The Chronic Illness & Disability Partnership

March 21, 2017

Member of Congress
Washington, DC

Dear Representative:

The undersigned organizations are writing as members of the Chronic Illness and Disability Partnership to **strongly oppose proposals to dramatically cut Medicaid and repeal the Affordable Care Act (ACA), which would jeopardize the health care of the nearly half of Americans who live with chronic illnesses and disabilities**.[1] Individuals living with these conditions are among those who have benefited the most from both the Medicaid program and the consumer protections established under the ACA, and these populations stand to lose the most under plans that weaken these programs and protections.

The Chronic Illness and Disability Partnership consists of national organizations representing individuals living with a wide range of chronic illnesses and disabilities, including cerebral palsy, HIV, Hepatitis B and C, and mental health and substance use disorders. While our organizations are national in scope, we also affiliate with strong regional, state, and community based advocacy networks.

We cannot afford to lose coverage for people living with chronic illnesses and disabilities.

Proposals being debated by Congress right now would jeopardize insurance access for 24 million people over the next ten years, including a significant proportion of individuals living with chronic illnesses and disabilities.[2] In 2012, 117 million Americans were living with a chronic illness and/or disability,[3] and before the ACA, these individuals often struggled to find affordable health insurance that met their care and treatment needs, with one in seven applicants nationwide being denied health insurance due to a pre-existing conditions. Approximately 27% of American adults under the age of 65, or 52 million Americans, are currently living with conditions that would leave them uninsurable if they applied for an individual health plan under pre-ACA underwriting practices, which allowed for pre-existing condition exclusions and premium rating based on health status.[4] These numbers will only increase as the baby boomer generation continues aging over the next four years: among current seniors 36% reported living with some type of disability.[5]

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[1] Wu S, Green A., Projection of Chronic Illness Prevalence and Cost Inflation, RAND Corporation (October 2000).
[2] Congressional Budget Office, American Health Care Act (March 2017), available at https://www.cbo.gov/publication/52486.
[2] Congressional Budget Office, American Health Care Act (March 2017), available at https://www.cbo.gov/publication/52486.
[3] U.S. Centers for Disease Control and Prevention, Chronic Disease Overview (February 23, 2016), available at https://www.cdc.gov/chronicdisease/overview/.
[4] Kaiser Family Foundation, Pre-existing Conditions and Medical Underwriting in the Individual Insurance Market Prior to the ACA (December 2016), available at http://files.kff.org/attachment/Issue-Brief-Pre-existing-Conditions-and-Medical-Underwriting-in-the-Individual-Insurance-Market-Prior-to-the-ACA.
[5] Administration on Aging, A Profile of Older Americans, available at https://aoa.acl.gov/Aging_Statistics/Profile/2015/16.aspx.

For further questions and information please contact Carmel Shachar, Center for Health Law and Policy Innovation, at cshachar@law.harvard.edu, Amy Killelea, National Alliance of State and Territorial AIDS Directors, at akillelea@NASTAD.org, or Jean McGuire, Northeastern University, at j.mcguire@neu.edu.

- **Impact of Medicaid Expansion**: State and national studies have found that in states that expanded Medicaid, there was a significant increase in adults receiving consistent care for their chronic conditions, an increase in the use of preventive services and screening, and increased access to specialty care.[6]

We cannot afford to lose the important gains we have made in access to Medicaid and private insurance, coverage that is necessary to maximize the health, productivity, and ability to live independently among the wider community for many Americans living with chronic illnesses and disabilities. For example, in states with Medicaid expansion, individuals living with disabilities were significantly more likely to be employed (38% verses 31% in non-expansion states) and significantly less likely to be unemployed because of disability.[7] Increasing the income requirements for Medicaid expansion allows these individuals to pursue employment and community participation that can lead to improved health outcomes and decreased dependence on cash assistance and other programs. A recent analysis found that among non-disabled adults with Medicaid coverage, nearly 8 in 10 live in working families, and a majority are working themselves.[8] Eliminating protections for people with chronic conditions and disabilities would be disastrous for many individuals who are finally able to access health care under the ACA and would undermine public health efforts to improve our nation's health and reduce medical spending on high cost, late stage interventions.

We must ensure that Medicaid is able to meet the needs of people living with chronic conditions and disabilities.

Maintaining the current Medicaid structure is essential to allowing states to respond to current need and increased demand for Medicaid coverage during tough economic times, unanticipated outbreaks or disasters and when there are health innovations, such as the recent curative breakthrough treatments for hepatitis C. For people living with chronic conditions and disabilities, Medicaid has been a critical source of care and coverage through both the Medicaid expansion and traditional eligibility categories:

- In the states that expanded Medicaid, 1.2 million people with substance use disorders that were previously uninsured have gained access to coverage[9]
- For people living with HIV, the proportion of people covered by Medicaid rose from 36% in 2012 to 42% in 2014[10]

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[6] Larissa Antonisse, et al., The Effects of Medicaid Expansion under the ACA: Updated Findings from a Literature Review, Kaiser Family Foundation (February 2017), available at http://kff.org/report-section/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review-table-2/.

[7] J. Hall et al., Effect of Medicaid Expansion on Workforce Participation for People with Disabilities, American Journal of Public Health (December 20, 2016), available at http://www.nationaldisabilitynavigator.org/wp-content/uploads/Materials/CHRIL/AJPH-CHRIL_MedicaidExpansion-WorkforceParticipation_2016-Dec-20.pdf.

[8] Rachel Garfield, et al., Understanding the Intersection of Medicaid and Work, Kaiser Family Foundation (February 2017), available at http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/.

[9] Lisa Clemans-Cope, et., Repealing The ACA Could Worsen The Opioid Epidemic, Health Affairs (January 30, 2017), available at http://healthaffairs.org/blog/2017/01/30/repealing-the-aca-could-worsen-the-opioid-epidemic/#two.

[10] Jennifer Kates and Lindsey Dawson, Insurance Coverage Changes for People with HIV Under the ACA, Kaiser Family Foundation, available at http://kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/.

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- Medicaid provides a safety net that allowed 1.5 million cancer patients, and one-quarter of all childhood cancer patients to obtain treatment in 2015[11]
- Medicaid covered 19% of all people living with diabetes in 2012[12]
- Medicaid covered 8.8 million adults and children living with disabilities and chronic conditions in 2010[13]

Many states are using Medicaid funding to provide innovative services to individuals living with chronic illnesses and disabilities in an effort to better manage their conditions and avoid higher cost later stage interventions or institutional care. Medicaid, for example, funds 40% of long-term services and supports spending,[14] including home and community-based long-term services and supports that were improved or expanded upon, including with enhanced match, through the ACA.

Either a per capita cap structure or block grant would result in significant federal cuts to the Medicaid program, crippling states' ability to respond to the needs of beneficiaries. These cuts will have a disproportionate impact on people living with chronic conditions and disabilities who rely on the Medicaid program as a lifeline to services and supports they need to stay healthy. Because neither a block grant nor per capita caps would keep pace with actual health care costs from year to year, restructuring Medicaid in these ways would require states to cut eligibility as well as many services and programs aimed at better management of chronic conditions. There is simply no way for states to absorb federal cuts of this magnitude without harming beneficiaries, particularly because Medicaid costs per beneficiary are already far below costs for private insurance.[15]

We must ensure that private insurance remains affordable for lower income individuals.
Lower socioeconomic status is associated with higher rates of chronic illnesses and disabilities.[16] At times, these individuals must choose between medically necessary treatment and care and their other bills, including housing, food, and childcare. Without subsidies (based, in part, on income) to defray the cost of premiums and cost sharing for treatment and care, meaningful care will quickly become unaffordable for these individuals. Coupled with the ACA's cost-sharing reductions, actuarial value requirements – which ensure that plans cover a certain percentage of insurance costs – have been a critical protection to make sure that people have access to insurance that has affordable cost sharing. Taking away the actuarial requirements will mean that people living with chronic conditions and disabilities will have access to less generous plans with high deductibles and high cost sharing.

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[11] American Cancer Society – Cancer Action Network, available at https://secure3.convio.net/acscan/site/Advocacy?cmd=display&page=UserAction&id=13812

[12] Sarah Stark Casagrande and Catherine C. Cowie, Health Insurance Coverage Among People With and Without Diabetes in the U.S. Adult Population, Diabetes Care 2012 Nov; 35(11): 2243-2249, available at https://doi.org/10.2337/dc12-0257.

[13] Kaiser Family Foundation, People with Disabilities and Medicaid Managed Care: Key Issues to Consider (February 2012), available at https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8278.pdf.

[14] Kaiser Family Foundation, The Affordable Care Act's Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities, available at http://kff.org/health-reform/issue-brief/the-affordable-care-acts-impact-on-medicaid-eligibility-enrollment-and-benefits-for-people-with-disabilities/.

[15] Edwin Park and Judith Solomon, Per Capita Caps or Block Grants Would Lead to Large and Growing Cuts in State Medicaid Programs (June 22, 2016), available at http://www.cbpp.org/research/health/per-capita-caps-or-block-grants-would-lead-to-large-and-growing-cuts-in-state.

[16] Adler NE, Rehkopf DH, U.S. Disparities in Health: Descriptions, Causes, and Mechanisms, *Annual Review of Public Health,* (2008).

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Additionally, subsidies that support access to insurance in the individual and small group market are a more efficient and more affordable way to cover people with pre-existing conditions than high risk pools. In over 30 years of state and federal high risk pool experience, these programs are often expensive to administer, expensive for consumers to purchase, and are severely limited in enrollment capacity and coverage of enrollees.

We must ensure that people with pre-existing conditions are protected from discriminatory insurance practices.

- ***Guaranteed Issue***
  The ACA is important to individuals living with chronic illnesses and disabilities because it prohibits insurers from denying coverage based on pre-existing conditions or charging individuals higher premiums based on health status or gender. In the past, pre-existing conditions and health status underwriting were popular tools for preventing higher cost enrollees, such as those living with chronic illnesses and disabilities, from obtaining private insurance. Additionally, these consumer protections should not be contingent on continuous coverage requirements. Our concern is that continuous coverage requirements will result in individuals being unable to find affordable coverage and then finding themselves permanently locked out of coverage due to increased premiums. Individuals living with chronic illnesses and disabilities are most vulnerable to the penalties of the continuous coverage requirements because they are more likely to have unavoidable gaps in coverage as a direct result of those conditions.

- ***Coverage Requirements***
  Individuals living with chronic conditions and disabilities need a minimum benefits package that includes the range of services and treatments needed to manage their conditions, including prescription drug benefits, substance use and mental health treatments, and preventive services. Without a minimum standard of benefits, people living with chronic conditions and disabilities could find themselves with access to insurance that does very little to provide meaningful access to care and treatment, which will ultimately harm individual health and community health and drive up the costs of health care. For instance, studies show that people living with HIV who are enrolled in Qualified Health Plans under the ACA have higher viral suppression rates (84.6%) compared to those who are uninsured (78.6%).[17] This is because this population had access to a strong prescription drug benefit and other services they needed to stay healthy.

- ***Discriminatory Plan Designs***
  Protections that prohibit insurers or providers from discriminating against individuals on the basis of disability have been critical to ensuring these populations have meaningful access to care and treatment. For instance, lifetime and annual caps, before the ACA, often resulted in people living with chronic illnesses and disabilities 'maxing out' on their coverage and getting cut off from health care when they needed it the most. Without strong consumer protections, insurers will once again utilize benefit designs that penalize individuals living with chronic illnesses and disabilities and prevent them from getting the care they need. Individuals living

[17] Kathleen A. McManus, Affordable Care Act Qualified Health Plan Enrollment for AIDS Drug Assistance Program Clients: Virginia's Experience and Best Practices, AIDS Res. Hum. Retroviruses (2016) 32(9): 885-91.

with chronic illnesses and disabilities face significant discrimination in the insurance markets because they are often more expensive to insure. In order to allow for meaningful access to health care coverage, these individuals need strong anti-discrimination protections.

We urge you to ensure that policy decisions on the future of Medicaid and ACA maintain access to affordable care and treatment for individuals living with chronic illnesses and disabilities. Strong consumer protections and comprehensive, affordable coverage for this population are critical to improve the nation's public health and reduce health care spending. Additionally, replacement without strong consumer protections, programs, and funding will result in a health care system that only provides meaningful access for the healthy and leaves individuals with chronic illnesses and disabilities behind. We are hopeful that any health care reforms proposed under the new Administration and the 115th Congress will provide the necessary protections for those living with chronic illnesses and disabilities.

Respectfully submitted by the undersigned organizations,

American Association of People with Disabilities
The Arc of the United States
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Cancer Support Community Center
Cystic Fibrosis Foundation
Center for Health Law and Policy Innovation
Christopher & Dana Reeve Foundation
Harm Reduction Coalition
HIV Medicine Association
Justice in Aging
Legal Action Center
National Alliance of State & Territorial AIDS Directors
National Alliance on Mental Illness
National Association of State Head Injury Administrators
National Disability Rights Network
National Viral Hepatitis Roundtable
National Multiple Sclerosis Society
United Cerebral Palsy
Treatment Access Expansion Project

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