COMMUNITY CATALYST

Building on the Foundation:

Consumer Advocacy's Role in Successful Health Care Reform

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COMMUNITY CATALYST

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Preface

With the generous support of the Public Welfare Foundation, Community Catalyst developed this report to highlight the challenges and opportunities that lie ahead for consumer advocacy organizations following passage of national health care reform legislation.

This report is just a first step in Community Catalyst's efforts to help consumer advocates chart a course for the post-reform environment. In the coming months, we will develop detailed descriptions of key provisions in the law and timelines for implementation, lead workshops to help state groups map strategies for moving forward, and provide analysis in critical areas to help groups develop the technical expertise necessary to successfully represent consumers in important policy discussions. Our ultimate goal is to establish coordinated and linked systems of advocacy in all 50 states in which advocates representing health care consumers, low- and moderate-income families, racial and ethnic minorities, immigrants, seniors, people with chronic conditions, and vulnerable populations work together to implement health care reform. Community Catalyst will also continue to collaborate with national partners on advocacy at the federal level and a variety of state initiatives and projects.

Implementing the national health care reform law will require a broad and sustained collaborative effort. It is a great opportunity not just to move toward the goal of affordable, quality health care for all, but also to develop new models of consumer participation and empowerment. Working with state and national consumer advocacy organizations, we hope to realize the full potential of this legislation to bring about meaningful, positive change throughout the health care system.

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About Community Catalyst

Community Catalyst is a national nonprofit advocacy organization dedicated to making quality, affordable health care accessible to everyone. Since 1997, Community Catalyst has worked to build consumer and community leadership to transform the American health system. With the belief that this transformation will happen when consumers are fully engaged and have an organized voice, Community Catalyst works in partnership with national, state and local consumer organizations, policymakers, and foundations, providing leadership and support to change the health care system so it serves everyone—especially vulnerable members of society.

For more information about Community Catalyst projects and publications, visit www.communitycatalyst.org.

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Executive Summary

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.

Introduction

The enactment of the Patient Protection and Affordable Care Act, the historic national health care reform law, will have a profound impact on our health care system and affect the country in many areas beyond health care. By providing more affordable health insurance coverage to many more Americans, it will strengthen the financial stability of families and communities, improve the sustainability of businesses, and begin to rectify an injustice that has long plagued our society.

In the prolonged struggle to enact a national health care reform law, consumer advocates played a critical role. Consumer advocates were important to the passage and implementation of the incremental national, state and local health care reforms that paved the way for comprehensive federal reform. Their experience and the effective strategies they learned have been crucial in creating a favorable environment for national legislation. Consumer advocates also worked to strengthen the legislation to make health insurance more affordable, to provide greater consumer protections in the health insurance market, and to support changes in the way health care is delivered to improve quality while reducing costs.

In these efforts, consumer advocates represented the interests of many vulnerable people whose voices are often not heard in discussions of national policy, such as low- and moderate-income consumers, racial and ethnic minorities, immigrants, and people with disabilities and other special health care needs. They formed systems of advocacy – networks of organizations that represent various constituencies as well as those with specialized skills such as organizing, policy analysis, legal analysis and communications. Consumer advocates acted as a counterforce to insurer and provider organizations and other well-funded groups devoted to protecting the interests of their members. At other times, consumer advocates found common ground with these stakeholders and formed alliances to pursue shared agendas.

The need for consumer advocacy efforts at both the national and state levels has not ended with the passage of the national health care reform law – in fact, advocacy will only increase in importance as the law is put into effect. Implementation will occur at the national level and in all fifty states. It will require expertise in areas that are new to advocates. And it will address many issues simultaneously, stretching resources to their limits. In the months and years to come, consumer advocacy organizations and their supporters will have an important role to play – and significant challenges to overcome – to ensure that the law is implemented in a way that maximizes access to coverage and care for people in need.

History tells us that reforms can fail. For example, the Massachusetts Health Security Act, enacted in 1988, was designed to achieve universal health care coverage in the state through programs rolled out over a period of years. From the beginning, the law was attacked by business organizations. The attacks picked up steam during the economic downturn of the early 1990s, and major parts of the bill were ultimately repealed.

Consumers also turned against The Medicare Catastrophic Coverage Act (MCCA), also enacted in 1988, when opponents' negative messages overpowered any information about potential positive impacts of the law. The majority of seniors did not fully understand the complex policies in MCCA, and there was little organized messaging to highlight the potential benefits of the legislation, especially for low-income seniors. The bill's opponents

were able to infuse the debate with messages that caused seniors to fear the law's changes. Without coordinated messaging to support the law and highlight its benefits, the opposition won. Seniors mobilized to call for the law's repeal and, faced with an overwhelmingly negative public reaction, Congress repealed the legislation 16 months after its passage.

While the current national health care reform law will provide significant benefits to tens of millions of people, it also has features that put it at risk. The law has many opponents, and the major benefits are not scheduled to go into effect for several years. The scope of the law and the nation's difficult environment (a weak economy and a partisan political climate) also mean that success will be difficult to achieve and will require significant ongoing advocacy and support.

About This Report

This report specifically addresses the roles of consumer advocates and funders now that national health care reform has been enacted, but it should be useful to everyone who is committed to the successful implementation of the law. The goals of the report are to describe:

- The new environment following passage of the law.
- The key tasks, challenges and opportunities for consumer advocacy organizations in this new environment.
- The skills, capacities and support consumer advocacy organizations will need to carry out these efforts effectively and with the greatest possible chance of success.
- Funders' critical role in ensuring that advocates can effectively represent health consumer needs and interests in the many negotiations and decisions to come.

A New Environment for Health Care Reform

Following the failure to enact national health care reform in 1993, efforts to improve the country's health care system largely devolved to the states. Many funders recognized this shift and invested significantly in developing and strengthening state consumer advocacy organizations to increase their ability to represent consumers in state-based initiatives.

As a result, consumer advocates in many states across the country developed strong track records in successfully advocating for state and local coverage expansions. The passage of the State Children's Health Insurance Program (SCHIP) in 1997 created opportunities to expand health insurance coverage for children, and children's advocates in nearly every state pushed policymakers and state agencies to maximize use of the available funding. Some states developed broader reforms. Maine, with the strong support of advocates and others, created an insurance plan designed to make health insurance more affordable for individuals and small businesses. Vermont and Massachusetts passed major health care reform legislation that greatly expanded coverage. Successful expansions also occurred in Colorado, Florida, Minnesota and Oregon. Although much progress was made, in many cases lack of funding and other constraints limited the impact of state-level reforms. California attempted to enact major reform but was ultimately stymied by the state's financial collapse.

In 2008, the election of a president with a commitment to health care reform and strong support in both houses of Congress offered a new opportunity to aggressively pursue health care reform at the national level. The first victory was the passage of the Children's Health Insurance Program Reauthorization Act (CHIPRA) early in 2009, in which children's advocates played a major role. In the ensuing months, national and state consumer advocacy organizations invested tremendous energy in the campaign for more comprehensive national reform. National advocacy organizations worked to build the overall environment for reform; state and local advocates formed new and stronger relationships with congressional delegations and brought both their experience and their knowledge of local needs and concerns to the debate. The demands of the campaign highlighted the importance of engagement at both levels, the value of collaboration between state and national advocates, and the importance of relationships with other key stakeholders such as providers and insurers. These combined efforts contributed significantly to the enactment of comprehensive national health care reform.

Putting the law's provisions and programs into effect will involve intensive efforts at both the federal and state levels. At the federal level, implementation will require extensive rule setting and policymaking; for example, to specify minimum insurance benefit requirements, to set overall rules for new health care Exchanges, and to create a variety of new quality standards and reporting requirements. The federal government will also be responsible for conducting numerous pilot and demonstration projects designed to improve the delivery of care and payment methods.

These federal decisions will have a major impact on states in many areas. Moreover, states will have substantial responsibility for putting major components of the law into effect. This is especially true because the law assigns major responsibility for implementing important reform components – such as the health insurance Exchanges – to the states, and gives them substantial flexibility in determining their governance, rules and regulations.

Thus states, like the federal government, will need to devote significant resources to establishing programs and setting new rules and guidelines. They will also need to find ways to bridge the gaps between existing state programs and requirements and those newly created at the federal level. In some cases, states will need to pass conforming legislation. And they will need to enroll people in new and expanded programs and assist people in understanding coverage options and navigating the enrollment process. In short, states will have a critical role in ensuring that implementation of reform is ultimately successful.

It is also important to note that the passage of health care reform was immediately followed by attempts to undermine it. There have been challenges to the law through state constitutional amendments, ballot initiatives and lawsuits. Many of the state-based challenges are part of nationally-coordinated opposition efforts. Moreover, health care reform will inevitably be a factor in many 2010 mid-term elections and, depending on the electoral results, opposition to reform in Congress could substantially increase.

At the same time, state legislatures will begin considering state budgets in the context of extremely constrained fiscal situations. This may result in threats to cut back or eliminate existing state coverage programs, coupled with a greater unwillingness to bear the costs of the reform initiatives. Concerted resistance in a number of states for any of these reasons could seriously threaten successful implementation of health care reform, if not the law itself.

The Role of Consumer Advocates in the New Environment

Both national and state consumer organizations have key roles to play now that the health care reform law has been enacted. Collaboration among these organizations – building on the relationships established during the effort to pass the bill – will be essential. National groups will:

- Counter opposition to reform through the development of pro-reform communications (including nationally-coordinated support campaigns in the states), electoral strategies, and voter registration drives.*
- Participate in federal policymaking, providing input to the various commissions and processes that will establish federal regulations and standards. Regular participation by state advocates in these processes will ensure federal decision-making is grounded in state-level constituencies' experiences and needs.
- Support state advocates by developing positive messaging about reform adaptable to state-level audiences and by providing technical assistance in policy and program areas where state groups have little experience.
- Facilitate cross-state learning, communication and replication of best practices.
- Work with state groups to document progress and identify problems that need to be addressed.

* When this report discusses the role of consumer advocacy organizations, it refers to 501(c)3 advocacy groups, whose involvement in lobbying and electoral activity is subject to legal limits. A 501(c)(3) cannot do anything that supports or opposes a candidate for office but can provide important information that voters need as they elect their representatives. The report does not discuss 501(c)4 organizations, which have greater latitude in participating in these activities. However, the involvement of 501(c)4 organizations, especially in the upcoming electoral contests, will be of great importance, and collaboration between these types of organizations will be essential.

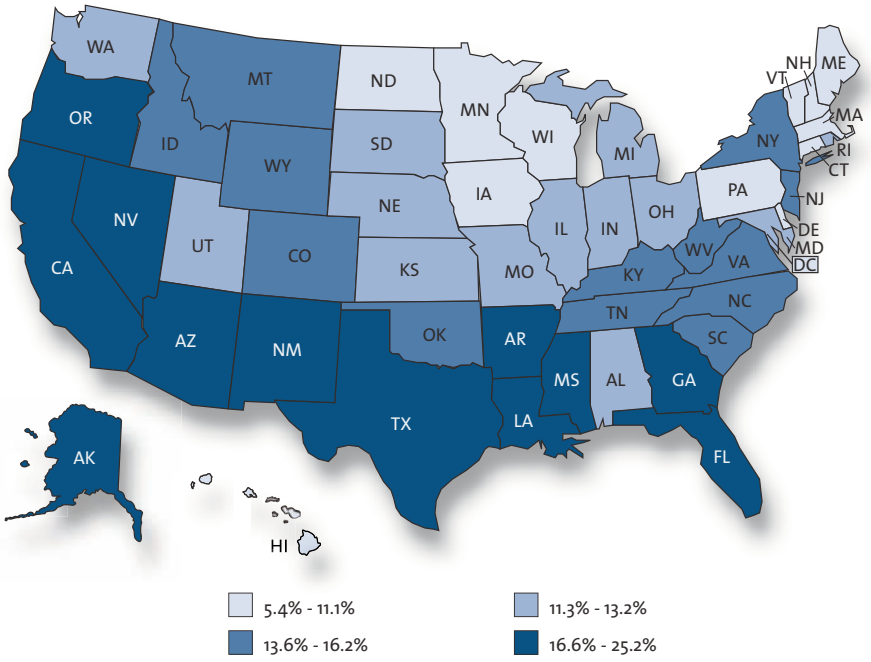
In many ways, however, the success of the health care reform law will depend on strong local and state-level support for implementation. State consumer advocacy groups will:

- Analyze the law's provisions in light of consumer needs and interests as well as state policy environments to develop priority agendas for implementation advocacy.
- As early as possible, develop communications strategies to highlight tangible benefits provided to consumers and positive impacts on other constituencies such as small businesses.
- Build grassroots and other local constituency support for state-level policy changes vital to implementation by engaging a diverse array of consumers including people with low and moderate incomes, racial and ethnic minorities, people with disabilities and chronic conditions, and immigrants.
- Engage like-minded providers, insurers, businesses and other opinion leaders in these efforts.
- Establish consumer representation in state planning and decision-making bodies, ensuring transparency and engagement of disenfranchised and other consumers in hearings and deliberations.
- Provide relevant input to federal policymakers, working in conjunction with national organizations.
- Assist state officials in developing effective regulations, implementation strategies, and enforcement.
- Educate and help consumers navigate new programs.
- Collect data and document the actual experiences of consumers to identify program implementation areas in need of improvement.
- Build campaigns for health care delivery system innovations that improve the coordination and quality of care while containing costs.
- Maintain relationships with members of Congress.
- Defend existing programs.

Although state advocates will face many common challenges, their activities will be shaped by differences in their political and economic environments. There is enormous variation among states in their starting points for health care reform implementation, and their support for health care reform itself. In many states, particularly in the Northeast and West, there is a long tradition of coverage expansion at the state level and a history of stronger regulation of both insurance and health care markets. In the South and Southwest, where poverty rates are higher and therefore the impact of the law should be greater, there is also less political support for regulatory reform and less organized health care delivery capacity for poor and vulnerable populations. Uninsurance rates are one of many indicators of the significant differences in state environments; in 2007-2008, they ranged from five percent in Massachusetts to 25 percent in Texas. This map illustrates the wide variation in uninsurance rates across the country.

Percentage Uninsured by State (2007-2008)

Source: Kaiser Family Foundation, statehealthfacts.org



Regional differences and unique state circumstances could either facilitate or impede effective implementation of the law. The success of health care reform across the country will depend on credible implementation in all types of states:

- ***Leader states*** where support for reform is strong, the insurance market is well-regulated, and eligibility for public programs is generous. These states typically have reasonably responsive political environments. Leader states will have to push the envelope around health care delivery system reform, insurance Exchanges, and cost and quality issues like payment reform and care coordination, to move the national agenda further in these important areas.
- ***Defensive states*** where political opposition to reform is strong and health insurance coverage is low. These states tend to have high poverty rates, low rates of employer-sponsored health insurance and limited tax bases. Advocates will need to quickly mobilize and mount pro-reform campaigns and leverage opportunities to expand coverage and increase workforce and health care delivery system capacity.
- ***Swing states*** where voters will have a disproportionate influence on whether the political will for reform can be sustained. Advocates will need to highlight the early successes of the legislation and build pro-reform constituencies.

In all states, advocates will need to focus on strategies to reduce health care disparities and provide access to those who remain uninsured. Consumer advocates can help drive effective implementation across all of these environments, but advocates in each state will need to develop agendas and strategies based on their unique circumstances.

The Work Ahead

The health care reform law is far-reaching and affects almost every segment of the health care financing and delivery system. Commercial and professional organizations are well-organized and focused on protecting their members' interests. Real reform will require significant effort by a broad coalition of consumer groups with well-developed policy agendas, strategies, and communications capabilities working at both the national and state levels to ensure the law is not eroded or delayed.

Implementation of the law will extend over four years or more, and through at least two major elections (the mid-term elections in 2010 and the presidential election in 2012). Successful implementation of the law will require a wide range of activities and efforts. Generally speaking, the work will fall into five areas. Some are defined by the political environment in which implementation is taking place, others by the provisions of the law itself, and still others by the need to make national reform sustainable over time. The five areas are listed in rough chronological order, although they will often overlap.

1. Building Public Support and Implementing Early Reforms

2. Defending Existing Programs and Current Levels of Coverage

3. Developing Policy and Regulations at the National and State Levels

4. Enrolling People in New Programs and Monitoring the Impact of Reform

5. Ensuring Sustainability through Health Care Delivery System Reforms

The following sections offer an overview of each area, the opportunities and challenges they present, and the key tasks advocates will need to accomplish to ensure the opportunities are realized. While the role of state advocates is highlighted in each section, the role of national advocacy organizations is also discussed.

The descriptions are designed to give readers a sense of the range and complexity of the work ahead. In the months ahead, much more work will need to be done to understand the specific political and regulatory processes that will govern implementation and to develop effective strategies to inform and influence them.

1. Building Public Support and Implementing Early Reforms

Through the 2012 elections and beyond, opponents will mount concerted attacks on the health care reform law and its supporters. Much of this work is funded by well-organized special interest groups with vested interests in altering or overturning parts of the law.

These efforts to oppose reform will occur in an environment in which much of the public is confused about the content of the law and how it will affect them. This is an especially serious problem because many of the law's most important provisions, such as the creation of Exchanges and the provision of subsidies for the purchase of insurance, are not scheduled to go into effect for three or four years. Thus, many consumers will not experience immediate gains from the law.

KEY THREATS TO HEALTH CARE REFORM

- Intensive lobbying and organizing by well-funded special interest groups aimed at blocking implementation of some or all of the health care reform law
- State budget shortfalls that will allow states to claim that they cannot afford to implement health care reform
- Long delays in the implementation of certain key health care reform measures, which will make it harder to quickly identify and engage consumers who benefit from reforms
- Consumer confusion over the provisions of reform, which makes it easier for opponents to mislead people in order to strengthen public opposition
- Possible changes in the composition of Congress after the 2010 mid-term elections that could increase the strength of reform opponents
- State constitutional amendments, referenda and/or legal challenges aimed at blocking some or all of the health care reform measures

Consumer advocacy organizations will need to be ready to counter anti-reform initiatives. National organizations will take the lead in areas such as conducting polls to assess public opinion, developing effective messaging strategies to counter opponents' arguments, and providing broad-based public education about the actual provisions of the health care reform law. State advocates will need to tailor messages to reflect their particular political environments.

KEY TASKS FOR STATE ADVOCATES TO BUILD PUBLIC SUPPORT

- ✓ Develop broad-based coalitions of advocates and other stakeholders in support of reform, including organizations with the capacity to do electoral work
- ✓ Adapt nationally-developed messages in support of health care reform for particular state and local political environments – taking into account local stakeholder dynamics, public perceptions about existing state programs, and existing political coalitions – and disseminate them to key audiences
- ✓ Respond quickly and effectively to local attacks on the law
- ✓ Identify and engage individuals who will benefit from early reforms and communicate their stories to the public to support pro-reform activity
- ✓ Mobilize grassroots support for reform

Some components of the health care reform law are scheduled to go into effect at or shortly after the passage of the legislation, and one key element in building support for reform will involve successfully implementing these provisions.

Putting these early reforms into effect will require immediate action at the federal level to develop the rules and regulations governing their implementation. At the same time, states will need to begin their own implementation efforts. It will be important for state advocates to push for rapid and successful implementation of these early reforms so they can quickly highlight some of the positive effects of the law.

Private Insurance Market Reforms: Reforms in the private health insurance market will be of particular importance immediately. Some will be implemented within six months of enactment; additional private insurance reforms will be implemented in later years. Major rating and underwriting changes are scheduled to go into effect in 2014.

PRIVATE INSURANCE MARKET REFORMS THAT GO INTO EFFECT QUICKLY

- Set up temporary high-risk pools to provide coverage to people unable to purchase insurance because of pre-existing conditions
- Prohibit pre-existing condition exclusions for children
- Prohibit insurance from including lifetime caps
- Prohibit insurance companies from rescinding coverage when enrollees develop conditions that are expensive to treat
- Require coverage of preventive services and immunizations
- Ensure that consumers have access to and assistance in navigating an effective insurance appeals process
- Develop federal standards for how insurers must provide information to consumers
- Extend dependent coverage in all health plans up to age 26
- Require insurers to spend 80-85 percent of premiums on health care services and pay rebates to enrollees if they do not meet this threshold
- Require insurers to report "unreasonable" premium increases and provide funding for states to oversee insurance rate increases

Many of these immediate changes will be of particular value to specific constituencies. For example, prohibiting pre-existing condition exclusions for children is enormously important for families with children with chronic diseases. Extending dependent coverage to age 26 helps new college graduates and other young adults who may have trouble finding employment with health insurance coverage in a weak economy. Such provisions offer advocates good opportunities to reach out and engage groups representing specific populations to support implementation and help communicate the benefits of health care reform.

In many states, advocates have focused on protecting public programs, devoting less time to reforms in the private insurance market. With assistance from national organizations, these advocates will need to educate themselves about the complexities of the private insurance market so they can facilitate efforts to quickly implement market reforms. In other states, consumer advocates have worked extensively on private insurance issues. Advocates in these states will be an important resource to other state and national advocacy organizations. They can share their knowledge and experience with these groups and offer valuable input on new insurance regulations and standards.

Until now, insurance regulation has largely been the province of states, and states have widely varying levels of regulation and consumer protections. For example, only six states require insurers to sell all policies to everyone in the non-group individual market, regardless

of their health status, and only 18 states set any limits on insurance premium rates in this market. (Table 1 in the Appendix provides information about the differing levels of insurance regulation in the non-group market among the states.)

In states where protections included in the national health care reform law do not currently exist, consumer advocates will need to develop campaigns to support them. In states where current regulations exceed federal requirements, advocates will need to defend these enhanced protections. To be successful, advocates will need to build broad-based coalitions of key stakeholders, including providers. Some insurance companies have been supportive of certain types of reforms and could also be allies in efforts to put new consumer protections into place.

Monitoring and oversight of the new programs will also be crucial. Consumer assistance programs will be an important mechanism for tracking problems in the insurance market and compliance with new regulations, and the law includes funding for their creation. By identifying problems and helping consumers resolve them, these programs are also a way to engage consumers in support of reform and to push for necessary changes.

Some of the changes called for in the law require insurance companies to be more transparent in their activities. For example, the law requires that insurers report the percentage of insurance premium dollars they actually spend on health care and requires them to provide rebates to enrollees if they spend too much in other areas, such as marketing and executive salaries. The law also requires states to conduct greater oversight of health insurance premium increases. Advocates will need to monitor and support state implementation to ensure that state insurance departments develop adequate capacity to oversee insurer activities. In addition, they can make use of the information insurers will be required to make public to learn more about insurer operations and advocate for improved consumer protections. Because some of these issues are highly technical, advocates will require the assistance of a variety of experts like actuaries and economists to help with analysis and the development of policy proposals.

KEY TASKS FOR STATE ADVOCATES TO IMPLEMENT EARLY REFORMS

- ✓ Develop a knowledge base about the private insurance market
- ✓ Work with national organizations to shape national policy and regulations
- ✓ Educate the public and state legislators and policymakers about the new protections
- ✓ Advocate to protect consumer interests in state regulation and rule-making processes
- ✓ Monitor implementation, for example through helplines and consumer assistance programs, to identify consumer problems, and work with key state agencies and officials to address these problems
- ✓ Identify consumers who benefited from the early reforms and communicate their stories
- ✓ Learn from newly-available information from insurers and begin to develop new policy goals and initiatives

Non-Profit Hospital Community Benefits: Another component of the law that goes into effect immediately after passage concerns the community benefit requirements for non-profit hospitals. In recent years, advocates have extensively documented the failure of

many non-profit hospitals to fulfill their charitable missions of offering free or affordable care to people with limited resources. These new requirements may be important to state advocates as they look for ways to help uninsured and underinsured consumers gain access to needed care and to engage consumers in pro-reform activities.

CHANGES TO NON-PROFIT HOSPITAL COMMUNITY BENEFIT REQUIREMENTS

- Require hospitals to conduct community needs assessments at least every three years, with input from people representing a broad array of interests in the community, and make them widely available to the public
- Require hospitals to establish written financial assistance policies that clearly specify eligibility criteria and widely publicize them in their communities
- Limit hospital charges for medically necessary care for people who qualify for financial assistance
- Prohibit "extraordinary" collection actions before making a "reasonable effort" to determine whether patients qualify for financial assistance
- Require hospitals to report on how they are addressing needs identified in their community assessments
- Require the federal government to report on the costs hospitals incur from bad debt and charity care, and the costs non-profit hospitals incur in providing community benefits

The new community benefit requirements are a step forward in holding non-profit hospitals accountable for their charitable obligations, although they fall short of establishing mandatory minimum levels of charity care. In the short term, the provisions offer consumers some level of assistance in accessing care and reducing medical debt. They also provide advocates with an opportunity to enhance one component of the existing safety net and to engage consumers in reform initiatives.

KEY TASKS FOR STATE ADVOCATES REGARDING HOSPITAL COMMUNITY BENEFITS

- ✓ Provide input on federal community benefit regulations and guidelines and advocate for more strenuous charity care requirements at the state level
- ✓ Participate in hospital community needs assessments, advocating for best practices and a focus on population health
- ✓ Educate consumers about hospital financial assistance policies
- ✓ Monitor hospitals' compliance with the new legal requirements; for example through "secret shopper" programs, consumer surveys, and storybanking; and keep policymakers and the media informed about the findings
- ✓ Track the utilization of charity care to make the case for its continued funding

2. Defending Existing Programs and Current Levels of Coverage

At the same time that advocates will need to build a constituency for federal reform, states will be facing the full impact of the recession. In most states, revenues will continue to fall and millions may face cutbacks in coverage. In FY2010, 48 states had or still have budget

shortfalls totaling $193 billion. This constitutes 28 percent of state budgets – the largest gap on record. (Table 2 in the Appendix shows FY2010 state budget gaps as a percentage of each state's general fund budget.) These problems will be exacerbated by the ever-increasing costs of health care.

Maintaining current levels of coverage (especially for Medicaid, the Children's Health Insurance Program, and programs for the unemployed) is essential for protecting low-income populations and reducing disparate health care outcomes of minority groups, who tend to be disproportionately poor. Defending Medicaid assumes special importance, since much of the coverage expansion for low-income people that will go into effect in later years is built on existing Medicaid programs. The defense of public programs will require strong efforts at the state and national levels.

State advocates will also need to work to ensure continued support for safety-net institutions and programs in their states. These include community health centers; uncompensated care pools; or special state or local programs for children, people with disabilities, low-income uninsured people, and other special populations. Some policymakers may assume that these institutions and programs are no longer necessary upon passage of health care reform. On the contrary, they will be very important in the short term, because many reform provisions will not go into effect for three or four years. Even when all reform components are implemented, a significant number of people will remain uninsured or underinsured.

KEY THREATS TO MEDICAID AND OTHER PUBLIC PROGRAMS

- Declining state revenues in a period of high unemployment, when the number of people seeking coverage through public programs is increasing rapidly
- Uncertainty about the duration and scope of certain federal programs that support state coverage initiatives, such as the program that subsidizes COBRA payments for laid-off workers and enhanced federal matching payments (FMAP) to help states cover Medicaid costs

State advocates traditionally play an important role in defending public coverage programs and other safety-net institutions and programs, and they will need to continue to do so. The activities that state advocates focus on will depend strongly on the political environments in their states.

KEY TASKS FOR STATE ADVOCATES TO DEFEND EXISTING PROGRAMS

- ✓ Coordinate with national and state groups on messaging and advocacy in support of public programs and on enhancing federal funding for public programs
- ✓ Develop or strengthen state coalitions among key stakeholders, including providers
- ✓ Support CHIP and Medicaid through enhanced outreach and efforts to improve enrollment policies and procedures
- ✓ Look for cost-saving measures in Medicaid and other public programs, for example through improved pharmaceutical purchasing, care coordination, and delivery and quality improvements
- ✓ Look for new sources of revenue for Medicaid and other public programs, for example through campaigns to levy taxes on tobacco products and products with high sugar content
- ✓ Build coalitions around broader state revenue solutions
- ✓ Defend and strengthen state and local safety-net programs for consumers who remain uninsured or underinsured

3. Developing Policy and Regulations at the National and State Levels

Implementation of the provisions of the health care law will require developing regulations and setting standards that will affect almost every area of the health care system.

Federal Policies, Regulations, and Standards: Current proposals assign responsibilities for developing new federal regulations and standards to existing federal officials and myriad new commissions and entities created under the law.

EXAMPLES OF AREAS FOR FEDERAL RULE MAKING AND STANDARD SETTING

Private Health Insurance

- Rating and underwriting reforms
- Essential benefits that health insurance plans must cover
- Consumer information that insurers must provide for all health plans
- Standards for state Exchanges
- Standards for multi-state health insurance plans to be offered in the Exchanges
- Standards for electronic enrollment and administrative simplification in health plans
- Quality standards and reporting requirements for health plans

Medicaid and Other Public Programs

- Rules governing coordination between Medicaid, CHIP, and Exchanges
- Rules for targeting Medicaid Disproportionate Share Hospital (DSH) funding for safety-net institutions

Access to Prescription Medications

- Standards for public disclosure by pharmaceutical manufacturers of payments to prescribers and health care organizations
- Standards of disclosure to health plans by pharmacy benefit managers of drug industry rebates and payments to pharmacies

Data Collection

- Collection of data on race, ethnicity, gender, language, and disabilities in federal health programs

National organizations will play a lead role in representing consumer interests by participating in relevant national committees and providing input on suggested rules and guidelines. However, state consumer advocates will also be important in this process. Through their work on insurance regulation and state coverage expansions, some state consumer advocacy groups developed experience and expertise that should be brought to bear on federal decision-making in these areas. Because of their on-the-ground knowledge, state advocates will also have much to offer regarding the feasibility of federal proposals and the likely impact of policy decisions on people. Maintaining relationships with congressional delegations will also be important in informing and influencing the policy and regulatory process.

KEY TASKS FOR STATE ADVOCATES TO INFLUENCE FEDERAL POLICYMAKING AND RULE SETTING

- ✓ Develop an understanding of relevant provisions of the law and timelines for implementation
- ✓ Identify key decisions that will have particular impact on consumers in their states
- ✓ Provide input to national consumer organizations, federal officials or commissions involved in setting regulations and standards
- ✓ Coordinate with other state groups to develop a unified message on federal standards and regulations
- ✓ Identify consumers with relevant personal stories to testify before lawmakers and speak with the media

State Policies, Regulations and Standards: The roles of states in implementing national reform are not yet clearly defined, although states will have substantial responsibility for putting reforms into effect. In particular the law assigns significant responsibility to the states for creation of Exchanges and grants them considerable leeway in setting the rules for their operation.

With respect to the Exchanges and many other areas, states will need to make key regulatory and program design decisions, pass conforming legislation to address new federal requirements and options, and decide how to integrate existing state programs and initiatives with federal guidelines and requirements. States will also need to develop systems for establishing eligibility for and enrollment in new Medicaid and premium assistance programs. State governments will need to begin addressing these issues soon, even for measures not scheduled to go into effect for three or four years.

States may also exercise options under the law. For example, states will have the option of implementing new programs or expanding existing ones, such as expanding Medicaid coverage to new populations. States can also request waivers from federal requirements such as health plan standards, insurance cost-sharing limits, and standards for new Exchanges, as long as the coverage under the waiver would be at least as good as it would be without a waiver.

EXAMPLES OF AREAS REQUIRING STATE PLANNING FOR PROGRAM IMPLEMENTATION

Private Insurance

- Creation of state Exchanges
- Eligibility for and administration of subsidies for health insurance
- Creation of websites to provide "apples-to-apples" comparisons of health care plans for consumers

Medicaid and Other Public Programs

- Expanded eligibility for Medicaid and simplified enrollment procedures
- Coordination between Medicaid, CHIP, and the Exchanges
- Changes in federal Medicaid Disproportionate Share Hospital (DSH) payments starting in 2014

Optional Programs and Provisions

- Expansion of Medicaid eligibility to families and childless adults with incomes up to 133 percent of the Federal Poverty Level (FPL) prior to its required implementation in 2014
- Creation of a basic health plan for people with incomes between 133 and 200 percent FPL as an alternative to providing subsidies for the purchase of private insurance
- Development of Medicaid and other waiver requests

It is important to note that while options offered to states can result in expanded coverage and other benefits for consumers, they can also have negative effects. For example, if states choose to develop a basic health plan for people earning between 133 and 200 percent FPL, these plans must have "scaled-back benefits." Which benefits states decide to include would obviously have a major impact on the value of such plans for low-income consumers.

In many ways, the success of the health care reform law overall will depend on a strong local constituency advocating for its successful implementation at the state level. State advocates will need to mobilize support for implementation. They will also need to get involved early in the decision-making and planning processes in order to ensure that consumer interests are forcefully represented and that programs and policies ultimately benefit consumers to the greatest extent possible.

KEY TASKS FOR STATE ADVOCATES TO INFLUENCE STATE POLICYMAKING AND RULE SETTING

- ✓ Identify areas of key concern for state advocates, including state options
- ✓ Develop policy analysis capacity to support participation in rule-making activities and establish policy and program goals and strategies
- ✓ Educate state legislators and government officials about specific provisions of the law and key consumer concerns
- ✓ Ensure that decision-making processes are transparent and accessible to the public, and that consumer interests are strongly represented in decision-making bodies
- ✓ Advocate for consumer-friendly rules and regulations
- ✓ Defend state programs and protections that exceed federal requirements
- ✓ Begin planning outreach and enrollment efforts for newly-eligible Medicaid enrollees and people eligible for premium subsidies in the Exchanges

4. Enrolling People in New Programs and Monitoring the Impact of Reform

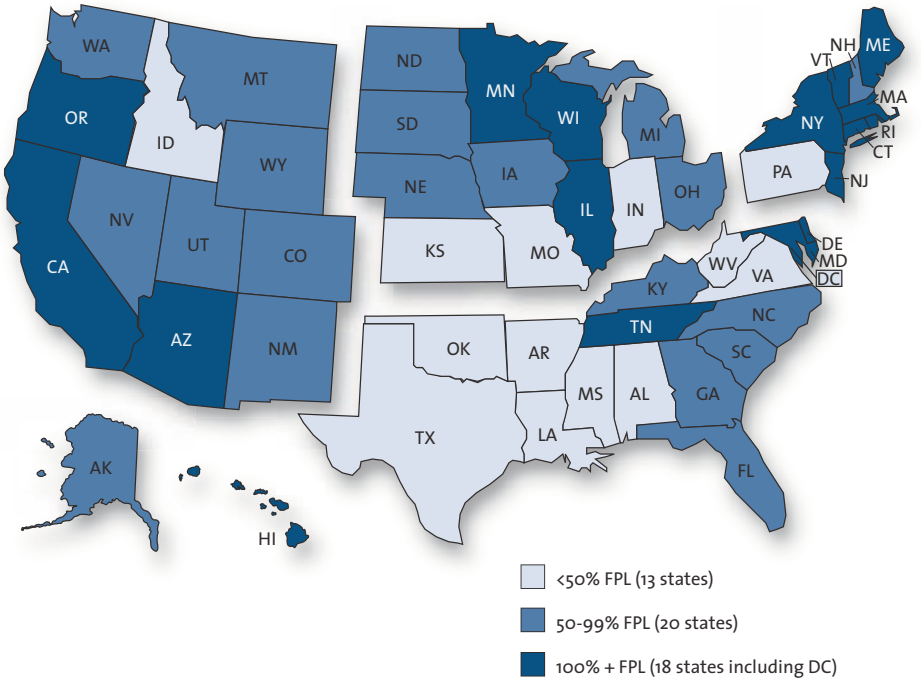
Experience in Massachusetts and elsewhere makes it clear that a great deal of work will remain after programs and policies created by the law go into effect. Consumers will need to learn about and take advantage of newly available options. Programs will need to work out the kinks and revise and adjust rules, regulations, and approaches as necessary. And policymakers and advocates will need to start assessing the overall impact of health reform and planning for refinements and modifications. Because programs and provisions in the law go into effect at different times over a four-year period or longer, many of these activities will be ongoing.

Some of the measures that become operational soon after enactment of the law have already been described. However, some of the key reform measures, such as implementation of Exchanges, the expansion of Medicaid eligibility levels, and the individual mandate (the requirement for individuals to have health insurance) are not scheduled for implementation until 2014. Once they go into effect, millions of people will become eligible for and/or need to obtain health insurance. States will need to invest heavily in outreach and enrollment efforts for these new programs.

The size of the task will vary by state. Although all states will need to conduct significant outreach and enrollment efforts, those with high uninsurance rates and/or less generous Medicaid eligibility criteria will be especially challenged. The federal requirement extends Medicaid eligibility to anyone earning up to 133 percent FPL. The map below shows variations among the states in current Medicaid eligibility levels for working parents – the majority set eligibility limits below 100 percent FPL, well under the new federal requirement. (Table 3 in the Appendix shows how many people in each state are expected to become newly insured.)

Medicaid Eligibility for Working Parents by Income, January 2009

*The Federal Poverty Line (FPL) for a family of four in 2009 is $22,050 per year.
SOURCE: Based on a national survey conducted by the Center on Budget and Policy Priorities for KCMU, 2009.



Another important task will be documenting the impact of programs and provisions. This will involve tracking program operations and outcomes as well as key population indicators.

EXAMPLES OF PROGRAMS AND OUTCOMES TO MONITOR

- Increase in percentage of the population with health insurance coverage
- Effectiveness of Medicaid outreach and enrollment efforts
- Effectiveness of Exchanges in promoting consumer choice and offering high value plans
- Adequacy of minimum benefit standards in health plans
- Adequacy of tax credits to subsidize purchase of insurance for some consumers and small businesses
- Effectiveness of limits on cost-sharing and out-of-pocket expenses in health insurance plans in making health care affordable for enrollees
- Impact of reform on insurance premiums and adequacy of coverage
- Impact of reform on people with employer-sponsored coverage who are not eligible for subsidies or purchase of insurance in the Exchanges
- Impact of the individual mandate on consumers, including identifying groups that remain uninsured
- Compliance of insurers with key insurance reforms, such as the limitations on pre-existing condition exclusions and limits on premium variations by age

Community-based non-profit organizations will be especially important in initiatives to enroll people in Medicaid and other programs. The law includes some funding for consumer assistance and patient navigator programs designed to assist consumers in finding affordable insurance coverage and accessing affordable care. Consumer organizations are particularly qualified to run these programs because they have expertise in health care programs; understand the cultural, linguistic and geographic needs of their communities; have experience working with low-income populations; and are able to provide long-term support. In several states, consumer groups have already created helplines, web-based enrollment tools, medical debt resolution programs, and other mechanisms that put them in direct contact with consumers who need assistance. These initiatives can serve as models for consumer advocates in states where robust consumer assistance programs do not already exist.

Advocates will also want to focus on tracking the impact of reform on consumers. They will need to work with government officials, academics, policy organizations and foundations to put in place appropriate methodologies for documenting the effects of reform. Advocates can make a unique contribution with on-the-ground data collection through consumer assistance and other programs to identify implementation successes and problems. This information will be valuable for documenting the impact of reform on consumers, and also for informing advocacy proposals to revise systems and policies to respond to identified needs. One area of particular importance for advocates will be documenting the effectiveness of the law's affordability standards in allowing consumers to obtain adequate insurance coverage without jeopardizing their financial security or ability to access needed care.

KEY TASKS FOR STATE ADVOCATES TO ENROLL PEOPLE IN PROGRAMS AND MONITOR THE IMPACT OF REFORM

- ✓ Conduct outreach and enrollment initiatives to help consumers access new programs and options
- ✓ Document the impact of new program and provisions on consumers, for example through outreach programs, data collection or services for people with medical debt
- ✓ Work with government officials and other stakeholders to respond to identified problems

Inevitably, as implementation proceeds, advocates will also identify areas in which the health care reform law needs to be strengthened and improved. One immediate area requiring attention is coverage for the 23 million people who are expected to remain uninsured in 2019 even after the health care reform law is implemented. Some other areas likely to require improvement include the affordability provisions in the law, consumer protections in the private insurance market, access to public programs for the working poor (such as people earning between 133 and 300 percent FPL), more affordable prescription medications, and coverage for immigrants. Some of these issues will require additional legislation at the federal and/or state levels.

For a number of reasons – including issue fatigue, a backlog of other business, and the delayed impact of some problems – it will be difficult to get Congress to focus on these issues immediately following passage of the reform law. In addition, to maintain support for the law, Congress and the White House may want to focus on successes rather than deficiencies. Thus, correcting and improving the bill is likely to be a multi-year effort with low visibility at first but increasing importance over time.

5. Ensuring Sustainability through Health Care Delivery System Reforms

As we have seen, many advocacy activities are necessary to ensure the sustainability of health care reform. In the short term, advocates will need to mobilize support for reform and counter attempts to repeal the law. In the mid term, they will need to help ensure the successful implementation of programs. However, in the long term, the key to sustaining health care reform is reducing overall health care spending. The rapid rise in health care spending in the United States has increased insurance premiums to the point that health insurance coverage has become unaffordable for many people and has bankrupted or caused extreme financial hardship for many others. For health care reform to succeed, these ever-increasing costs must be significantly curbed. One critical element in controlling costs will be reforms in the health care delivery system designed to bring down costs while improving the quality of care. These efforts need to begin now and extend over the course of health care reform implementation and beyond.

Some of the major goals of health care system delivery reforms are to increase preventive care, reduce harmful or unnecessary care, and better coordinate care especially for people with chronic conditions. Achieving these goals will require changes in the way providers are paid to better align financial incentives with the provision of effective and efficient care. It will also require changes in the health care workforce to meet a growing need for primary care clinicians who can coordinate and manage their patients' overall health care needs. For consumers, the development of care models that are patient- and family-centered and that empower patients in making decisions about and managing their own care will also be of great importance.

The law responds to delivery system reform needs primarily through the creation of a number of new federal and non-profit organizations, and through the inclusion of funding for myriad demonstration and pilot programs.

EXAMPLES OF MEASURES IN THE HEALTH CARE REFORM LAW DESIGNED TO IMPROVE HEALTH CARE DELIVERY

New organizations to:

- Research, develop, test, and expand innovative payment and care delivery models (Center for Medicare and Medicaid Innovation)
- Support comparative effectiveness research (non-profit Patient-Centered Outcomes Research Institute)
- Improve coordination of care for people dually eligible for Medicare and Medicaid (Federal Coordinated Health Care Office within the Centers for Medicare and Medicaid Services)

Grant programs to:

- Develop community health teams to support patient-centered medical homes
- Develop networks of providers to deliver coordinated care to low-income populations
- Promote positive health behaviors and outcomes for medically underserved communities through use of community health workers
- Implement evidence-based public health activities to address health disparities
- Develop local and state workforce development strategies

State and local demonstration projects to:

- Create and disseminate educational tools to help patients and caregivers understand treatment options
- Use public health interventions to reduce chronic illness and associated costs
- Establish medical homes for patients
- Test use of home-based primary care teams to allow Medicare recipients to live independently at home
- Reduce childhood obesity
- Develop a campaign on oral health care prevention activities
- Train alternative dental health care providers
- Develop, test, and evaluate provider payment methodologies

Other measures to:

- Develop a national strategy to improve care delivery, outcomes and population health, including appropriate quality measures
- Give states the option to provide community-based attendant services for Medicaid beneficiaries with disabilities (includes increased federal funding for these services)

Consumer engagement – both as patients and advocates – will be essential throughout the design, implementation and evaluation of these programs. Because many consumer advocacy organizations have not previously been involved in health care delivery system reform efforts, national consumer organizations have an important role to play in educating advocates about these issues. Along with increasing their knowledge of these issues, state advocates will need to build coalitions of consumers, providers, insurers and others to support the development of innovative care models using the tools the law provides. With the

knowledge gained by developing and testing these new models, coalitions will be better positioned to build policy and advocacy agendas designed to replicate and extend effective innovations.

Some of the new organizations created by the health care reform law include seats for health care consumers on their governing boards. This will be one vehicle consumers can use to provide input to delivery system reform efforts. Consumer groups may also be able to apply for grants, either on their own or in partnership with other organizations. In some cases, consumer groups will need to advocate for state participation or the participation of other key stakeholders.

KEY TASKS FOR STATE ADVOCATES TO REFORM THE DELIVERY SYSTEM

- ✓ Build or strengthen knowledge of health care delivery system reform issues
- ✓ Work with national consumer advocates to provide input to federal organizations created to research and test delivery system reform models
- ✓ Build networks and coalitions for delivery system reform and collaborate on pilot and demonstration programs
- ✓ Encourage states or other entities to apply for funding in areas of benefit to various consumer populations
- ✓ Develop policy and advocacy agendas based on the demonstrated effectiveness of new care models
- ✓ Campaign for community engagement and empowerment in health care delivery
- ✓ Build grassroots support for delivery system reform

Consumer Advocacy: Why It Matters

The history of health care reform efforts clearly demonstrates that strong, organized consumer advocacy can play a major role in whether implementation succeeds or fails. Consumer advocates have increased enrollment, shaped policy decisions, recommended needed improvements and built broad-based support. These experiences, which were documented through a literature review and interviews with advocates across the country, provide lessons for implementing national reform in 2010 and beyond.

Lessons from Past Consumer Advocacy Initiatives

Lesson 1: Advocates provide important leadership in outreach and enrollment for federal programs.

The State Children's Health Insurance Program (SCHIP) was implemented successfully in large part because of outreach and enrollment efforts led or heavily staffed by consumer advocates.

SCHIP (now CHIP) was enacted in 1997 with major support from children's advocates to help states insure low-income children. States had considerable flexibility in how they designed SCHIP, which provided consumer advocates with an opportunity to push for the best possible benefits and eligibility standards. The law also offered incentives to improve outreach and enrollment procedures, and the Robert Wood Johnson Foundation funded

coalitions in all 50 states through the Covering Kids and Families initiative to support enrollment efforts. Consumer advocates in many states took the lead in making families aware of the new coverage and helping them enroll.

For example, Illinois saw SCHIP as an opportunity to move toward universal coverage of children in the state. Backed by the Robert Wood Johnson Foundation, advocacy organizations – including the Illinois Maternal and Child Health Coalition (IMCHC) and the Campaign for Better Health Care (CBHC), the principal consumer health advocacy organization in the state – established a comprehensive community-based enrollment program. CBHC and the statewide coalition coordinated with school lunch programs and hospitals to enroll children and new mothers, developed a rural outreach kit, and conducted outreach at libraries, churches and career centers.

When grant funding for the coalition ended in 2006, Illinois's enrollment increases in CHIP and Medicaid were among the largest in the nation. The efficacy of the approach was confirmed by an evaluation of Covering Kids and Families, which found that the most efficient way to enroll consumers was to rely on existing organizations with strong ties to the community. In addition, the trust and relationships that developed among coalition members over the course of the initiative proved important in the 2004 passage of state legislation designed to move Illinois toward universal health insurance coverage for all of its residents.

Across the country, philanthropic funds that were available shortly after passage of SCHIP legislation enabled advocates to quickly enroll many children and thus develop a strong constituency for the program. Alliances of providers, schools, and businesses built through SCHIP outreach coalitions also proved valuable in 2009 when advocates pushed for reauthorization of the federal program.

Lesson 2: Advocates develop and promote policy based in consumer experiences.

A key component of the successful 2006 Massachusetts health reform law is an affordability schedule that defines how much people can afford to pay for health insurance. The schedule was developed with significant input from consumer advocates, who drew on consumer experiences to develop a pragmatic policy solution.

The Massachusetts reform law instituted an individual mandate, which requires everyone to have insurance coverage if affordable coverage is available. People without access to affordable coverage are exempt from the individual mandate. Defining affordability was left to the newly established Connector Board, a state agency overseeing reform. By statute, the Connector Board was required to have consumer representatives, and advocates worked with them to make sure consumer interests were represented.

A major faith-based grassroots organization, the Greater Boston Interfaith Organization (GBIO), was a member of the statewide Affordable Care Today (ACT!!) coalition, whose mission was to monitor implementation of the Massachusetts reform legislation. GBIO conducted budget workshops with over 600 people throughout Eastern Massachusetts to research families' budgets, to provide public education, and to mobilize grassroots support for an affordability campaign.

At the same time, advocates studied the amount families were asked to pay for coverage in other public programs, as well as typical premiums and out-of-pocket costs in the private insurance market. This, coupled with the family budget information, provided the framework for an affordability scale that was fair for consumers. The advocates' affordability scale was publicized through media coverage of their presentation to the Connector Board.

In addition, Health Care for All, convener of the ACT!! Coalition, posted research about affordability on its blog, a major source of information for advocates and people interested in health care reform in Massachusetts.

Meanwhile, GBIO's organizing brought consumers to rallies at the State House in support of affordable health care reform. Advocates and GBIO members turned out in large numbers at Connector meetings to underscore the importance of the affordability decision in people's lives. The result was a reasonable standard of affordability based on consumers' experiences. By directly engaging hundreds of consumers, the effort also built a base of support for health reform.

Lesson 3: Advocates monitor implementation and provide feedback to policymakers.

The 2006 Vermont Catamount Health Plan (Catamount), a comprehensive health care reform law, has improved over time because of feedback provided to legislators by consumer advocates running an insurance coverage helpline.

Four months prior to passage of Catamount, the Vermont Campaign for Health Care Security (VCHCS), a leading consumer advocacy group, received funding from the Public Welfare Foundation to begin work on outreach and enrollment. Although it had no state funding, over time the organization became the major provider of outreach, training, and enrollment support for Catamount.

VCHCS, a trusted and credible source for health information, runs a statewide helpline that receives about 575 calls per month. It provides responsive, detailed answers to consumers' questions about eligibility and helps them fill out program applications. VCHCS also runs a website with eligibility and enrollment information that is comprehensive, accessible and clear.

The helpline serves another unique purpose: it identifies barriers to enrollment and systemic implementation problems. Using this information, VCHCS makes recommendations to the legislature to improve the program. For example, Catamount has suffered from lower than anticipated enrollment. Speaking with consumers on the helpline has helped VCHCS to understand the reasons for this low enrollment, and the advocacy group worked in the last legislative session to improve the program by reducing the six-month waiting period for people to qualify for Catamount. Findings from an evaluation of health care reform implementation by Mathematica Policy Research, Inc. and the Urban Institute and Health Management Associates showed that the role of consumers was vital to promoting and monitoring the program once it was enacted. The data and reports VCHCS provides from its helpline and outreach work are one of the primary ways that the legislature and administration learn how Catamount is working for consumers.

Lesson 4: Organizing and building alliances with other stakeholders is essential.

In Tennessee, the state rolled back a major expansion of Medicaid coverage in 2004 when state revenues fell. Advocates, who were under-funded and unable to form broad-based coalitions, were unable to prevent the rollback.

In 1993, to address a funding crisis in the state's Medicaid program, Tennessee's then-Gov. Ned McWherter developed a plan to replace Medicaid's existing fee-for-service payment structure with a capitated managed-care program called TennCare. The plan also extended coverage to people who were uninsured. Just 45 days after the legislature approved the plan, TennCare began enrollment. Although the program was not without problems, Medicaid expenditures decreased and access to care improved. However, the governor

retained sole authority to change program rules – neither the legislature nor consumer advocates had input.

In the early 2000s, Tennessee again faced budget problems. When an effort to increase revenues by instituting a state income tax was soundly defeated, state officials looked for ways to cut TennCare.

In 2004, Gov. Phil Bredesen announced plans to eliminate coverage for more than 300,000 TennCare members. The state's leading consumer health advocacy organization, the Tennessee Health Care Campaign (THCC), managed to reduce that number to 200,000 but was unable to prevent the governor's plan from being implemented.

THCC Executive Director Tony Garr says that the lack of a formal role for advocates in deciding TennCare's program rules impeded advocates' efforts to stop the cuts. Because the governor was unresponsive to consumer concerns and experiences, the administration did not address TennCare's implementation problems early. Advocates were also hurt by their inability to form a broad-based coalition to support the program because providers were unwilling to collaborate. In addition, advocates did not have the funding to place staff across the state to build relationships with stakeholders or organize consumers. In the end, thousands of Tennessee residents lost health insurance coverage and the TennCare experiment is now regarded as a failure.

Consumer Advocates Can Make a Difference

These examples highlight the impact of well-organized and well-resourced consumer advocates in implementing reform. State and national consumer advocates are preparing to work together to implement national health care reform, building on a foundation laid over the last few years. Community Catalyst, its allies, and supportive funders played a significant role in developing this capacity.

In 2006, a Community Catalyst report entitled *Consumer Health Advocacy: A View from 16 States* created a methodology for assessing state advocacy capacities and a framework for investing in strengthening them. The report classified states based on the capacities of their advocacy organizations, their political environments and their resource levels. It identified which states had the greatest likelihood of pursuing strong health access initiatives and which faced the greatest political and economic obstacles to reform.

The Community Catalyst report proved to be a useful tool for both advocates and funders. Advocates used the report to assess their own capacities and to develop strategies to increase their effectiveness. In particular, advocates undertook efforts to build stronger and more coordinated networks. Funders used the report to help guide decisions about investments in building advocacy capacity.

The Robert Wood Johnson Foundation funded the *Consumer Voices for Coverage* program to strengthen the capacities of consumer organizations in 12 "leader" states that were on the cusp of advancing health care reforms. The Public Welfare Foundation provided funding for *Southern Health Partners*, which supports advocates in 11 "defensive" states on a variety of state and regional issues. Other national funders, including the Nathan Cummings Foundation and the W. K. Kellogg Foundation, also invested significantly in strengthening state consumer advocacy programs. Foundations in several states made similar investments; among them, the George Gund Foundation in Ohio, the Missouri Foundation for Health, the Foundation for a Healthy Kentucky, and Healthcare Georgia Foundation. Under all of these programs, Community Catalyst provides technical assistance and support to state health care consumer organizations. In addition, state-based foundations – including in

California, Illinois, Maine, Maryland, Minnesota, New Mexico, North Carolina, Oregon and Virginia – supported the work of consumer-based health advocacy organizations, coalitions and campaigns in their states.

Because of these investments, a national network of vibrant consumer health advocacy organizations now exists. These organizations are tested and experienced in all aspects of health care reform at the state level. Groups in "leader" states formed stronger partnerships and made strides in expanding coverage. Groups in "defensive" states, which previously had little history of organized consumer involvement, have begun the process of developing a consumer voice.

Consumer advocacy organizations are ready to implement national health care reform. They have immediate, trusted access to consumers – especially those populations who will benefit the most from the new law – and have established working coalitions and relationships with stakeholders, state agencies and legislators. Because of the enormity of the task, advocates need renewed support. Now is the time to mobilize the national network of state advocacy groups to ensure that national reform is implemented well and millions are able to access coverage.

Recommendations and Conclusion

In the current partisan and volatile political environment, advocacy efforts will need to be informed, forceful, widespread, sustained and coordinated. States in particular are proving grounds. If states execute implementation tasks well, consumers will reap the benefits of reform. If many states execute these tasks poorly, the outcomes have the potential to turn much of the public against reform. Success is especially important in "defensive" southern states, where the largest and most glaring access, quality and disparities issues exist. Successful implementation in these states would give real meaning to national health care reform.

Achieving success requires:

1. Expanding upon the state-based systems of advocacy built over the past several years.

- State-based consumer health advocacy capacity is now established in over 30 states. This development effort has involved increasing the capacities of leadership organizations and also creating systems of advocacy comprised of organizations that represent many different constituencies and possess a variety of specialized skills. In turn, these networks have developed working relationships with other health sector stakeholders and with policymakers. These networks now need to expand to reach more people who will be affected by reform.
- Ongoing support for advocacy infrastructure in these states will remain important, but it must also be extended so that advocacy groups can take hold in all 50 states.

2. Developing new coordination mechanisms among national consumer advocacy organizations, state organizations, and between national and state groups.

- National consumer organizations often have specialized functions, such as policy analysis, communications, mobilization or providing technical assistance to state-based organizations. They need to coordinate their work with state organizations to avoid duplication of efforts and to ensure that state organizations know where to turn for assistance. State organizations should be participants in developing national advocacy strategies and coordination mechanisms.

- The knowledge and experience of on-the-ground state advocacy organizations should help guide resource deployment. National organizations should reach agreement with state advocates before taking state-level action, including seeking financial support from local funders.
- State groups need to communicate effectively with one another to coordinate messaging and other activities related to national work and to share information and best practices with one another. Funders helped establish peer-to-peer communications infrastructures among some states. These need to be maintained and expanded to coordinate state and federal activities and make the best use of assistance offered by national advocacy organizations.
- State advocacy groups should mentor groups in other states: those with private insurance experience can help those without; those with more organized systems of advocacy can mentor states that have not built their core capacities or coordinated efforts effectively.
- Enhance the communications capacity of consumer advocacy organizations.
- Sophisticated communications and messaging strategies will strengthen all aspects of advocacy on reform implementation, both national and state, and support to develop capacity in this area will be of great importance.
- National organizations should provide coordinated messaging and communications campaign support that state advocates can tailor to their own environment, circumstances and audiences.
- State organizations need well-developed communications strategies that include identifying beneficiaries of reform and telling stories about positive impacts.

4. Using policy analysis to shape advocacy strategies.

- Consumer advocates may need expert assistance in understanding federal regulatory processes, the technical aspects of various policy issues, opportunities for federal engagement, and constraints.
- State advocates will benefit from a regular flow of information about federal regulatory and policy developments and the ability to participate in development of national advocacy strategies where they have expertise.
- State-based experts should be supported to offer technical assistance to state and national groups and to provide leadership in coordinating state and federal policy.
- National groups will have more effective working relationships with state groups on federal policy issues if they can coordinate their education and technical assistance efforts such as calls, materials and alerts, including some division of labor or collaboration on specific policy issues.

5. Providing adequate resources for sustained advocacy.

- Implementation of the national reform law will occur over a number of years. Both state and national advocacy groups will need resources to maintain and expand their activities over the long term. Current levels of support are critical to maintaining core capacities. Additional resources will be needed to expand to more states, build new expertise and capacities, and handle the increasing volume of work.

- Local funders will be especially important in working with advocates to develop appropriate agendas and resources for their individual states.
- New funders seeking to promote social and economic justice, greater civic engagement, and economic development in poor communities should be recruited to support critical on-the-ground organizing and advocacy for implementing health care reform, especially in the states that have the greatest need and most hostile environments.
- Current funders can play a critical role in drawing new funders into supporting advocacy for the first time.

6. Increasing coordination among funders, and between funders and advocates.

- Smart investment in consumer advocacy calls for coordination among funders, so that funds are efficiently distributed and consumer groups are not forced to compete among one another for limited resources.
- Coordinated funding strategies should be based on developing shared agendas with consumer advocacy groups to ensure that needed advocacy infrastructure and capacities are put in place.
- Funders and advocates should work together to map the political and economic environments of particular states in order to determine the advocacy activities that will be most important in those states.

This report will end where it began – with a reminder that Congress has enacted the most sweeping piece of social legislation in over 40 years. The new law has the potential to provide health care coverage to 32 million people – many of whom will be covered for the first time. It will have implications for the entire health care system and, indeed, for the country.

In this effort, consumer advocates have a role that no other organizations can fill – to represent the interests and needs of consumers, especially vulnerable consumers, in every aspect of the implementation process. Working in a sector in which powerful commercial and economic groups have a major stake – one that does not always support the public interest – consumer advocacy groups always face long odds. Nonetheless, with the help of visionary foundations and individuals, they have become enormously influential in achieving gains for people in need. It is essential to keep investing in them to educate and mobilize the many millions of parents, children, seniors, and individuals for whom – and with whom – health care reform must be made to work.

Funders and advocates must work together to identify priorities, coordinate activities, develop and strengthen capacities, support one another, and make corrections when necessary. And they must commit to these efforts not for one year or two, but for as long as it takes to make health care reform a reality. If we can accomplish this, we can build a health care system that holds both the promise and reality of access to affordable, quality health care for all.

Appendix

This appendix contains tables illustrating some of the wide variations in state environments that will affect the ease with which states are able to implement the requirements of national health care reform.

Table 1: State Individual Market Insurance Regulation

The national health care reform law implements a number of reforms in the non-group individual health insurance market. One is guaranteed issue, a requirement that insurance companies sell all policies to everyone who applies, regardless of their health status. (This will not be implemented until 2014.)

The law also places some limits on the amount insurers can charge for premiums. It sets up a rate review process that would, beginning in 2011, require insurers to publicly disclose and justify rate increases. In 2014, when the state Exchanges become operational, states will also have the right to exclude insurers who impose excessive rate increases from selling in the Exchange.

Adjusted community rating is another tool states use to limit the cost of insurance. Under adjusted community rating, states prohibit insurers from setting rates based on applicants' health status and specify the criteria they can consider when setting premium rates. Under the national health care reform law, insurers will not be allowed to vary rates based on people's health status; they will only be allowed to vary rates based on age, geography, and family size. Some states also use rate bands to limit premium costs; rate bands establish a maximum percentage an insurer can increase an applicant's premium from an average index price based on the applicant's health status.

Finally, the law provides immediate funding for states to set up temporary high-risk pools to provide insurance to people who have been turned down in the individual market because of their health status. Some states have already created high-risk pools.

The following table shows which states have already established guaranteed issue and rating restrictions in their individual non-group markets, as well as which states have already established high-risk pools. The table shows the wide variation that currently exists in state insurance regulation in the individual market and the extent to which the national health care reform law will require states to implement new regulations.

Individual Market Insurance Regulations and High Risk Pools

	Guaranteed Issue 2008-09	Rating Restrictions 2008-09	High Risk Pool (Enrollment) 2007
United States	NA	NA	199,649
Alabama	No	No	2,631
Alaska	No	No	488
Arizona	No	No	NA
Arkansas	No	No	2,976
California	No	No	7,801
Colorado	No	No	7,136
Connecticut	No	No	2,599
Delaware	No	No	NA
District of Columbia	No	No	NA
Florida	No	No	329
Georgia	No	No	NA
Hawaii	No	No	NA
Idaho	No	Rate Bands	NA
Illinois	No	No	16,427
Indiana	No	No	6,833
Iowa	No	Rate Bands	2,676
Kansas	No	No	1,886
Kentucky	No	Rate Bands	4,158
Louisiana	No	Rate Bands	1,139
Maine	Continuous for all individuals	Adjusted Community Rating	NA
Maryland	No	No	12,468
Massachusetts	Continuous for all individuals	Adjusted Community Rating	NA
Michigan	No	No	NA
Minnesota	No	Rate Bands	28,859
Mississippi	No	No	3,660
Missouri	No	No	2,915
Montana	No	No	3,053
Nebraska	No	No	5,112
Nevada	No	Rate Bands	NA
New Hampshire	No	Rate Bands	1,011
New Jersey	Continuous for all individuals	Pure Community Rating	NA
New Mexico	No	Rate Bands	4,701
New York	Continuous for all individuals	Pure Community Rating	NA
North Carolina	No	No	NA
North Dakota	No	Rate Bands	1,541
Ohio	No	No	NA
Oklahoma	No	No	2,200
Oregon	No	Adjusted Community Rating	18,659
Pennsylvania	No	No	NA
Rhode Island	No	No	NA
South Carolina	No	No	2,376
South Dakota	No	Rate Bands	686
Tennessee	No	No	2,458
Texas	No	No	27,733
Utah	No	Rate Bands	3,379
Vermont	Continuous for all individuals	Adjusted Community Rating	NA
Virginia	No	No	NA
Washington	Continuous for some individuals	Adjusted Community Rating	3,477
West Virginia	No	No	497
Wisconsin	No	No	17,126
Wyoming	No	No	659

Guaranteed Issue and Rating Restrictions: Data compiled after review of federal and state law and interviews with government regulators. Data collection and analysis by researchers at the Health Policy Institute, Georgetown University. Data for the individual market as of December 2008.

High Risk Pool Enrollment: Data collection and analysis by Eliza Bangit and Karen Pollitz, Health Policy Institute, Georgetown University. Sources include state laws and regulations, interviews with state high-risk pool staff, state high-risk pool websites, and the Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis. National Association of State Comprehensive Health Insurance Plans, 22nd Ed., 2008/2009. Data are as of December 31, 2007.

Table 2: State Budget Gaps

State budget gaps represent the extent to which a state's revenues fall short of the cost of providing services. States have already closed most of the gaps for FY2010 through a combination of spending cuts, withdrawals from reserves, revenue increases, and use of federal stimulus dollars. However, 39 states identified mid-year budget gaps.

The table combines these new gaps with previously reported gaps for 2010 – the gaps that were addressed when states wrote their budgets for this year. It lists each state's budget gap as a percentage of its general fund budget.

States with FY2010 Budget Gaps

	FY2010 Before Budget Adoption	FY 2010 Mid-Year Gap	FY Total	FY 2010 - % of General Fund Budget
Alabama	$1.2 billion	$400 million	$1.6 billion	22.20%
Alaska	$1.3 billion	0	$1.3 billion	30.00%
Arizona	$3.2 billion	$2.0 billion	$5.2 billion	53.00%
Arkansas	$146 million	$107 million	$253 million	5.60%
California	$45.5 billion	$6.3 billion	$51.8 billion	56.20%
Colorado	$1.0 billion	$561 million	$1.6 billion	21.00%
Connecticut	$4.2 billion	$549 million	$4.7 billion	27.00%
Delaware	$557 million	0	$557 million	17.60%
District of Columbia	$650 million	$150 million	$800 million	12.70%
Florida	$5.9 billion	$147 million	$6.0 billion	23.30%
Georgia	$3.1 billion	$1.2 billion	$4.3 billion	24.90%
Hawaii	$682 million	$533 million	$1.2 billion	23.70%
Idaho	$411 million	$151 million	$562 million	22.40%
Illinois	$9.3 billion	$5.0 billion	$14.3 billion	40.90%
Indiana	$1.1 billion	$309 million	$1.4 billion	9.60%
Iowa	$779 million	$415 million	$1.2 billion	20.20%
Kansas	$1.4 billion	$459 million	$1.8 billion	30.00%
Kentucky	0	$1.2 billion	$1.2 billion	12.90%
Louisiana	$1.8 billion	0	$1.8 billion	21.60%
Maine	$640 million	$209 million	$849 million	26.90%
Maryland	$1.9 billion	$936 million	$2.8 billion	20.40%
Massachusetts	$5.0 billion	$600 million	$5.6 billion	20.00%
Michigan	$2.8 billion	0	$2.8 billion	12.40%
Minnesota	$3.2 billion	$209 million	$3.4 billion	22.30%
Mississippi	$480 million	$370 million	$850 million	17.10%
Missouri	$780 million	$690 million	$1.5 billion	16.40%
Nebraska	$150 million	$155 million	$305 million	8.60%
Nevada	$1.2 billion	$67 million	$1.2 billion	40.00%
New Hampshire	$250 million	$38 million	$288 million	18.70%
New Jersey	$8.8 billion	$400 million	$9.2 billion	31.30%
New Mexico	$345 million	$650 million	$995 million	18.10%
New York	$17.9 billion	$3.2 billion	$21.0 billion	38.00%
North Carolina	$4.6 billion	0	$4.6 billion	21.90%
Ohio	$3.3 billion	$296 million	$3.6 billion	13.40%
Oklahoma	$777 million	$550 million	$1.3 million	23.20%
Oregon*	$4.2 billion	0	$4.2 billion	29.00%
Pennsylvania	$4.8 billion	$450 million	$5.2 billion	19.70%
Rhode Island	$590 million	$400 million	$990 million	32.20%
South Carolina	$725 million	$439 million	$1.2 billion	20.10%
South Dakota	$32 million	0	$32 million	2.90%
Tennessee	$1.0 billion	$96 million	$1.1 billion	10.70%
Texas	$3.5 billion	0	$3.5 billion	9.50%
Utah	$721 million	$279 million	$1.0 billion	19.80%
Vermont	$278 million	$28 million	$306 million	27.30%
Virginia	$1.8 billion	$1.8 billion	$3.6 billion	22.00%
Washington*	$3.4 billion	$2.6 billion	$6.0 billion	26.00%
West Virginia	$184 million	$100 million	$284 million	7.50%
Wisconsin	$3.2 billion	0	$3.2 billion	23.20%
Wyoming	0	$32 million	$32 million	1.70%
Total	**$158.5 billion**	**$34.1 billion**	**$192.6 billion**	**28.10%**

Notes: Some or all of the pre-budget shortfalls have already been addressed. *Oregon and Washington have two-year budgets. For Oregon, the size of the combined shortfall before budget adoption for FY10 and FY11 is shown here. For Washington, the mid-year gap shown is the projected gap for the two years ending in FY11.

Source: Center on Budget and Policy Priorities, Recession Continues to Batter State Budgets, McNichol and Johnson, December 18, 2009

Table 3: Estimated Increase in Number of Insured People under Health Care Reform by State

Families USA used national estimates of the reduction in the number of uninsured from the Congressional Budget Office's analysis of the Health Care and Education Reconciliation Act of 2010 to arrive at state-by-state estimates of coverage gains. The 2019 estimates of the uninsured were apportioned across the states, assuming that coverage gains would occur relative to the share of total non-elderly uninsured individuals residing in each state.

Estimates of Those Gaining Health Coverage Under the New Health Care Reform Law, by State

State	Net Gain in Coverage, 2019
Alabama	385,000
Alaska	90,000
Arizona	846,000
Arkansas	334,000
California	4,666,000
Colorado	551,000
Connecticut	235,000
Delaware	66,000
District of Columbia	40,000
Florida	2,521,000
Georgia	1,170,000
Hawaii	67,000
Idaho	156,000
Illinois	1,163,000
Indiana	519,000
Iowa	196,000
Kansas	236,000
Kentucky	438,000
Louisiana	574,000
Maine	88,000
Maryland	497,000
Massachusetts	*
Michigan	795,000
Minnesota	306,000
Mississippi	369,000
Missouri	513,000
Montana	107,000
Nebraska	156,000
Nevada	324,000
New Hampshire	94,000
New Jersey	880,000
New Mexico	315,000
New York	1,806,000
North Carolina	1,023,000
North Dakota	48,000
Ohio	921,000
Oklahoma	394,000
Oregon	438,000
Pennsylvania	829,000
Rhode Island	82,000
South Carolina	500,000
South Dakota	63,000
Tennessee	638,000
Texas	4,188,000
Utah	245,000
Vermont	44,000
Virginia	724,000
Washington	536,000
West Virginia	184,000
Wisconsin	346,000
Wyoming	50,000

* Data for Massachusetts are not reportable because state-level data on the uninsured do not fully reflect changes in coverage under Massachusetts's health reform law, implementation of which began in 2006.

Source: Health Care Reform Central: From the State, Families USA, www.familiesuse.org/health-reform-central/from-the-state.html

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