



Protecting Rare Disease Patients: Principles for Health Coverage Reform

Before the Affordable Care Act (ACA) was enacted in 2010, rare disease patients could not access health care coverage due to various discriminatory insurance practices, limited Medicaid eligibility, and debilitating cost-sharing. While imperfect, the Affordable Care Act 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, it must:

- ✓ **Protect rare disease patients against discriminatory insurance medical underwriting:**
 - **Guaranteed Issue and Renewal:** Require 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:** Ensure discriminatory benefit exclusions or limitations aimed at individuals or groups of individuals with expensive pre-existing conditions are banned.
 - **Community Rating:** Guarantee 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, or similar caps, must remain.

- ✓ **Ban annual and lifetime limits on benefits and coverage:**
 - Annual or lifetime caps on benefits and coverage disproportionately harm individuals with rare diseases due to the genetic, life-long nature of their disease, as well as the incredibly expensive therapies and orphan drugs used to treat them. Prior to the Affordable Care Act rare disease patients often hit lifetime caps before adolescence.

- ✓ **Prohibit any newly-created high-risk pools from including:**
 - Eligibility standards based upon health status, diagnosis, or other discriminatory factors
 - Waiting periods for coverage and enrollment
 - Enrollment caps
 - Benefit caps or medical underwriting
 - Inadequate funding mechanisms

- Premiums, deductibles, or other plan structures that are more burdensome than those in the small and large group markets
- ✓ **Allow children to remain on their parents' health plans until age 26.**
- ✓ **Oppose plans to weaken state Medicaid programs that currently provide meaningful coverage to rare disease patients:**
 - Medicaid block grants or per-capita caps could unwittingly cut coverage for rare disease patients by capping Medicaid expenditures for the sickest patients.
 - Many children with a rare disease and their families are on Medicaid because the high-cost of the 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 long-term coverage for rare disease patients in states that chose to expand eligibility under the ACA-funded Medicaid expansion.**
- ✓ **Continue the closure of the Medicare Part D donut hole:**
 - Many individuals with rare diseases rely on Medicare Part D due to their age or disability status. The closure of the Part D donut hole has relieved a significant financial burden.
- ✓ **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:** Ensure baseline levels of benefits are required in small and large group plans, including prescription drugs in each USP class or similar categorization structure.
 - **Adequate provider networks:** Plans must maintain adequate provider networks for their beneficiaries.
- ✓ **Provide adequate and equitable financial assistance to low-income Americans in order for them to purchase and maintain insurance.**
- ✓ **Adequately and effectively incentivize individuals to purchase insurance while accommodating all valid reasons 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):**
 - Sec. 1557 of the ACA extends Americans with Disabilities Act (ADA) protections to additional health-related areas, including insurance protections.

Updated: February 27, 2017