select an EHB-benchmark plan that could:

- maintain its current EHB-benchmark plan;
- choose another state's EHB-benchmark plan, either in part or in whole;
- choose elements from EHB-benchmarks in multiple states; or
- select an entirely new EHB-benchmark plan so long as it is comparable to a "typical employer plan."

This new flexibility allows states to design benchmark plans that offer not just less generous coverage, but the *least* generous coverage of each of the 10 EHBs available across the country. Under the rule, other states can then duplicate these benchmark plans and subject even more Americans to limited or skimpy EHB coverage.

We are also concerned that the flexibility allowed under this policy, combined with other administrative actions, such as the expansion of AHPs and short-term plans and new guidance on 1332 waivers, could allow states to degrade patient protections and jeopardize the integrity of the ACA and the policies that underpin its quality.

In 2017, the Department also allowed plans to **adjust their actuarial value (AV)** between nine of the 10 EHB categories (with the exception of the prescription drug category). By allowing plans to adjust the AV between categories, issuers can shift the generosity of the benefit to less frequently used categories. This provision allows states to design plans with little or no coverage in a specific category, allowing them to strategically avoid certain types of patients. For example, a plan could shift AV away from behavioral health services into another category. As a result, access to services for patients with behavioral or substance use disorders, for example, would be restricted.

Our patients have unique health needs. Limiting changes to AV within a category provides our patients a baseline of coverage in each category. Without this baseline in each category, patients could easily end up in a plan that does not cover or severely limits coverage for their condition.

Recommendation #17: Our organizations request that the Administration reverse all of the changes listed above in the 2022 NBPP and address any other policies that reduce the overall quality, accessibility, and affordability of care. For example, we urge the Administration to:

- Restore an strengthen meaningful federal oversight of QHP plan certification requirements for network adequacy, including essential community providers;

62 *Patient Protection and Affordable Care Act; HHS notice of Benefit and Payment Parameters for 2019.* (2017, November 27). Patient Coalition. https://www.lung.org/getmedia/f706c88f-2261-4c71-95d6-655e4109cf9b/partner-comments-to-hhs-re-ppaca-benefit-and-payment-parameters-2019.pdf

63 *Patient Coalition Comments on Patient Protection and Affordable Care Act: HHS Notice of Benefit and Payment Parameters for 2020*. (2019, February 19). Patient Coalition. https://cqrcengage.com/mda/file/bDbTylsAx3q/2019.02.19_Coalition_Comments_NBPP_2020_FINAL.pdf

64 *Patient Coalition Comments on Patient Protection and Affordable Care Act: HHS notice of Benefit and Payment Parameters for 2021.* (2020, March 2). Patient Coalition. https://cqrcengage.com/efa/file/g3iQ9YtGieM/Coalition%20Comments%20on%20NBPP%203.2.20_final.pdf

65 *Change to Insurance Payment Formulas Would Raise Costs for Millions*. (2019, April 26). Center on Budget and Policy Priorities. https://www.cbpp.org/research/health/change-to-insurance-payment-formulas-would-raise-costs-for-millions-with-marketplace

- Improve the appeals process to be more consumer friendly;
- Consider implementing standardized plan options; and
- Increase state and federal oversight of issuer compliance, especially regarding essential health benefits.

Employer-Sponsored Coverage

Changes to the regulatory structure of Employer-Sponsored Coverage (ESC) have also eroded the quality of coverage for individuals and families who are insured through their employer. Ensuring the quality of ESC is especially critical for our organizations as the vast majority of Americans, and thus patients, receive their insurance from their employer.

#18: Reverse the Excepted Benefit Health Reimbursement Account Rules

In 2019, the Administration finalized a rule that expanded the use of health reimbursement arrangements (HRAs). Prior to the finalization of this rule, employers could only offer an HRA to employees that enrolled in the employer's group health plan, which is subject to ACA protections.

The rule allows employers to offer an excepted benefit HRA, to which employers can contribute up to $1,800 annually and can be offered if the employer also makes a group health plan available. However, there is no obligation that employees enroll in the group health plan in order to take advantage of the excepted benefit HRA. As a result, the excepted benefit HRA can be used to buy short-term plans or other types of non-compliant plans that are deeply concerning to our organizations.

Recommendation #18: Our organizations ask that the Administration to reverse the excepted benefit HRA rule, which promotes with federal tax benefits substandard coverage that fails to provide adequate financial protection.

ADDRESSING CHALLENGES IN THE COURTS

Regulations and statutes that greatly impact patients' ability to access high-quality, affordable care have increasingly been the subject of litigation nationwide. A lawsuit may determine whether the Affordable Care Act (ACA) survives, and legal challenges to rules and waivers issued by HHS that allow discrimination in health insurance and provision of care will affect whether those rules stay in place. Together, our organizations have filed comments and amicus briefs in several impactful cases to ensure the judiciary has a strong understanding of the scientific evidence and personal experiences of the patients and consumers we represent.

#19: Defend the ACA in California v. Texas

The *California v. Texas* case currently pending before the Supreme Court of the United States (SCOTUS) represents one of the most dire threats to the patient community's gains over the ACA's 10 year history, and the most serious challenge to the law since Congress rejected repeal efforts in 2017. Prior to the enactment of the patient protections included in the ACA, people with serious illnesses found it difficult—and often impossible—to get or to keep affordable and adequate health insurance. Since implementation of the ACA, our patient communities have benefited from protections enacted as part of the health care law, including a guarantee that people with serious or chronic illnesses are not discriminated against on the basis of pre-existing conditions, assurance of comprehensive coverage, bans on annual or lifetime caps on spending by insurance companies, and a prohibition on unfair coverage rescissions.

Our communities know firsthand that access to affordable, basic, preventive health care and life-saving treatments is fundamental to successful health outcomes. Returning to a system that limits access to care and makes treatment unaffordable for people with a chronic disease would likely result in declining health outcomes, and place at risk the gains that have been made. In a brief filed with SCOTUS, our organizations offered detailed examples of how the critical protections of the ACA provide an essential lifeline for millions of Americans who experience serious illnesses and conditions, as well as how the ACA has improved health outcomes for our patient communities.[66] For example, access to health insurance improves numerous health outcomes for children with asthma, including reductions in the number of asthma-related attacks and hospitalizations.[67] Furthermore, provisions of the ACA have increased access to care, decreased the number of costly hospitalizations, and improved outcomes of individuals with mental health and substance use disorders.[68]

Without access to affordable, comprehensive health insurance coverage, many patients with serious and chronic conditions were often forced to delay or forego necessary health care. Before the ACA, more than half of heart patients reported difficulty paying for their care and, of those patients, more than 40% said they had delayed care or had not filled prescriptions.[69] Uninsured patients with diabetes were six times more likely to forgo necessary medical care than those with coverage.[70] Uninsured patients were less likely to be screened for cancer and more likely to be diagnosed with later-stage disease which is harder to survive and more costly to treat.[71]

66 American Cancer Society & Coalition Partners. (2019). *Amici Curiae Brief in Support of the Petitioners and Reversal by the American Cancer Society et al.* Https://www.Supremecourt.Gov/Docket-PDF/19/19-840/143397/20200513110123668_19-840%20American%20Cancer%20Society%20et%20al%20brief.Pdf

67 Szilagyi, P. G., Dick, A. W., Klein, J. D., Shone, L. P., Zwanziger, J., Bajorska, A., & Yoos, H. L. (2006). Improved asthma care after enrollment in the State Children's Health Insurance Program in New York. *Pediatrics*, *117*(2), 486–496. https://doi.org/10.1542/peds.2005-0340

68 Office of the Assistant Secretary for Planning and Evaluation. (2017, January). *Continuing Progress on the Opioid Epidemic: The Role of the Affordable Care Act*. U.S. Department of Health and Human Services. https://aspe.hhs.gov/system/files/pdf/255456/ACAOpioid.pdf

69 American Heart Association. (2010). *Affordable Access to Health Care: Top Priorities of Heart Disease and Stroke Patients Results from an American Heart Association Patient Survey.* https://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_432322.pdf

70 Centers for Disease Control and Prevention. (2010, November 12). *Vital Signs: Health Insurance Coverage and Health Care Utilization—United States, 2006–2009 and January–March 2010*. Morbidity and Mortality Weekly Report. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5944a5.htm

71 Ward, E., Halpern, M., Schrag, N., Cokkinides, V., DeSantis, C., Bandi, P., Siegel, R., Stewart, A., & Jemal, A. (2008). Association of Insurance with Cancer Care Utilization and Outcomes. *CA: A Cancer Journal for Clinicians*, *58*(1), 9–31. https://doi.org/10.3322/ca.2007.0011

This challenge poses an existential threat not just to patients who have come to rely on the high-quality coverage offered through the ACA, but also to our health infrastructure and system of care as a whole. Since its enactment in 2010, the ACA has impacted almost every aspect of our health care system, including Medicaid, Medicare, the Children's Health Insurance Program (CHIP), employer-sponsored coverage, the Indian Health Service, health information technology, prescription drug approvals, and more. We were therefore pleased to see that a diverse number of stakeholders from every part of the health care system filed over 30 amicus briefs describing the benefits of the law for the constituencies we represent as well as the potential disruption that would occur if the ACA were to be found unconstitutional.[72,73]

Despite its far-reaching implications, the case has been complicated by the fact that the Department of Justice (DOJ) has taken the highly unusual step of declining to defend the law, and has changed its position regarding how much of the law should be "severed" and thus remain in effect. At trial, DOJ declined to defend the constitutionality of the individual mandate following Congressional action to halt the assessment of penalties for non-compliance, but took the position that while critical patient protections, including the ban on pre-existing condition exclusions, must also fall, other provisions of the law, including the Medicaid expansion, could be severed and remain in effect.

Subsequently, on appeal to the Circuit Court, DOJ argued the law should be struck down in its entirety. DOJ reportedly took this position over objections by the Attorney General and the Secretary of HHS, and the move drew criticism across the political spectrum.[74,75] Although there were reports of efforts to change positions once again before briefs were filed, DOJ has continued to argue to SCOTUS that, should the Court agree with its position that the individual mandate is no longer constitutional, the provision is not severable from the rest of the law and the entire ACA should fall.

Recommendation #19: Our organizations are gravely concerned by the Administration's failure to fully and robustly defend the constitutionality of the ACA and the consumer protections it offers to those we represent. We therefore strongly encourage the federal government to fully defend the Affordable Care Act, and to acknowledge and support the evidentiary record that has been created with regard to the benefits of the law for our patient population.

#20: Discontinue Support for Work & Community Engagement Requirements

Our organizations are similarly concerned about the impact of work and community engagement requirements on patients with pre-existing conditions. Residents of Kentucky and Arkansas brought suit challenging approval of the provisions of each state's Section 1115 demonstration waivers that required certain adults to work or lose access to Medicaid. The lawsuits argued that the waivers were arbitrary and capricious, running afoul of the Administrative Procedure Act. In ruling for the plaintiffs, the district court judge stopped Kentucky from implementing its program and halted the Arkansas program. The court held that HHS's approval of the work requirements did not address how the program would implicate the "core objective" of Medicaid: access to health services for those who need them most.

HHS appealed the ruling on Arkansas, and in February 2020, the D.C. Circuit Court of Appeals unanimously upheld the lower court's decision. The appeals court found that while HHS claimed it had considered a number of objectives in its evaluation of section 1115 demonstration waivers, it had failed to consider how the project promoted the statutory objective of Medicaid: coverage for those who cannot afford health care coverage. The D.C. Circuit specifically held that by failing to consider *loss* of coverage, HHS had acted in a manner that was arbitrary and capricious. HHS and Arkansas filed a petition for certiorari in July 2020, including the Arkansas case and a similar case from New Hampshire, but the Supreme Court has not yet decided whether it will take up the case.

Recommendation #20: Our organizations agree with the court rulings that have invalidated these work and community engagement requirements within the Medicaid program, and we urge HHS to retract its guidances allowing for work and community engagement requirements (including the original 2018 work requirement guidance and the subsequent "Healthy Adult Opportunity" guidance), and discontinue its consideration of any future 1115 waiver applications which include such requirements.

72 Keith, K. (2020, January 19). *Diverse Stakeholders Ask Supreme Court To Promptly Hear Texas*. Https://Www.Healthaffairs.Org/Do/10.1377/Hblog20200118.227701/Full/

73 American Cancer Society & Coalition Partners. (2020). *Amici Curiae Brief in Support of Petitioners and Reversal by the American Cancer Society Et al.* Supremecourt.Gov. https://www.supremecourt.gov/DocketPDF/19/19-840/143397/20200513110123668_19-840%20American%20Cancer%20Society%20et%20al%20brief.pdf

See also: Brief of the National Hospital Associations; Brief for Amicus Curiae Blue Cross Blue Shield Association; Brief of amici curiae Public Health experts. https://www.supremecourt.gov/search.aspx?filename=/docket/docketfiles/html/public/19-840.html

74 Haberman, M. (2019, March 27). Trump Sided With Mulvaney in Push to Nullify Health Law. The New York Times. https://www.nytimes.com/2019/03/27/us/politics/trump-aca.html

75 Cannon, M. F. (2019, March 29). ObamaCare's Enemy No. 1 says this is the wrong way to kill it. *New York Post*. https://nypost.com/2019/03/28/obamacares-enemy-no-1-says-this-is-the-wrong-way-to-kill-it/

#21: Other Administrative Rules in Litigation

Federal courts are currently considering challenges to three other rules that have significant impact on our patient populations. Section 1557 of the ACA prohibits discrimination across the health care delivery system. In 2016, the Obama Administration issued a rule that Section 1557 bars discrimination against LGBTQ individuals and protects individuals with Limited English Proficiency (LEP). In July 2020, the Administration finalized a new version of the rule that could encourage health care providers to discriminate against LGTBQ individuals and allowed issuers and other entities to forego tagline and translation services that help LEP individuals understand their rights and options. The Administration finalized this rule just prior to the landmark SCOTUS decision in *Bostock v. Clayton County,* interpreting discrimination on the basis of "sex" to include LGBTQ individuals in the employment law context. To date, two courts in at least five pending challenges to the new 1557 rule issued an injunction that stopped provisions impacting LGBTQ populations from taking effect, holding that HHS has likely violated the APA by failing to take the Supreme Court decision into account. The Administration is expected to appeal those decisions, and more decisions are expected soon.

Additional litigation regarding rules allowing short-term, limited-duration insurance plans and rules governing AHPs are both pending in different stages before the D.C. Circuit. The *Short-Term, Limited-Duration* plan rule and the *Association Health Plans* rule issued in June and August 2018 both sought to expand the use of plans that do not meet the requirements of the ACA: the short-term plan rule by allowing non-compliant plans to be offered for up to three years; and the AHP rule by drastically expanding the types of employers and the required relationships between employers that could offer non-complaint plans through an association. Our organizations have worked with a wide array of stakeholders challenging these expansions of subpar plans, including filing amicus briefs in support of challenges to plans that undermine the ACA.[76]

Recommendation #21: Our organizations do not support the expansion of plans that do not comply with the ACA's patient protections and that undermine the effectiveness of the law, nor do we support efforts to limit non-discrimination in health care settings. Insurance plans that lack the protections offered by the ACA should be strictly regulated and, in some circumstances, eliminated altogether. We therefore urge HHS to rescind rules allowing for these approaches.

76 See Brief of American Cancer Society et. al. as Amici Curiae Supporting Motion for Preliminary Injunction. https://www.fightcancer.org/sites/default/files/National%20Documents/2018-10-08%20SLDP%20Amicus%20Brief.pdf; Brief of the American Cancer Society et. al. as Amici Curiae Supporting Plaintiffs Motion for Summary Judgment. https://www.fightcancer.org/sites/default/files/docs/Short-term-Plan-amicus-brief.pdf; Brief for Amici Curiae National American Cancer Society et. al. in Support of Plaintiffs-Appellants. https://www.fightcancer.org/sites/default/files/docs/JAI/2019-11-12-American-Cancer-Society-e-al-Amicus-Brief.pdfet.

ENACT A COMPREHENSIVE PRO-PATIENT LEGISLATIVE AGENDA

Our organizations urge the Administration to pair a robust pro-patient legislative agenda with strong administrative action to ensure that patients are able to access adequate and affordable health insurance coverage in years to come. Codifying patient and consumer protections, affordability policies, and robust transparency and reporting standards in statute will help underpin the integrity of our system of care for years to come.

#22: Codify Limits and Bans on the Sale of Non-Compliant Plans

In addition to reversing the deregulation of non-compliant plans, including STLD insurance and AHPs, through the rulemaking process, our organizations believe that patients, consumers, and the overall integrity of our system of care would benefit from codifying pro-patient protections into law.

Recommendation #22: Prohibit the Department of Health and Human Services, the Department of Treasury, and the Department of Labor from implementing, enforcing, or in any way giving effect to final rules that expanded availability of short-term, limited-duration and association health plans. For those individuals who are already covered by these plans, ensure that any people who lose this sub-par coverage due to rescission of the rule have options to purchase comprehensive, affordable coverage that meets their needs.

Additionally, Congress should move to enshrine patient protections into law by codifying the suite of patient and consumer-focused protections outlined in the above section on STLD plans and AHPs. It is critical to note, however, that such policies are interdependent. As such, any individual policy enacted alone will fail to offer the type of comprehensive protection consumers require.

#23: Rein in Insurance-Like Products

As we have previously discussed, our organizations are deeply concerned about the proliferation of non-ACA-compliant health plans, as well as insurance-like products such as limited-indemnity plans, farm bureau plans, health care sharing ministries, and AHP-like insurance cooperatives. While many of these plans are not intended to be a substitute for health insurance, many are marketed as such—some even mimicking the metallic value levels of QHPs sold on the ACA marketplace.[77] Enrollees may believe that they are enrolled in health insurance, only to find that the product they have purchased provides little if any coverage.[78]

Because these products are not insurance, they are frequently not subject to state or federal regulations and the number of individuals enrolled in them is poorly understood. However, anecdotal evidence and some self-reporting indicates that they continue to enroll a growing number of individuals.

These unregulated products are subject to neither key consumer protections nor state or federal oversight, resulting in two primary consequences: these plans are fully permitted to engage in practices that threaten harm to patients and consumers and, when issues arise, patients and consumers often have no avenue for legal recourse. Consumers are left to hope that authorities in their states will take action on behalf of broad groups of consumers. Federal legislative action is needed to protect all patients and consumers from these subpar, and in some cases fraudulent, products.

77 *Instant quote: Christian Healthcare Ministries*. (2020). Christian Healthcare Ministries. https://www.chministries.org/programs-costs/instant-quote/

78 Aleccia, J. (2019, May 21). *'Sham' Sharing Ministries Test Faith Of Patients And Insurance Regulators*. Kaiser Health News. https://khn.org/news/sham-sharing-ministries-test-faith-of-patients-and-insurance-regulators/

Recommendation #23: Revise the federal definition of "insurance" to curtail the inappropriate sale, marketing, and development of insurance-like-products which jeopardize patient health and safety. This should include any products that are marketed to consumers as—or resembling—health insurance, such as farm bureau plans, health care sharing ministries, and some limited-indemnity plans.

#24: Immediately Prohibit Surprise Medical Bills

Our organizations strongly support Congressional and Administration efforts to protect consumers from the high medical bills that can result from surprise billing, and in the fall of 2018 published principles by which we evaluate any proposed solution to ending the practice.[79]

Millions of consumers receive a surprise bill each year, including patients with serious and chronic illnesses. Recent academic studies have found that the practice of surprise billing is common and widespread. Approximately one out of every five emergency department visits involves care from an out-of-network provider[80] and even among large employer plans, nearly one-in-ten non-emergent inpatient procedures involved a potential surprise bill.[81] Another study found that the physician specialties most likely to send surprise bills are anesthesiology, interventional radiology, emergency medicine, pathology, neurosurgery, and diagnostic radiology,[82] but notes that surprise bills occur in almost all medical settings regardless of the type of provider or insurance.

An increasing number of individuals utilize urgent care facilities for emergency care. Between 2007 and 2016, urgent care utilization in the United States grew by 1,725%, with significantly higher utilization in rural areas.[83] While some patients with, for example, lung ailments may go to the emergency room for a severe asthma attack or other difficulty breathing, others may instead go to an urgent care facility. Accessing timely care is critical and patients should be held harmless from surprise medical billing regardless of where they receive treatment.

Our organizations are similarly concerned about the impact of balance billing practices on individuals who require emergency transportation, specifically air ambulances. Emergency transportation services reduce transport time for patients during life-threatening situations and are a critical component of successful treatment for individuals experiencing an emergency event. Patients in these situations have no choice over who provides care or how they are transported and are frequently balance billed for exorbitant sums as a result. This is particularly true of air ambulance services, which are a critical lifeline for people in rural areas.

Fear of cost, and subsequent surprise medical bills should never keep patients and consumers away from care and treatment for necessary medical and preventive care. Not only will discouraging people from seeking appropriate care lead to worsening health, but during the COVID-19 pandemic, avoiding treatment can also perpetuate the spread of the virus, prolonging its health and economic impacts. Therefore, it is critical that Congress gain consensus and enact legislation to permanently end all surprise medical bills now. Congress has recently considered legislation that would provide robust protections for patients from receiving unexpected medical bills—an effort which our organizations strongly support.

Recommendation #24: We urge the Administration and Congress to work together to immediately pass bi-partisan legislation that meets our coalition principles.

#25: Increase FMAP for Remaining States that Have Not Expanded Medicaid

Medicaid expansion is critical for patients with and at risk of serious and chronic health conditions. For example, in Medicaid expansion states, more individuals are being screened for diabetes than in states that did not expand.[84] Research shows an association between Medicaid expansion and early-stage cancer diagnosis, when cancer is often more treatable. [85] Medicaid expansion states have seen increased use of prescription drugs to help manage chronic conditions in patients with diabetes and cardiovascular disease.[86] This will help patients manage their conditions and avoid more expensive care in emergency departments and hospital settings.

79 *Coalition Principles on Surprise Medical Billing.* (2020, February). https://cqrcengage.com/mda/file/MR7G24UyMDP/022420%20SMB%20Coalition%20Principles%20-%20FINAL.pdf

80 Cooper, Z., & Scott Morton, F. (2016). Out-of-Network Emergency-Physician Bills—An Unwelcome Surprise. *New England Journal of Medicine*, *375*(20), 1915–1918. https://doi.org/10.1056/nejmp1608571

81 Garmon, C., & Chartock, B. (2017). One In Five Inpatient Emergency Department Cases May Lead To Surprise Bills. *Health Affairs*, *36*(1), 177–181. https://doi.org/10.1377/hlthaff.2016.0970

82 Bai, G., & Anderson, G. F. (2017). Variation in the Ratio of Physician Charges to Medicare Payments by Specialty and Region. *JAMA*, *317*(3), 315–318. https://doi.org/10.1001/jama.2016.16230

83 Health Payer Intelligence. (2018, March 23). *Urgent Care Center Utilization Skyrocketed by 1725% in Last Decade*. https://healthpayerintelligence.com/news/urgent-care-center-utilization-skyrocketed-by-1725-in-last-decade

84 Lee, J., Callaghan, T., Ory, M., Zhao, H., & Bolin, J. N. (2020). The Impact of Medicaid Expansion on Diabetes Management. *Diabetes care*, *43*(5), 1094–1101. https://doi.org/10.2337/dc19-1173

85 Ibid.

86 Ghosh, A., Simon, K., & Sommers, B. D. (2019). The Effect of Health Insurance on Prescription Drug Use Among Low-Income Adults: Evidence from Recent Medicaid Expansions. *Journal of health economics*, *63*, 64–80. https://doi.org/10.1016/j.jhealeco.2018.11.002

State Medicaid expansions provide continuous care to pregnant women before, during, and after pregnancy, leading to decreases in both maternal deaths and infant mortality.[87] Another study found that Medicaid expansion was associated with reductions in deaths from opioid overdose, including those involving heroin and synthetic opioids.[88] Additionally, Medicaid expansion is associated with improvements in quality measures at federally qualified health centers, which are critical health care providers for low-income patients.[89] Medicaid expansion is also playing an important role in addressing health disparities—one recent study found that states that expanded Medicaid under the ACA reduced racial disparities in timely treatment for cancer patients.[90] As of September 2020, 38 states and the District of Columbia have adopted Medicaid expansion, leaving 12 states that have not yet expanded.

Prior to the COVID-19 pandemic, the expansion of Medicaid coverage to all individuals with incomes below 138% of the federal poverty level ($2,497/month for a family of three) could have extended quality and affordable coverage to 4.8 million uninsured adults living in states that had not yet taken up this expansion.[91] Now, 1.9 million more individuals are expected to fall in the coverage gap due to a loss of employer-sponsored insurance as a result of the COVID-19 pandemic.[92]

Recommendation #25: Congress should encourage the uptake of Medicaid expansion by the states that have not yet done so by providing 100 percent FMAP for the first three years that states expand their Medicaid programs, a financial incentive that was available to states that expanded their programs in 2013.

#26: Expand Subsidies for Marketplace Coverage

Increased premiums, deductibles, and co-pays have left many low- and middle-income families struggling to afford health care. By increasing the eligibility for and expanding the generosity of Advanced Premium Tax Credits (APTC), more consumers would be able to afford health insurance on the exchange. Currently, the APTCs are only available for consumers making between 100 and 400% of the federal poverty level and based on the cost of a silver plan. Additionally, many families with lower incomes find coverage to be unaffordable even with the current subsidies. Making APTCs more generous will ensure consumers can afford to buy coverage. Increasing the availability and amount of subsidy support will potentially improve the overall makeup of the risk pool as well as continue to stabilize the individual markets. Affordability remains a barrier for many Americans to purchase adequate insurance via the ACA's insurance marketplace.

Recommendation #26: Our organizations support increasing financial support for individuals and families, and we urge policymakers in the Administration and Congress to increase the number of people eligible for and the generosity of APTCs. Congress should also consider increasing affordability by changing the APTC benchmark from the current silver plan to a higher-level plan, such as gold.[93]

#27: Fix the Family Glitch

The "family glitch" refers to the unintentional effect of the ACA's mechanism for defining whether an employer-based insurance plan is affordable for a given employee. This glitch effectively bars many low- and middle- income families from receiving the ACA's premium and cost-sharing subsidies. Under current law, the IRS deems employer-based insurance as affordable when the premium for *self-only* coverage is less than 9.69% of an individual's annual income. When an individual in a family is offered employer-based insurance that technically meets this definition, the entire family becomes *ineligible* for tax subsidies on the Marketplace—even if the premium for family coverage under the same plan is significantly higher and unaffordable based on the family's total income. Eliminating the family glitch through regulation or legislation would allow families to afford high-quality coverage while also reducing the number of uninsured Americans, improving the risk pool and potentially decreasing premiums.

Recommendation #27: Immediately fix the family glitch through regulation or legislation to ensure that families with unaffordable employer-based coverage can access the ACA's advance premium tax credits. Ensure that families can immediately access coverage by implementing a special enrollment period.

87 Ibid.

88 Ibid.

89 Cole, M. B., Galárraga, O., Wilson, I. B., Wright, B., & Trivedi, A. N. (2017). At Federally Funded Health Centers, Medicaid Expansion Was Associated With Improved Quality Of Care. *Health Affairs*, *36*(1), 40–48. https://doi.org/10.1377/hlthaff.2016.0804

90 Ibid.

91 *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid*. (2020, January 14). KFF. https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/

92 Garfield, R., Claxton, G., Damico, A., & Levitt, L. (2020, July 14). *Eligibility for ACA Health Coverage Following Job Loss*. KFF. https://www.kff.org/coronavirus-covid-19/issue-brief/eligibility-for-aca-health-coverage-following-job-loss/

93 Brooks-LaSure, C., Fowler, E., & Mauser, G. (2020). Building On The Gains Of The ACA: Federal Proposals To Improve Coverage And Affordability. *Health Affairs*, *39*(3), 509–513. https://doi.org/10.1377/hlthaff.2019.01411

#28: Ensuring Genuine Affordability

The ACA established a pathway intended to allow consumers to purchase subsidized individual market coverage if their job-based insurance options are unaffordable. Unfortunately, the parameters on this pathway have locked out the very employees these provisions were meant to help, leaving too many Americans without any affordable insurance options. No consumer should be locked out of affordable marketplace coverage when employer or job-based coverage is not truly affordable.

The ACA's mechanisms for determining the consumer affordability of employer-based insurance has two critical flaws that must be addressed to ensure consumers have affordable access to necessary health care services. First, the current test of whether an employer-sponsored insurance plan is adequate and meets Minimum Value is tied to the lowest metal level of coverage available in the marketplace and imposes few requirements on the scope of coverage. This flaw treats comprehensive health plans the same as plans that do not cover prescription drugs, mental health services, and other essential health benefits. As a result, consumers can be locked out of affordable marketplace coverage, even if they could face tens of thousands of dollars in costs for necessary services not covered by their employer's plan.

Second, the current affordability test places inordinate weight on premium costs as a measure of whether an employer-sponsored plan is affordable. Unfortunately, too many plans lower premiums by increasing the cost sharing associated with accessing health services under the plan. In recent years, employers have dramatically increased health insurance plan deductibles, adding to the total spending required by employees before their health plan begins to cover even the most essential treatments. While the average employee contribution to their employer-sponsored plan is $5,431,[94] the average employer-provided family coverage requires consumers to spend an additional $3,392[95] to meet their deductible. Patients with pre-existing conditions need true access to health care. Yet, focusing federal affordability tests on premiums, rather than a more realistic measure of the costs employees incur in order to access care through an employer-sponsored plan, bars consumers from federal premium and cost-sharing support for individual market coverage, even if such coverage would prove to be their only affordable option.

The expansion of high-deductible health plans (HDHP) is further evidence of the growing issue of unaffordability for employer-sponsored insurance (ESI). In fact, enrollment in HDHPs has increased among those with employer coverage, from 4% in 2006, to 20% in 2014 to 30% in 2019.[96]

HDHPs tend to offer lower monthly premiums than traditional health plans but require enrollees to pay all costs upfront, with some exceptions, prior to fulfilling their deductible. The proliferation of HDHPs demonstrates a growing trend in cost shifting from employers to consumers.

Although HDHP enrollment triggers eligibility for a tax-advantaged health savings account (HSA), employers providing HDHPs are not required to make contributions to offset pre-deductible costs, and those employers that contribute to their employees' HSAs often fail to make the large deductible affordable for many consumers. In fact, in 2019, the average employer contribution to an individual-only HSA was $572,[97] while the average annual individual-only deductible for an HDHP was $2,846, twice the limit to be eligible for an HSA.[98] As a result, consumers of all income levels may have difficulty affording care.

For patients with chronic and serious conditions, high-deductible plans can prompt individuals to delay or skip necessary care. For low-income populations, HDHPs can cause patients to forego care altogether. While HDHPs may result in short term cost savings, they also pose significant risks to consumers without additional patient protections.

Recommendation #28: Update federal employer-sponsored coverage affordability standards to allow employees to access subsidized individual market coverage in cases in which their only employer-sponsored or job-based insurance option fails to provide comprehensive coverage. Update the cost inputs to federal ESI affordability standards to capture both premium and deductible costs in comparison with employee income. Policymakers should consider applying additional patient protections to HDHPs, including potential options for consumer off-ramps to more affordable coverage through the ACA marketplaces and Medicaid when employer or job-based HDHPs fail to meet basic affordability tests.

94 *Average Annual Family Premium per Enrolled Employee For Employer-Based Health Insurance*. (2020, September 11). KFF. https://www.kff.org/other/state-indicator/family-coverage/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D

95 *Many People with Employer-Sponsored Insurance Would Face High Out-of-Pocket Costs for COVID-19 Treatment*. Johnston, E. M. (2020, March 23). Urban Institute. https://www.urban.org/urban-wire/many-people-employer-sponsored-insurance-would-face-high-out-pocket-costs-covid-19-treatment

96 Claxton, G., Rae, M., Damico, A., Young, G., & McDermott, D. (2019). *Employer Health Benefits 2019 Annual Survey*. Kaiser Family Foundation. http://files.kff.org/attachment/Report-Employer-Health-Benefits-Annual-Survey-2019

97 Ibid.

98 Ibid.

#29: Key Considerations for Developing a Public Option

In the past, Congress and the Administration have debated the value and impact of implementing a "public option" insurance plan within the individual health insurance marketplaces. Public options have been touted as mechanisms to improve affordability for consumers and thereby broaden coverage access and promote competition. However, to effectively implement a public option that meets the stated goals, it is important that Congress and the Administration take steps to minimize negative impacts on consumers by pairing public option legislation with additional patient- and consumer-focused reforms. While not a comprehensive list, the Administration and Congress should, at a minimum, account for the following considerations should a public option be developed:

Adequate: A public option should be at least as comprehensive as ACA marketplace plans. We recommend that the public option be a robust benefit. At a minimum, a public option should cover preventive services without cost-sharing, cover the essential health benefits, and ensure that plans meet a minimum actuarial value. This includes ensuring patients have access to prescription medications, preventive and emergency services, and reproductive and maternity care.

Affordable: A public option must improve affordability of coverage. A public option must include caps on out-of-pocket costs and other protections that reduces consumer costs. Affordability should be measured not on premium alone, but also take into account deductibles and other out-of-pocket costs. A public option should be designed thoughtfully; the program must enable more individuals to access high-quality, affordable care while preserving or improving affordability for existing individual market enrollees. To this end, proposals should be paired with increases in eligibility for and the generosity of the ACA's subsidies in order to expand high-quality coverage to more individuals and families.

Accessible: A public option must increase the number of insured individuals and ensure patients have access to the services and providers that they need. A public option that is broadly available to people in a variety of coverage situations is likely to have a much bigger increase in coverage than a program with relatively narrow eligibility criteria. Additionally, patients must have access to adequate and robust provider networks. Policymakers must ensure that patients have timely access to providers and specialty services.

CONCLUSION

Our organizations appreciate the opportunity to share our joint priorities for the first 100 days of the next Administration. Patients, now more than ever, need access to adequate and affordable health insurance coverage. It is imperative that policymakers take steps immediately to pursue the changes we have outlined in this document.

For questions or comments regarding the content of this report, please contact Katie Berge, Director of Federal Government Affairs at The Leukemia & Lymphoma Society at katie.berge@lls.org.

The Leukemia & Lymphoma Society

American Lung Association

Epilepsy Foundation

American Cancer Society Cancer Action Network

Muscular Dystrophy Association

Cystic Fibrosis Foundation

National Multiple Sclerosis Society

National Psoriasis Foundation

American Heart Association

National Patient Advocate Foundation

National Health Council

Arthritis Foundation

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American Liver Foundation

National Organization for Rare Disorders

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American Kidney Fund

Cancer Support Community

ALS Association

The AIDS Institute

WomenHeart: The National Coalition for Women with Heart Disease

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