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NATIONAL COALITION





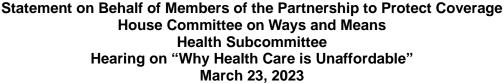
for Rare Disorders











Today marks the 13th anniversary of the Affordable Care Act (ACA). The passage of the ACA resulted in drastic reductions of our nation's uninsured rate and expanded coverage to millions of patients with preexisting conditions. The 31 undersigned organizations represent more than 120 million people with pre-existing conditions in the U.S.

Our organizations have a unique perspective on what individuals and families need to prevent disease, cure illness, and manage chronic health conditions. The diversity of our organizations and the populations we serve enable us to draw upon a wealth of knowledge and expertise that we believe are critical components of any discussion aimed at improving or reforming our system of healthcare. We urge you to support the policies that have done so much to protect the health and well-being of our nation, and urge you to enact the changes that we've outlined below to further improve upon the Affordable Care Act.

In early 2017, our organizations agreed upon three principles that we use to help guide our work on health care to continue to develop, improve upon, or defend the programs and services our communities need to live longer, healthier lives. These principles state that: (1) healthcare must be adequate, meaning that healthcare coverage should cover treatments patients need; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare should be accessible, meaning that coverage should be easy to get, keep, and understand and not pose a barrier to care.

The Affordable Care Act and Subsequent Actions Have Made Quality Healthcare More Affordable

People with pre-existing conditions have benefitted from recent increases in federal support for affording health insurance. For example, people with chronic conditions benefitted disproportionately from the passage of the Affordable Care Act. Over the first 5 years of ACA implementation, coverage increased among nonelderly adults with chronic disease by 6.9 percent versus 5.4 for adults without chronic conditions. State-level Medicaid eligibility expansions were associated with a coverage increase among people with chronic conditions of 2.8 percentage points.²

At the heart of affordability is Medicaid expansion. Individuals who live in states where Medicaid has expanded saw their medical debt drop dramatically (almost 50%) from 2013-2020; people who live in states that didn't expand Medicaid saw much less decline (only 10%) and in poor communities in non-expansion states, medical debt levels increased. Medical debt – much of which is owed to hospitals – leads to delayed care and poorer health outcomes. An analysis by the Commonwealth Fund published in the New England Journal of Medicine for the 10th anniversary of the Affordable Care Act found in the first 10 years, the law "reduced the number of uninsured people to historically low levels and helped more people access health care services, especially low-income people and people of color." Quite simply this law is saving lives.

Improvement in screening rates for colorectal cancer in early Medicaid expansion states
translated to an additional 236,573 low-income adults receiving screenings in 2016 and,
if the same absolute increases were experienced in non-expansion states, 355,184 more
low-income adults would have had colorectal cancer screening as of 2019. Colon cancer
screenings in accordance with US Preventive Services Task Force (USPSTF)
recommendations have reduced the incidence of colon cancer.⁵

¹ Consensus Healthcare Reform Principles: https://www.lung.org/getmedia/0912cd7f-c2f9-4112-aaa6-f54d690d6e65/PPC-Coalition-Principles-FINAL.pdf.

² Coverage for Adults With Chronic Disease Under the First 5 Years of the Affordable Care Act - PMC (nih.gov)

³ https://jamanetwork.com/journals/jama/article-abstract/2782187

⁴ https://www.nejm.org/doi/full/10.1056/NEJMhpr1916091

⁵ Jeff Legasse, First states to expand Medicaid saw larger screening rate increases, Healthcare Finance, (May 24, 2019), https://www.healthcarefinancenews.com/news/firststates-expand-medicaid-saw-larger-screening-rate-increases (citing Fedewa et al., Changes in Breast and Colorectal Cancer Screening After Medicaid Expansion Under the Case 4:20-cv-00283-O Document 103-2 Filed 11/30/22 Page 14 of 29 PageID 1999 313943270.17 8 Affordable Care Act, Am. J. of Preventive Med., (July, 2019), https://www.sciencedirect.com/science/article/abs/pii/S0749379719301163.).

- The ACA provision expanding dependent insurance coverage to young adults up to 26 was associated with a 3.67 percentage points increase in receipt of blood-pressure measurement among young adults aged 19-25 years.⁶
- An analysis by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) estimated that approximately 137 million Americans with private insurance had access to preventive services without cost sharing in 2015, which increased to 151.6 million by 2020. ASPE attributed the increase to growth in the number of people enrolled in private healthcare coverage subject to USPSTF recommendations, and a decrease in the share of such people enrolled in plans not subject to USPSTF recommendations.⁷

Below are recommendations our organizations have for Congress to make quality healthcare even more affordable:

Make the Enhanced Advance Premium Tax Credits Permanent

The passage of the Inflation Reduction Act in August will keep healthcare affordable for millions of people by extending the enhanced advance premium tax credits (APTCs) through the end of 2025. These tax credits help lower- and middle-income individuals and families afford health insurance purchased through the Affordable Care Act marketplaces. Because of this measure, approximately three million individuals will keep their health insurance and over 10 million individuals won't see their premiums rise. Our organizations urge the Congress to pass legislation that permanently codifies the increased generosity and expanded eligibility for advance premium tax credits (APTCs)

Limit Inadequate Short-Term Limited Duration and Other Non-compliant Plans

The need for adequate, affordable, and accessible coverage has become even more important during the COVID-19 pandemic. Unfortunately, sub-par insurance plans continue to proliferate, confusing consumers and leaving them under-covered, as many of our groups detailed in a recent report. Congress should take action to protect consumers by restricting access to short-term limited duration insurance and other non-compliant plans.

Address Affordability of Health Insurance Out-of-Pocket Costs

In addition to the continued unaffordability of premiums, many people with coverage still cannot access care due to high cost sharing requirements. Congress should take action to ensure that coverage provides meaningful, equitable, and affordable access to care by:

- Shifting the APTC benchmark from silver plans to gold plans to decrease out of pocket exposure for patients;
- Ensuring that actuarial value (AV) of plans accurately reflect the financial risk faced by most consumers enrolled in the plan.¹⁰ This can be achieved through adjusting the standard population used to calculate AV and disregarding claims from outliers¹¹; and

Methodology.pdf . pg. 11.

⁶ Dependent Coverage and Use of Preventive Care under the Affordable Care Act, New England Journal of Medicine (Dec 11, 2014), available at https://www.nejm.org/doi/pdf/10.1056/NEJMc1406586?articleTools=true.

⁷ Office of Health Policy: Assistant Secretary for Planning and Evaluation, at p. 6.

⁸ https://www.hhs.gov/about/news/2022/06/22/fact-sheet-what-happens-premiums-if-extra-help-american-rescue-plan-expires.html ⁹ Under-Covered: How "Insurance-Like" Products Are Leaving Patients Exposed. March 2021. undercovered_report.pdf

¹⁰ A study in published in Health Affairs found that the share of costs actually borne by consumers was typically much higher than would be suggested by the AV. Polyakova, M., Hua, L. M., & Bundorf, M. K. (2017). Marketplace plans provide risk protection, but actuarial values overstate realized coverage for most enrollees. Health Affairs, 36(12), 2078-2084. doi:10.1377/hlthaff.2017.0660
¹¹ As described in: Center for Medicaid & Medicare Services. (2020, March 6). Final 2021 Actuarial Value Calculator Methodology. Retrieved from https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Final-2021-AVCalculator-

 Taking other actions to address the rising out of pocket costs faced by enrollees in the individual market and employer-sponsored insurance, such as through potentially incorporating deductible and cost-sharing into definitions of affordability.

Support and Expand Medicaid Coverage

Our organizations thank Congress for making continuous coverage eligibility for one year mandatory for children under 19 and encourage you to build upon previous investments in postpartum coverage, as well as make funding for the Children's Health Insurance Program permanent. Additionally, Congress should take action to address coverage for individuals who live in states that haven't expanded Medicaid and fall in the "coverage gap."

Conclusion

We look forward to continuing to work with Congress to improve upon the advancements made by the Affordable Care Act to expand affordable, accessible and adequate healthcare coverage for patients. I

Sincerely,

Alpha-1 Foundation

ALS Association

American Cancer Society Cancer Action Network

American Diabetes Association

American Heart Association

American Kidney Fund

American Liver Foundation

American Lung Association

Arthritis Foundation

Asthma and Allergy Foundation of America

CancerCare

Cancer Support Community

Chronic Disease Coalition

Crohn's & Colitis Foundation

Cystic Fibrosis Foundation

Epilepsy Foundation

Hemophilia Federation of America

Lupus Foundation of America

Muscular Dystrophy Association

National Alliance on Mental Illness

National Coalition for Cancer Survivorship

National Eczema Association

National Health Council

National Hemophilia Foundation

National Kidney Foundation

National Multiple Sclerosis Society

National Organization for Rare Disorders

National Patient Advocate Foundation

Susan G. Komen

The AIDS Institute

The Leukemia & Lymphoma Society