



Principles for Health Coverage Reform

Before the Affordable Care Act (ACA) was enacted in 2010, rare disease patients struggled to access health care coverage due to discriminatory insurance practices, limited Medicaid eligibility and debilitating cost-sharing. While imperfect, ACA successfully reformed these practices by forbidding insurers from discriminating against rare disease patients, outlawing annual and lifetime caps, expanding Medicaid, closing the Medicare Part D donut hole, and more.

In order for any ACA replacement plan to not harm rare disease patients, we must:

- ✓ **Protect rare disease patients against discriminatory insurance medical underwriting:**
 - **Guaranteed Issue and Renewal:** Requires insurers to offer insurance to all patients, regardless of health status, during annual open enrollment periods, special enrollment periods, and renewal periods.
 - **Prohibition on Benefit Exclusions:** Ensures discriminatory benefit exclusions or limitations aimed at individuals or groups of individuals with expensive pre-existing conditions are banned.
 - **Community Rating:** Guarantees that patients are not charged higher premiums because of their health status, including if they have a gap in coverage.

- ✓ **Cap out-of-pocket costs at affordable annual or monthly levels:**
 - Under the ACA, the out-of-pocket maximum for 2017 can be no more than \$7,150 for an individual plan and \$14,300 for a family plan before marketplace subsidies. These caps must remain.

- ✓ **Ban annual and lifetime limits on benefits and coverage**

- ✓ **Prohibit any newly-created high-risk pools from including:**
 - Eligibility based upon health status or other discriminatory factors
 - Waiting periods for coverage after enrollment and enrollment caps
 - Benefit caps or medical underwriting
 - Inadequate funds to ensure the viability of the plan
 - Premiums and deductibles higher than the small and large group markets

- ✓ **Allow children to remain on their parents' health plans until age 26**

- ✓ **Oppose plans to weaken Medicaid through financing mechanisms such as block grants or per-capita caps:**
 - Many children with a rare disease and their families are on Medicaid because the high-cost of their disease has resulted in financial hardship.
 - Block granting or instituting per-capita caps can disincentivize states from covering high-cost patients, adding orphan drugs to state formularies, or covering expensive but medically necessary inpatient care, outpatient care, habilitative services, and rehabilitative services.

- ✓ **Maintain coverage for rare disease patients that gained coverage under the ACA Medicaid expansion**

- ✓ **Continue the ongoing closure of the Medicare Part D donut hole**

- ✓ **Keep vital care options, such as the:**
 - **Community First Choice 1915(k) program:** Allows patients in need of skilled-care to stay in the home and out of skilled-nursing facilities under a Medicaid state-option.
 - **Concurrent Care for Children (ACA Section 2302):** Allows children who are enrolled in either Medicaid or CHIP to receive hospice services without foregoing curative treatment for a terminal illness.

- ✓ **Ensure quality health insurance at affordable prices by requiring:**
 - **Essential health benefits:** Requires baseline levels of benefits in small and large group plans, including prescription drugs in each USP class.
 - **Adequate provider networks:** Plans must maintain adequate provider networks for their beneficiaries.

- ✓ **Provide adequate subsidies for low-income Americans**

- ✓ **Adequately and effectively incentivize individuals to purchase insurance while accommodating any valid reason for going uninsured for a period of time**
 - Continuous coverage incentives must accommodate any appropriate and valid reason for going uninsured

- ✓ **Prohibit discrimination against individuals with disabilities (ACA Sec.1557)**

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