

Building on the Foundation:

Consumer Advocacy's Role in Successful Health Care Reform

The United States has enacted a historic health care reform law that will have the most profound impact on our health care system since the passage of Medicare and Medicaid in 1965. Consumer advocates played a critical role in making this possible through their work on incremental national, state and local health care reforms that paved the way for comprehensive federal reform. Consumer advocates also strengthened the federal legislation to make health insurance more affordable, to provide greater consumer protections in the health insurance market, and to support delivery system reform to improve quality while reducing costs. They represent the interests of low- and moderate-income people, racial and ethnic minorities, immigrants, seniors, people with chronic conditions, and others whose voices are often not heard in health care debates.

The need for consumer advocacy at both the national and state levels has not ended with the passage of the national law. Implementation will occur at the national level and in all 50 states. It will require new expertise. And it will address many issues simultaneously, stretching resources to their limits. In this technically complex and politically polarized environment, consumer advocacy organizations and their funders have an essential role in ensuring that the law's implementation maximizes access to coverage and care. In particular, state-based consumer health advocates have important on-the-ground knowledge and experience, and they know the best ways to achieve policy goals. These advocates will need significant support to strengthen core capacities, to add new skills and to handle increased demands. Ensuring that consumer voices are not drowned out by well-funded special interests is crucial to success.

While advocates' agendas and strategies will vary depending on the local and state environments in which they operate, the work will generally fall into five areas.

1. Building public support and implementing early reforms: Health care reform is already facing well-organized attempts to repeal and undermine it. Advocates will need to counter these efforts by educating consumers, mobilizing grassroots support, working for successful implementation of the provisions that go into effect immediately, and quickly demonstrating the positive impacts of reform.

2. Defending existing programs and current levels of coverage: State revenues continue to drop sharply and, in many states, threaten funding for Medicaid, the Children's Health Insurance Program (CHIP) and other public programs. These programs are essential for low-income families now, and they also provide the foundation for later coverage expansions mandated by the health care reform law. Advocates need to defend these programs by developing broad-based coalitions with creative proposals and campaigns to increase revenues and to reduce program costs without harming enrollees.

3. Developing policy and regulations at the national and state levels: Implementation of the law will occur over several years. Federal and state officials will need to develop new rules and regulations that will shape how the programs and provisions are implemented. State governments will have substantial responsibility and flexibility in implementing complex components of reform, such as the new insurance Exchanges, premium subsidies and

Medicaid expansions. State consumer advocates, working closely with national organizations, need to ensure that consumer needs are actively represented in policymaking and implementation decisions.

4. Enrolling people in new programs and monitoring the impact of reform: As the major components of reform go into effect, states will face the monumental task of helping newly eligible people enroll in Medicaid, purchase insurance in the Exchanges, and apply for premium-assistance subsidies. Consumer assistance programs will be essential to help people gain coverage and take advantage of new options. Many consumer organizations already provide this type of assistance and are the best qualified to run consumer assistance programs. Such programs will also provide information about what is and is not working, which will be important in assessing the impact of the reforms and in responding to identified problems.

5. Ensuring the sustainability of reform through health care delivery system reforms: In the long term, the success of reform will depend on constraining overall health care spending in the United States. The law provides funding for a host of pilot and demonstration programs to test new models of care designed to achieve these goals. Consumer engagement throughout the design, implementation and evaluation of these programs will be imperative. Advocates can use the knowledge gained through these efforts to help replicate and extend effective innovations.

These efforts require coordination and close collaboration among national and state advocacy organizations. Consumer advocacy success will require:

- Strengthening and expanding state-based systems of advocacy that have been developed over the last several years.
- New mechanisms of coordination among and between national and state organizations.
- Enhanced advocacy capacity to develop policy analysis and sophisticated communications and messaging strategies.
- Adequate resources to sustain advocacy over the many years it will take to implement national health care reform.
- Increased coordination among funders to ensure effective application of limited resources, and between funders and advocates to develop shared agendas and strategies based on local environments and needs.

Consumer groups have always faced long odds. But with the help of visionary foundations and individuals, they have achieved important gains for people in need. We must keep investing in consumer advocacy organizations to build a health care system that holds both the promise and reality of access to affordable, quality health care for all.



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