Perspective

The Affordable Care Act in the United States and HIV Disease: Past, Present, and Future

From its beginning, the AIDS epidemic crystallized some of the major flaws of the American health care system. Most private health insurance was associated with employment, and job loss meant insurance loss. Private insurers refused new coverage for people with HIV infection. Medicaid, an important program for uninsured people with low income, was limited to only those in certain categories (eg, pregnant women or children), and although people who had progressed to AIDS were categorized as eligible (ie, "disabled"), those with early stage HIV disease were not. The Patient Protection and Affordable Care Act is a landmark change in health care law in general and for people with HIV infection in particular. Its provisions offer dramatic improvements in health coverage, although a Supreme Court ruling that limited the expansion of Medicaid poses ongoing problems in some states. This article summarizes a presentation by Timothy M. Westmoreland, JD, at the IAS–USA continuing education program Improving the Management of HIV Disease, *held in Washington, DC, in May 2015.*

Keywords: HIV, Affordable Care Act, ACA, Medicaid, insurance

Health Care Prior to the Affordable Care Act

Since the late 1970s, several attempts have been made to reform health care in the United States, including those by the Carter, Clinton, and Obama administrations. These proposed reforms were crucial to persons with HIV infection. In the 1980s, the US Food and Drug Administration began to approve drugs for the treatment of HIV and associated opportunistic infections, drugs that would potentially prevent death and disability. However, these drugs were expensive. Because most private insurance in the United States is provided through employment, when some people with AIDS became too sick to work or others lost their jobs owing to discrimination based on their HIV serostatus, they also lost their insurance. Moreover, many individuals held jobs that did not offer insurance or were unemployed. Consequently, people with HIV/AIDS were often uninsured, and many with low income did not have access to needed treatments. Although some of these individuals qualified for Medicaid, a public program that provides insurance for persons with low income, many did not.

Many Americans think that Medicaid is simply a program for persons with low income. However, it is not available to all of these individuals. It is a program for persons with low income who are also in some specific category (eg, women who are pregnant, persons aged >65 years or <18 years, or those who are disabled and unable to work). Many people with HIV infection did not meet the standard for full disability because they had not yet progressed to AIDS. As research improved treatment, this created a particularly ironic conundrum: drugs were available to prevent disability caused by HIV infection but the only people who could generally qualify for Medicaid coverage were those who were already categorized as disabled by the disease. Since the late 1980s, Congress attempted to amend the Medicaid program to broaden access to treatment for HIV-infected persons with low income, but political support was not wide enough to find the budget resources that would be needed to do so.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was created as an alternative to expanding insurance for everyone with HIV infection. The Ryan White CARE Act has helped many people, but as a grant program instead of a true insurance program it has limited funding and consequently offers limited care in some places. It cannot reach all HIV-infected persons in low-income settings; it is simply not that well funded.

For persons with HIV infection, the Obama administration's health care reform program represents a comprehensive attempt at health care reform, because one of the principal goals of the Patient Protection and Affordable Care Act (referred to as the Affordable Care Act; ACA) was to expand health care coverage for persons with low income who did not fit into existing Medicaid categories for coverage eligibility.[1]

Passing the Affordable Care Act

The ACA has been continually in danger of political collapse or dismantlement. During the consideration of the legislation, southern Democrats advocated for the cost of the proposal to be lower but for payments to rural hospitals in their home states to be higher. Some members of Congress supported including prohibition of abortion in the statute, and others supported including guaranteed access to abortion services. Some wanted to abolish the existing employer-based insurance system and create single-payer coverage for all, and others wanted to provide vouchers for individuals to buy whatever insurance was available in the market.

In addition, the support of each of the 60 Senate Democrats was needed to avoid a filibuster under Senate rules, effectively giving each senator veto power. This created

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Box. Status of the US Health Care System Before the Affordable Care Act

- Not having health insurance has a substantial impact on a person's life. It is the single largest cause of personal bankruptcy in the United States. Because uninsured persons frequently postpone getting preventive services, they are diagnosed for serious conditions, including AIDS, much later than those who have health insurance.
- By 2009, only 5% of Americans had individual insurance (ie, coverage that was not provided to a group), because the quality of coverage had been in decline for the past 20 years; most insurance plans would cover little beyond emergency situations and would not cover preexisting conditions.
- In addition to the employer-based system, small group markets, and the individual insurance market, there were a variety of public programs for persons who were excluded from the health care system. These public programs covered approximately one-third of the population and cost approximately $800 billion per year, or 20% of the federal budget. Medicare was available for the elderly and disabled and Medicaid was accessible to individuals with low income who were also in one of the specified categories. These Medicaid programs received 50% to 80% of their support from the federal government, with minimum federal standards and maximum state flexibility. However, these programs did not cover HIV-infected persons with low income unless they fit into one of the traditional categories, which many did not.
- Additional health care programs included the Child Health Insurance Program, TRICARE (formerly the Civilian Health and Medical Program of the Uniformed Services) for the individuals in the military and their families, insurance provided by the US Department of Veterans Affairs for veterans and their families, and the Federal Employees Health Benefits Program for federal civil servants and their families.
- In 2009, approximately 50 million persons in the United States (15%) were uninsured. Many uninsured were persons who had low-wage jobs that did not provide employer-based health insurance. The number of uninsured increased as employers discontinued private health insurance.
- The Affordable Care Act was created to supplement and amend the health care system. Some provisions went into effect in 2012 and 2013; most were not available until 2014.

a bidding war for what each senator needed before giving his or her approval. Yet, by December 24, 2009, there was a bill, and every Senate Democrat voted for it. It was a different version than had passed the House of Representatives, but it was expected to be the first step of a House-Senate compromise that could be enacted and sent to the President for signature.

In 2010, Congress began working on this House-Senate compromise legislation. However, Senator Kennedy died in August 2009. His Democratic replacement would only serve temporarily, until a special election was held. In January 2010, Senator Kennedy's empty seat was filled by a Republican, and a filibuster seemed inevitable. It was assumed that a House-Senate compromise could never pass the Senate and that the ACA would not be passed. Another attempt at national health reform seemed to have failed. However, the bill was reinvented as a budget bill, the only type of bill that Senate rules exempt from a filibuster. As such, the bill had to be fully paid for by offsetting revenues and reductions in other spending. The bill raised taxes on some employer-based health insurance plans, some medical devices, and even some tanning parlors to pay for the program. The bill was created within the estimates of the Congressional Budget Office, which works in such detail that it estimated how much each section and paragraph of legislation would cost or save. The constraints were tight, and some of the policies in the final law are driven by these budget concerns.

The Structure of the ACA as Enacted

The ACA is a patchwork, covering holes and gaps in the existing private and public insurance systems without ending any of the underlying systems. Aspects of the health care system that have remained the same or changed as a result of the ACA are outlined below (the status of these programs before the ACA is outlined in the Box).

- Large, employment-based group health insurance remains essentially unchanged. Large employers routinely provide health insurance as a benefit, and more than half of people living in the United States are projected to be insured through their employers.
- Medicare, the insurance program for individuals older than 65 years, is largely unchanged. Reimbursement levels for hospitals will be somewhat lower in the future, but hospitals agreed to this in order to allow enactment of other coverage expansions that would minimize debt from uncompensated care. There is also some improvement in Medicare coverage: for the first time, there is substantial coverage of preventative health services and better reimbursement for prescription drugs.
- Insurance provided by the US Department of Veterans Affairs, TRICARE (formerly the Civilian Health and Medical Program of the Uniformed Services), and the Federal Employees Health Benefits Program remains largely unchanged.
- For Medicaid, the ACA made all persons with low incomes eligible, not just persons with low income who fit in a specific category. The ACA expanded Medicaid by creating a new category for persons whose income is below 138% of the poverty level but who are not members of another category. If a state expands its Medicaid program, the federal government will pay 100% of Medicaid costs for states in the first few years of the ACA, which

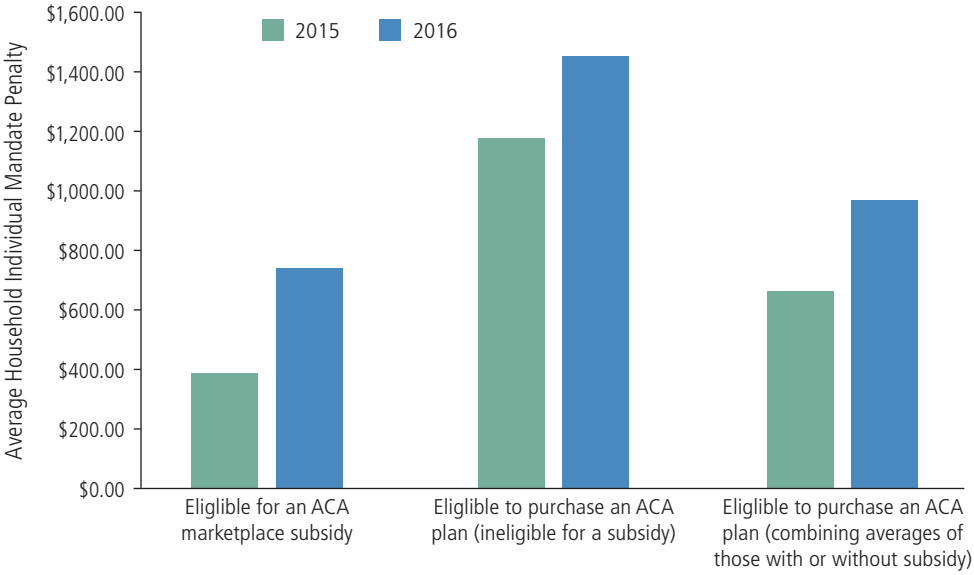

Figure 1. The average household individual mandate penalty among uninsured individuals eligible for Affordable Care Act (ACA) insurance plans, 2015 to 2016. Adapted from Jeter et al.[2]

will reduce to 90% matching by 2020 and in perpetuity. As will be discussed, the Supreme Court has complicated this change a great deal, but in more than half of states, the ACA has expanded Medicaid.

Exchanges were created for persons who did not have large group health insurance and who were not enrolled in Medicare, Medicaid, or other public programs. These are state-based marketplaces with a fallback system that the federal government oversees if states choose not to create a health care exchange. Subject to limitations of citizenship, individuals without health insurance from other sources can purchase health insurance in these exchanges. Health care exchanges are used for small business or individual coverage and operate like employer-based insurance, in that the risks of catastrophic expenses are pooled among all participants.

Private commercial insurers voluntarily offer to sell private policies through these insurance exchanges. Such policies provide essentially the same benefit structure as employer-based plans, offering preventive services, prescription drugs, women's health services (including contraception), maternity care (which was often omitted from private health insurance), and mental health services. The main variations in the exchange plans involve the level of premiums and cost sharing. The lower the monthly premium, the higher the cost sharing that comes with services.

The ACA includes a mandate that requires employers to provide health insurance or to contribute money to health insurance exchanges. The ACA also includes a mandate requiring all individuals to have insurance or pay a penalty. This mandate is an effort by the US government to make the insured group large enough to support the cross-subsidies that are intrinsic to all insurance pooling systems (ie, that everyone pays a set amount in advance so that they have insurance if they later need expensive care). The individual mandate acts to avoid having people wait until they are seriously ill and in need of expensive care before they buy health insurance. The penalty for not purchasing health insurance is currently small, but it will grow over time until it is a substantial enough penalty to persuade most persons to comply with the mandate.[2] In order to make this health coverage affordable, tax subsidies on a sliding scale are provided to persons with incomes from 100% of the poverty level to up to 400% of the poverty level, amounting to an income of approximately $45,000 per year for a single person or approximately $80,000 per year for a family of 3.[2]

In addition, the ACA requires long-overdue fundamental reforms for private insurance, including eliminating waiting periods or exclusions for pre-existing conditions, annual and lifetime limits on health care coverage, retroactive cancellations of policies (called "rescissions"), and price discrimination based on diagnosis (eg, HIV infection). Under the ACA, all individuals, even those with HIV infection, pay essentially the same insurance premiums; variations in cost are still allowed by age and geographic location but not by diagnosis or need. All insurance plans provide preventive and screening benefits (such as HIV testing) without cost sharing, as well as "minimum essential benefits" (eg, physician visits, hospital stays, and prescription drugs, including those used to treat HIV infection).

Recent Challenges to the Affordable Care Act

Actual ACA enrollment faced many workability obstacles in the beginning. For example, Oregon was unable to enroll participants, even after spending a large sum of money on its software system; ultimately, the state turned the running of its exchange over to the federal government. However, in other states, exchanges went smoothly and well. For example, in Kentucky, more than 400,000 individuals were newly insured in private plans or Medicaid in the first year, taking the number of uninsured individuals in the state from 20% to 11%. Currently, 34 states have chosen not to establish their own health care exchanges and have let the federal government do so for them. Despite several obstacles, there are now 7 million insured individuals who were not insured before the ACA.

In 2012, the Supreme Court was asked to rule that the mandate requiring all individuals to purchase health insurance was unconstitutional. Those challenging the mandate argued that the federal government cannot force individuals into commerce for the purpose of regulating commerce. Debate ensued, with serious legal scholars on each side of the issue.

In addition, there was a secondary claim that the required Medicaid expansion was unconstitutional, that it amounted to coercion and violated states' rights under the Tenth Amendment to the US Constitution. This was a surprising argument to most because there had not been a limit placed on what the federal government could require of states as a condition of receiving federal money. Experience with the federal Medicaid program during the Clinton administration demonstrated that, although the government rarely enforced requirements to withdraw federal funding from states, it was able to require that states expand or change their Medicaid programs. It had never been in question that the federal government could expand Medicaid.

The Supreme Court decision came as a surprise to most legal observers. First, Supreme Court justices ruled that the individual mandate was indeed constitutional. As a matter of legal doctrine, some people believe that the Supreme Court ruled it was an unconstitutional exercise of the federal authority to regulate commerce (although this is still debated). However, the Supreme Court clearly ruled that mandating that all individuals purchase health insurance could be enacted as a permissible tax provision, in which individuals may receive a tax penalty if they do not enroll in a health insurance program.

Second, to almost everyone's surprise, the justices ruled that states cannot be required to expand their Medicaid programs. By ruling that Medicaid expansion was allowed but could not be required, the Supreme Court effectively made ACA expansion a state-by-state choice. This decision dramatically affected persons with HIV infection in states that chose not to expand their Medicaid program.

Since the ruling, a majority of states have expanded their Medicaid program, although many have not. States that have not expanded Medicaid are left with what is referred to as a "coverage gap." Many individuals are ineligible for Medicaid but are also ineligible for subsidies to purchase insurance from state exchanges because their income is below the 100% federal poverty level. Without exchange subsidies, insurance plans are unaffordable for most of these individuals. Before the Supreme Court opinion, it was anticipated that these people would be in the expanded Medicaid program, but instead they are left in the gap between Medicaid and exchanges.

An estimated 40% of uninsured, HIV-infected individuals reside in states that chose not to expand Medicaid. Where Medicaid expansion does not occur, those affected most are individuals with low income who do not have children, those of black race, and those who live in the Southern United States. Thus, individuals with HIV infection are directly affected by their state's decision regarding Medicaid expansion.

Even with the 2012 Supreme Court ruling, there are substantially more people enrolled in Medicaid than there were before the ACA. The rate of uninsured individuals in the United States has decreased dramatically. It is estimated that 16 million Americans were insured in 2015 who would be uninsured without the ACA. More than 80% of people in exchanges receive subsidies.[3] In a June 2015 ruling, the Supreme Court rejected yet another challenge to the ACA regarding the legality of these subsidies.

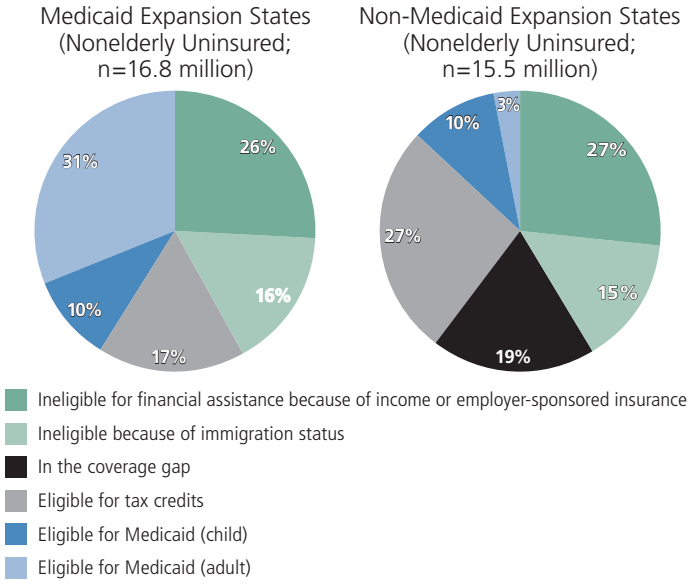

Figure 2. Eligibility status for Affordable Care Act (ACA) coverage among nonelderly uninsured individuals as of 2015, by state Medicaid expansion status. Because of rounding, totals may not equal 100%. Adapted from Garfield et al.[3]

The ACA has faced obstacles but has still been effective. New problems are arising with narrow physician networks, as insurance companies are competing in exchanges. Ideally, these would be addressed by quality assurance measures so that consumers and regulators alike would be able to see who is cutting back on insurance, but such measures are currently inadequate, especially in the context of HIV care. Other obstacles include limited drug formularies, although this is not a new problem and is not solely attributable to the ACA. Issues related to limited drug formularies, drug tiering, and requirements of prior authorization have arisen in private managed care and in Medicare and Medicaid over the last 10 years. Closed formularies are historically used as a tool to control cost of treatments, but they are also a tool for risk avoidance by insurance companies. Most obviously, health insurance companies in some states are beginning to assign HIV drugs to their top tier of cost sharing and restrictions, functionally discouraging individuals with HIV infection from choosing these health plans. This raises the legal question of whether having limited formularies or assigning HIV drugs to the top tier of cost sharing constitutes illegal discrimination.

All of these developments have implications for the current Ryan White HIV/AIDS Program. The Program is still very much needed for people living in states that have chosen not to expand Medicaid and those living anywhere in the United States who are undocumented and, therefore, ineligible for any public programs. Moreover, even for people who qualify for Medicaid, Medicare, or private insurance, the Ryan White HIV/AIDS Program will continue to act as a safety net for benefits that are not provided or are too thinly provided by traditional health care systems.

Conclusion

The Supreme Court opinion notwithstanding, progress will be made regarding Medicaid. Last year marked the 50th anniversary of Medicare and Medicaid, programs that are now accepted as standard to the US health care system. It must be remembered that when these government programs were created, they were litigated all the way to the Supreme Court as well, and that the last state to join the Medicaid program did not do so until 16 years after the program's creation (Arizona, in 1981). It should be noted that Medicare and Medicaid are still being improved. Similarly, the ACA should be monitored with patience and conviction. It is a dramatic improvement, but it can be made better.

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