



State-Based Consumer Advocacy After Health Care Reform

While the fate and shape of health care reform legislation is hanging in the balance, consumer advocates cannot afford to wait to begin thinking about the work they will need to do in a post-reform environment. Assuming reform legislation similar to what is now on the table does indeed pass, advocates will face major challenges and opportunities in the period following passage of a national reform law. These challenges and opportunities will shape the work we have to do at both the state and national levels. Success requires a cooperative relationship between state-based and national organizations.

As key implementation tasks and defense of the law occur at the state level, effective consumer capacity in all states will remain necessary. While major differences in political and economic environments will persist across states, the common challenges that many confront will also lend themselves to greater cross-state coordination than has sometimes been possible. The implementation period will most likely be marked by continued high-intensity political conflict, as well as major demands generated by the complexities and scope of the implementation task. This will require resources for all the same capacities that were essential during the effort to win passage of reform (i.e., policy, organizing, communications, coalition building, campaign planning and resource development).

In this new environment, health care industry groups will be well positioned to dominate the decisions of federal regulators and state governments. Unless consumer interests are also at the table, over-extended state and federal policymakers will only get a partial picture of the policy options and will be unduly swayed by special interest arguments.

Success in the period ahead will also require national organizations to coordinate technical assistance to state allies as much as possible and to build on relationships with national membership/chapter organizations that have been developed in the course of the campaign for national reform. Coordination among national groups can maximize the different strengths and capacities that organizations bring to the table.

The work ahead can be broken down into a number of major categories, each of which is discussed in more detail below:

- Maintaining and expanding public support for national reform
- Protecting existing state coverage
 - National level (e.g., continuation of enhanced Federal Medical Assistance Percentages [FMAP] and Consolidated Omnibus Budget Reconciliation Act [COBRA] premium subsidy)
 - State level (e.g., Medicaid defense and waiver-monitoring)

- Implementation
 - National level (e.g., regulations, rule making)
 - State level (e.g., legislation, system development, applications for federal resources)
- Making improvements in the law (e.g., affordability, children's coverage and insurance regulation)
- Taking advantage of new opportunities (e.g., community benefits and care coordination)
- Identifying and addressing the gaps left out or inadequately addressed by the law (e.g., racial and ethnic health disparities, access to dental and mental health care, and long-term care)

Maintaining and Expanding Public Support

Although we expect a bill to pass, the margin is likely to be narrow. There will be substantial confusion from the public regarding the impact of the law, exacerbated by the attacks from opponents. We expect that attacks will begin immediately upon passage of the national health care reform law and will continue through at least two election cycles. This could tip the balance of political support away from reform if it is not successfully countered. The immediate task will be to win the struggle to define health care reform in the minds of the American public in the period leading up to the 2010 election.

Because of the delayed timeline for coverage and many of the insurance reforms, it is particularly important to sustain public support across the extended period of time before the benefits of the new law become evident. The first universal health care law in Massachusetts and the Medicare Catastrophic Act (MCCA) both passed in 1988 and were repealed in large part. This underscores that defense of the law must be step one of implementation.

The strategy for responding to anticipated attacks must include:

- Public education and messaging
- A concerted effort to get earned media for the interim steps leading up to reform
- A coordinated strategy to respond to efforts to create legal and political roadblocks to implementation
- Shoring up support among activists, many of whom will be disappointed or frustrated by the inevitable compromises that will be part of the new law
- Creating a grassroots demand for implementation to counter efforts to scale back, delay or repeal the law

State-based consumer advocates will need to be particularly active in identifying more immediate wins that will come out of reform and in building demand from the grassroots to see it through to full implementation. Consumer advocates must also continue to strengthen their relationships with lawmakers, especially those connections they've built during the past year gearing up for national reform.

To carry out this work, consumer health advocates will need data from polling and focus groups about the issues raised by attacks and the issues about which the public cares most. From that, we will need messages, as well as an understanding of the opportunities for earned media to deliver those messages. In addition to overall messaging, state-based advocates should develop targeted messaging to appeal to the specific concerns of their states and of targeted constituencies. For example, in states that have more expansive public programs or stronger insurance reforms in

place, advocates will need to defend the law in the context of possible losses of already established consumer protections. For Medicare beneficiaries, advocates will need to educate the public on new benefits and to rebut continued efforts to undermine support for reform. In some states, advocates will have to actively counter potential challenges to the national reform law.

Protecting Existing State Coverage

At the same time consumer advocates are working to defend the new law, they must also defend existing coverage programs, primarily Medicaid. States are likely to remain in fiscal trouble for at least the next couple of years, which will jeopardize existing coverage for vulnerable populations. States' struggles to pay for Medicaid will also be framed in the context of national reform and will be used to delay or prevent implementation.

The Medicaid defense effort should occur at the state and national levels. At the state level, the fiscal crisis and the issue of paying for Medicaid in a period of heightened demand and weak revenue does present a challenge. However, it also creates the opportunities to promote cost-saving delivery-system and quality improvements within the Medicaid program and to attack structural weaknesses in state tax codes.

There will be new opportunities for state advocates to build alliances with state and local provider groups, including hospitals, around protecting existing coverage. States struggling to maintain Children's Health Insurance Program (CHIP) coverage may also be a testing ground for campaigns to support children's health. These could be transferred to the national level to respond to unresolved issues in national reform regarding children. At the national level, a concerted effort to promote an extension of enhanced FMAP (unless it is included in the reform legislation) and COBRA premium assistance can help people maintain coverage and states manage their budget crises.

In addition to preserving enhanced federal matching rates to help states weather the current economic downturn, we can expect a number of states to pursue Medicaid waivers to help them manage the cost of their Medicaid

National organizations will take the lead in coordinating a campaign to preserve enhanced federal funding for coverage. They can identify cross-state themes and provide technical support around waivers, while state groups will need to take the lead in coalition building, mobilization and communication with state-level decision-makers, as well as with their federal delegations.

Implementation: National Level

Implementation of national health care reform will create innumerable commissions and rule-making opportunities in which consumer health advocates should participate. One advantage of the shift from legislation to rule making is that there are fewer lobbying restrictions involved.

Implementation efforts at the national level will create both an opportunity and a necessity for a strong state-federal partnership, as many state-based advocacy organizations have direct experience with the kinds of decisions that federal agencies need to make. These federal agencies should be tapped for their expertise, as well as for their political contribution.

Advocates need to identify key federal decision points that will affect the architecture of reform and will shape the decisions that can be made at the state level. There will be critical health delivery system issues. This is a policy-heavy undertaking that requires a detailed analysis of federal responsibilities and a timeline for implementation. These efforts will require considerable policy support for state advocates from national groups. This also means that state-based organizations will need to increase their own policy capacity.

State and grassroots activists can play a key role in keeping Congress' attention focused on implementation. State advocates will also have an important role to play in organizing a counterweight to the industry seeking to shape implementation in its own interest. Coordination across national groups will further enhance the strength of the consumer voice. Strong coordination among state-based advocates will also be critical in keeping implementation decisions on track. Once a national reform law is passed, we cannot allow consumer groups to break apart over how we get the work done.

Implementation: State Level

The national reform law will presumably leave many key decisions to the states around insurance reform, exchange development and operations, integration of subsidies with Medicaid, development of coordinated care systems and more. Advocates will likely need extensive policy and political support to help them make appropriate choices for their state, as well as a sounding board on how to navigate the state-based political issues involved with implementation. In-state policy capacity is also critical.

Key tasks at the national level include identification of key issues and state opportunities, development of model legislation/best practices for states, and working with state allies on campaign plans suited to specific state environments. It will also be critical that advocates bring the lessons from state-level implementation back to Washington so they can feed the efforts to fix and refine the bill. National organizations can cultivate relationships with federal administrators and facilitate access for state organizations. And national groups can also play a role in facilitating communication across state lines, which is important because state groups will have vital information and experiences to share with their peers.

Fixing the Law

The final bill is likely to fall short in a number of crucial areas, such as affordability and children's health. There may also be significant, state-specific or regional issues (e.g., enhanced FMAP for "leader state" issues related to provider reimbursement). For a number of reasons, including "issue fatigue," a backlog of other business that has been neglected during the health care reform debate and the hypothetical nature of some of these problems (e.g., why should they worry in 2010 about affordability problems that don't occur until 2013?), it may be very difficult to get Congress to focus on these issues in the period immediately following reform. Another problem is that drawing attention to the law's shortcomings may conflict with the desire of Congress and the White House to depict the law as a success, and this may also come in conflict with efforts to defend the law from attacks.

Advocates should assume a multi-year effort that starts with fairly low visibility. We need to be patient but persistent with respect to building a campaign or campaigns to respond to critical shortcomings. We will need to spend time carefully planning these campaigns, developing

strategies that allow us to navigate the environment, and identifying opportunities and partners that can help advance this work. There will need to be a careful assessment of the final provisions and dialog among state and national organizations to identify areas of mutual concern. Key tasks include the development of policy analysis and other materials that explain the problems, overall campaign development, and a strategy to begin education of policymakers, opinion leaders, consumers and other stakeholders.

Immediate Opportunities

While major provisions of the law do not go into effect for several years, some provisions are effective immediately and present state advocates with new opportunities to improve access, quality and cost-effectiveness. For example, if the Senate's community-benefit provisions remain in place, they provide a new opportunity to improve access and to reduce medical debt during the interim period. They also offer an opportunity to strengthen the base of local grassroots activists. Over time, it should be possible for this base to pivot to a more public health orientation on community benefits as the demand for free and reduced-cost care declines. Other immediate opportunities include Medicaid expansion for those states that have the ability to undertake it, and the development of improved models of care delivery, especially for high-risk and high-need populations such as seniors with multiple chronic illnesses.

Filling the Gaps

Health care reform will leave many issues untouched or under-addressed. These include cost-containment, quality-improvement, health equity, and dental and long-term care. At this point, it is also difficult to forecast the final outcome of the debate over closing the Medicare Part D doughnut hole. This constellation of issues, and perhaps others, represents the future of consumer health advocacy. In addition, reform is unlikely to be the last word on "entitlement reform" and deficit reduction, which could have a major impact on Medicare, Medicaid and new coverage provisions going forward.