



RDLA Policy Primer: *Affordable Care Act (ACA)*

The Affordable Care Act (ACA) is a comprehensive health care reform law that was enacted in March of 2010. The Affordable Care Act, also frequently called Obamacare, had three primary [goals](#).

1. Make affordable health insurance available to more people regardless of their pre-existing conditions by providing consumers with subsidies or “premium tax credits” that lower costs for households with incomes between 100% and 400% of the [federal poverty level and by establishing marketplaces for people to shop for private health insurance plans that meet minimum coverage standards](#).
2. [Expand Medicaid](#) to cover all adults with incomes below 138% of the federal poverty level.
3. Support innovative medical care delivery models and payment policies designed to improve the quality of care and identify ways to lower the costs of health care

The ACA was aimed at extending health insurance coverage to 32 million uninsured Americans by expanding private and public insurance. Key provisions of the Affordable Care Act had the goal of expanding access to insurance coverage, increasing consumer insurance protections, emphasizing prevention and wellness, improvement of health quality and system performance, and curbing rising health costs.

Key ACA provisions include:

- Prohibit insurance plans from denying coverage to people with preexisting conditions
- Require employers to cover their workers or pay penalties (small employer exceptions).
- Require individuals to have insurance with some exceptions.
- Facilitate the creation of state-based insurance exchanges or access to a federally run insurance exchange to help individuals and small businesses purchase insurance.
- Require insurance plans to cover young adults (ages 26 and younger) on their parent’s policies.
- Prohibit lifetime monetary caps on insurance coverage and limit the use of annual caps.

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers. Please contact Shannon von Felden at svonfelden@everylifefoundation.org to learn more about RDLA.

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- Prohibit insurance plans from excluding coverage for children with preexisting conditions.
- Prohibit insurance from cancelling coverage
- Require insurance plans to cover certain preventive care with no co-pays such as immunizations, preventive care (wellness visits) for children, and certain screenings for adults for conditions such as high blood pressure, high cholesterol, diabetes, and cancer.
- Require most health plans to cover the federal Recommended Uniform Screening Panel RUSP newborn screens with no cost sharing (Note that state newborn screening programs vary widely in both the number of mandated tests and their funding mechanisms)
- Create the Centers for Medicare and Medicaid Innovation (the CMS Innovation Institute) to oversee efforts to test new models of delivering and paying for care.

-You can learn more about the specifics of these key provisions [here](#).

Before enactment of the Affordable Care Act, insurance companies discriminated against patients due to their preexisting conditions. Patients were denied coverage to therapies and specialists, or even denied coverage or employment altogether because they were diagnosed with a disease prior to obtaining insurance. The Affordable Care Act banned these practices and protected patients, including those with rare diseases, by outlawing annual and lifetime caps and by banning insurance providers from discriminating against those with pre-existing conditions.

Criticisms and Challenges

Since its implementation in 2010, the ACA has faced criticism and questions of legality. Critics of the reform bill argue that it has caused premiums to rise for many people who already had insurance and has increased taxes. The legality of the Affordable Care Act has been called into question in most part due to the individual mandate penalty, the requirement for individuals to have coverage if they are able to afford it or pay a fee called the individual Shared Responsibility Payment. The purpose of this mandate was to give insurance companies a large pool of customers since they were required to cover people with chronic medical conditions. However, since Congress reduced the tax penalty to zero in 2017, opposition argued that the mandate was no longer constitutional and a [federal appeals court](#) agreed -in a 2019 ruling. The case will be heard by the Supreme Court in November 2020. If the Supreme Court rules that the mandate is unconstitutional and that this part of the ACA can't be severed or taken out from the rest of the bill's provisions, the entire ACA would be ruled unconstitutional.

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