June 15, 2017

The Honorable Mitch McConnell
Senate Majority Leader
U.S. Capitol Building, S-230
Washington, DC 20510

The Honorable Orrin Hatch
Chairman, Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

Dear Majority Leader McConnell and Chairman Hatch:

The undersigned organizations, representing patients, consumers, and health care providers, write to express grave concern about potential changes to the fundamental structure and purpose of Medicaid, a vital source of health care for patients with ongoing health needs.

Proposals to phase out Medicaid expansion and implement per capita caps or block grants, like those included in the American Health Care Act (AHCA), HR 1628, threaten the ability of Medicaid to provide critical health care services to many of our most vulnerable citizens. These proposals aim to achieve billions of dollars in cost savings at the expense of tens of millions of patients and consumers who rely on Medicaid for life-sustaining care. We vehemently oppose converting Medicaid's financing into a capped funding structure, as well as phasing out Medicaid expansion, and will not accept any policy that cuts costs at the expense of patient and consumer access to care.

Medicaid is a Critical Lifeline for Patients and Consumers

Medicaid is a crucial source of coverage for patients and consumers with serious and chronic health care needs. Pregnant women depend on Medicaid, which covers roughly 50 percent of all births, including many high-risk pregnancies.[1] Medicaid covers cancer patients: nearly one-third of pediatric cancer patients were enrolled in Medicaid in 2013 and approximately 1.52 million adults with a history of cancer were covered by Medicaid in 2015.[2] Over 50 percent of children and one-third of adults living with cystic fibrosis rely on Medicaid to get the treatments and therapies they need to preserve their health.[3] Nearly half of children with asthma are covered by Medicaid or CHIP and adults with diabetes are disproportionately covered by Medicaid as well.[4,5] Over six million older adults also rely on Medicaid, many of whom depend on the program for long-term services—like help with bathing, dressing, eating, and toileting—and supports because there are no widely accessible and affordable alternative sources of payment for this care other than out-of-pocket. Americans with a history of cardiovascular disease make up 28 percent—nearly one third—of all Medicaid patients. The patients and consumers we represent are eligible for Medicaid through various pathways, including through income-related and disability criteria.

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[1] Markus A.R. and others. 2013. "Medicaid Covered Births, 2008 Through 2010, in the Context of the Implementation of Health Reform." *Women's Health Issues*. 23(5): e273-e280.

[2] American Cancer Society. *Estimate of Adults with a History of Cancer Covered by Medicaid in 2015*. January 2017., National Center for Health Statistics. *National Health Interview Survey*. 2015., NPCR: U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2013 Incidence and Mortality Web-based Report*. 2016.

[3] Cystic Fibrosis Foundation Patient Registry. *2015 Annual Data Report*. (Online). 2016. Available: https://www.cff.org/Our-Research/CF-Patient-Registry/2015-Patient-Registry-Annual-Data-Report.pdf

[4] Centers for Disease Control and Prevention. *Asthma: Health Care Coverage Among Children.* (Online). November 2016. Available: https://www.cdc.gov/asthma/asthma_stats/

[5] Kaiser Commission on Medicaid and the Uninsured. *The Role of Medicaid for People with Diabetes.* (Online). November 2012. Available: http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8383_d.pdf

Reject Per Capita Caps

The proposal to convert federal financing of Medicaid to a per capita cap or block grant system is deeply troubling. These policies are designed to reduce federal funding for Medicaid, forcing 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. These cuts would impact families across this country-including millions of middle class families who rely on Medicaid for long-term supports and services, nursing home care or services for a family member with disabilities.

While the AHCA proposed massive cuts to Medicaid, adjustments to the structure of the per capita caps, such as changing the baseline year or growth factor, do not resolve the fundamental problems with this policy. A per capita cap or block grant will result in less money for patients and consumers who get their care through Medicaid, plain and simple, and it creates a framework to further reduce spending down the road as lawmakers see fit. During every budget crisis or whenever legislators need a pay-for, Congress could decrease the inflationary adjustor to further reduce funding for the program.

In order to save money, per capita caps and block grants are set to grow more slowly than expected Medicaid costs under current law. As the gap between the capped allotment and actual costs increases over time, states will be forced to constrain eligibility, reduce benefits, lower provider payments, or increase cost-sharing. For patients and consumers with ongoing health care needs, per capita caps could mean that Medicaid no longer provides access to their health care provider or covers the care and treatments they need, including breakthrough therapies and technology. This could be devastating for people with serious diseases, for whom groundbreaking treatments represent a new lease on life. For people with cystic fibrosis, cancer, arthritis, and other chronic conditions, new therapies can greatly improve quality of life and increase life expectancy. In fact, our communities already have experiences, some dire, in which Medicaid programs have denied patients needed therapies because of budget constraints. A per capita cap will only exacerbate the downward pressure on Medicaid budgets and will further reduce access to these treatments for patients.

Per capita caps and block grants would also cut Medicaid most deeply when the need is greatest, because funding would no longer increase automatically in response to changing demographics or emerging public health threats. For instance, Medicaid has been a critical tool for states in fighting the recent opioid epidemic. Under a per capita cap proposal, no additional federal funds would flow to states to help them combat such crises. Constraining Medicaid in the face of the growing threat of the Zika virus could mean that states do not have the resources needed to care for infants who may be affected, leaving families with few options for care. Per capita caps are also not responsive to the aging of baby boomers because the caps make no distinction between the "young-old" (65-74) and the "old-old" (85 and older), the latter of whom will likely need much higher levels of service at significantly higher costs. In Medicaid, adults ages 65-74, on average, cost less than half per person than adults ages 85+.[6] A rigid funding structure that provides no flexibility for states in the face of shifting demographics or new public health crises is a stark contrast to the federal/state partnership that exists today and simply shifts costs to states, taxpayers, and families.

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[6] Flinn, Brendan, et al. *Capped Financing for Medicaid Does Not Account for the Growing Aging Population*. AARP Public Policy Institute. (Online) June 2017. Available: http://www.aarp.org/content/dam/aarp/ppi/2017/01/Capped-financing-for-Medicaid-Does-Not-Account-For-The-Growing-Aging-Population.pdf

Pairing financing reforms with increased flexibility, as has often been proposed, would further undermine Medicaid's role as a safety-net for patients and consumers. Without guardrails provided by federal requirements—coupled with reduced federal funding—states could reduce benefits and eligibility as they see fit and impose other restrictions, such as lock out periods and time limited enrollment, prioritizing cutting costs over patient care. The implications of this would be serious for those with complex health care needs. For a person with cancer, lock out periods could mean a later-stage diagnosis when treatment costs are higher and survival is less likely. For a person with diabetes, this would risk the ability to adequately manage the disease. This is true for rheumatoid arthritis as well; if patients do not have ready access to the treatments they need, they could end up costing the state much more in direct health and disability costs, and indirect costs in the forms of lost wages. For an older adult or person with a disability, a shortsighted cut to optional home and community based services could leave them with no choice but to move to a nursing home, a service that can actually cost three times as much per person on average in Medicaid. Many of our patients rely on costly but critical services that will quickly be targeted for cuts if states are given such flexibility, so it is imperative that current federal safeguards remain in place.

Maintain Medicaid Expansion

Nearly half of adults covered by the Medicaid expansion are permanently disabled, have serious health conditions—such as cancer, stroke, heart disease, arthritis, pregnancy, or diabetes—or are in fair or poor health.[9] Proposals to eliminate the state option to expand Medicaid and to eliminate the enhanced match for any enrollee with even a small gap in coverage would result in millions of vulnerable people losing coverage.[7,8] By eliminating the enhanced federal match for any enrollee with more than a month's gap in coverage, eventually states will be on the hook for billions of dollars to continue covering this population—an insurmountable financial hurdle. Additionally, seven states have laws that would effectively end Medicaid expansion immediately or soon thereafter when the expansion match rate is eliminated. Whether the trigger date is in three years or further down the road, the effect is the same: repealing Medicaid expansion will leave patients without the coverage they depend upon to maintain their health.

The proposed financing reforms are a fundamental shift away from Medicaid's role as a safety-net for some of the most vulnerable members of our society. Repealing Medicaid expansion would leave millions without the health care they rely upon. Our organizations represent and provide care for millions of Americans living with ongoing health care needs who rely on Medicaid, and we cannot support policies that pose such a grave risk to patients and consumers.

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[7] S&P Global Market Intelligence. *The U.S. Health Insurance Market is Poised to Move to a Defined-Contribution from a Defined-Benefit System of Federal Financing*. (Online). March 2017. Available: https://www.globalcreditportal.com/ratingsdirect/renderArticle.do?articleId=1811131&SctArtId=418648&from=CM&nsl_code=LIME&sourceObjectId=10006958&sourceRevId=3&fee_ind=N&exp_date=20270307-22:26:18

[8] Congressional Budget Office. *Cost Estimate: American Health Care Act*. (Online). March 2017. Available: https://www.cbo.gov/publication/52486

[9] Brantley, Erin, et. al. *Myths About the Medicaid Expansion and the 'Able-Bodied'*. Health Affairs Blog. (Online) March 2017. Available: http://healthaffairs.org/blog/2017/03/06/myths-about-the-medicaid-expansion-and-the-able-bodied/

We hope that we can maintain a productive dialogue as you move forward in this process to arrive at solutions that provide all Americans with high-quality, affordable care regardless of an individual's income, employment status, health status, or geographic location.

Thank you for your consideration.

Sincerely,

Original Signers:

AARP
ALS Association
American Cancer Society Cancer Action Network
American College of Physicians
American Congress of Obstetricians and Gynecologists
American Diabetes Association
American Heart Association
American Lung Association
American Parkinson Disease Association
American Society of Hematology
American Thoracic Society
Arthritis Foundation
Cancer Support Community
Children's Cause for Cancer Advocacy
COPD Foundation
Cystic Fibrosis Foundation
Huntington's Disease Society of America
Immune Deficiency Foundation
LeadingAge
March of Dimes
Muscular Dystrophy Association
National Alliance on Mental Illness
National Coalition for Cancer Survivorship
National Multiple Sclerosis Society
National Organization for Rare Disorders
Parent Project Muscular Dystrophy
Pulmonary Fibrosis Foundation
T1D Exchange

Additional Signers:

Academy of Integrative Pain Management
ADAP Advocacy Association
AIDS Action Baltimore
The AIDS Institute
Allergy & Asthma Network
Alliance for Aging Research
Alliance for Pediatric Stroke
Alliance for Prostate Cancer Prevention
Alliance of Dedicated Cancer Centers
Alpha-1 Foundation
American Academy of Addiction Psychiatry
American Behcet's Disease Association
American Brain Coalition
American Childhood Cancer Organization
American Epilepsy Society
American Society of Pediatric Hematology/Oncology
American Society of Clinical Oncology
Amyloidosis Support Groups Inc.
ARPKD/CHF Alliance
Association of Pediatric Hematology/Oncology Nurses
Batten Disease Support & Research Association
Beyond Batten Disease Foundation
Bladder Cancer Advocacy Network
Bridge the Gap - SYNGAP Education and Research Foundation
Bronx Lebanon Family Medicine
CancerCare
Center to Advance Palliative Care
Child Neurology Foundation
Community Access National Network
Consortium of Multiple Sclerosis Centers
Cooley's Anemia Foundation
Cutaneous Lymphoma Foundation
Cystinosis Research Network
Dystonia Medical Research Foundation
Easterseals
Epilepsy Foundation
Everylife Foundation for Rare Diseases
FORCE: Facing Our Risk of Cancer Empowered
Fibrous Dysplasia Foundation
First Focus Campaign for Children

FND Hope
Genetic Alliance
Global Liver Institute
Hannah's Hope Fund
Health Resources in Action
Hope4Bridget
Hope for Hypothalamic Hamartomas
Intercultural Cancer Council Caucus
International Alliance for Pediatric Stroke
International Organization of Multiple Sclerosis Nurses
International Pemphigus & Pemphigoid Foundation
Jeffrey Modell Foundation
Kids v Cancer
LIVE**STRONG**
Liver Health Connection
LUNGevity Foundation
Lung Cancer Alliance
Lutheran Services in America
Malecare Cancer Support
Medicare Rights Center
METAvivor
MLD Foundation
Moebius Syndrome Foundation
National Association of State Head Injury Administrators
National Blood Clot Alliance
National Council on Aging
National Health Council
National Hemophilia Foundation
National Patient Advocate Foundation
National Tay-Sachs & Allied Diseases Association
National Urea Cycle Disorders Foundation
National Viral Hepatitis Roundtable
NBIA Disorders Association
Noah's Hope
The Parkinson Alliance
PCa Blue
PCD Foundation
Pennsylvania Prostate Cancer Coalition
Polycystic Kidney Disease Foundation
PXE International
Rett Syndrome Research Trust
SADS Foundation
Sick Cells
Susan G. Komen
Tuberous Sclerosis Alliance
United Spinal Association
United Way Worldwide
US Pain Foundation
Veterans Health Council
Vietnam Veterans of America
Wilson Disease Association
Wishes for Elliot: Advancing SCN8A Research

CC: Senate Democratic Leader Charles Schumer
Finance Committee Ranking Member Ron Wyden