



# Staying the Course

The Essential Role of Consumer Advocates in Reforming Health Care

**Consumer Voices for Coverage**



## Consumer Voices for Coverage (CVC) is a joint initiative

of the Robert Wood Johnson Foundation and Community Catalyst to strengthen the consumer voice to promote innovative and comprehensive health reform efforts. The program emphasizes the important role state-based consumer health advocates play in ensuring consumer concerns are represented in both state and national health reform.

Beginning in February 2008, Consumer Voices for Coverage works to boost the enormous groundswell of state activity to reduce the number of people living without health insurance in 18 states. As the National Program Office, Community Catalyst provides significant coaching and strategic advice to grantees and coalitions, focused on improving their ability to advance health reform. The program recognizes the importance of a statewide system of advocacy, building the strength of multiple organizations in a single network working to change the state and national health system.

Community Catalyst provides the state-based consumer advocates with the skills, expertise and resources needed to have a stronger presence and play a more meaningful role in health reform debates.

### Consumer Voices for Coverage Grantee States

California	Minnesota	Pennsylvania
Colorado	New Jersey	South Carolina
Illinois	New York	Tennessee
Iowa	North Carolina	Texas
Maine	Ohio	Utah
Maryland	Oregon	Washington



## **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](http://www.communitycatalyst.org).

## **About the Robert Wood Johnson Foundation**

The Robert Wood Johnson Foundation focuses on the pressing health and health care issues facing our country. As the nation's largest philanthropy devoted exclusively to improving the health and health care of all Americans, the Foundation works with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful and timely change. For more than 35 years, the Foundation has brought experience, commitment, and a rigorous, balanced approach to the problems that affect the health and health care of those it serves. When it comes to helping Americans lead healthier lives and get the care they need, the Foundation expects to make a difference in your lifetime.

For more information, visit [www.rwjf.org](http://www.rwjf.org).

# Staying the Course

## The Essential Role of Consumer Advocates in Reforming Health Care

Executive Summary	2
Introduction	4
The Devil is in the Details	6
Let's Get Organized	8
Are They Getting the Message?	10
We Can Do This Better Together	12
In This Environment, the Best Offense May Be Defense	14
Now Comes the Hard Part	16

# Executive Summary

**For more than a decade, significant health care policymaking had shifted from the federal government to the states. Across the country, states made great strides where networks of consumer advocates pushed to expand coverage and improve care, culminating in Massachusetts' comprehensive health care reform in 2006.**

In 2008, the Robert Wood Johnson Foundation joined with Community Catalyst to cement the critical role state-based consumer health advocates play in innovative health reform by creating Consumer Voices for Coverage (CVC).

CVC strives to build and sustain a network of state advocates, to ensure that consumers are represented in health reform debates both during the program and beyond, alongside well-funded health industry stakeholders. Within 18 states, CVC coalitions work to create a statewide network of advocacy, building on the strengths of multiple organizations in a single network to change the state and national health system.

Based on its advocacy model, Community Catalyst provides coaching and strategic advice to help state advocates develop and improve across six core capacities: (1) conducting policy research and analysis, (2) designing and executing strategic communications plans, (3) developing and implementing policy campaign, (4) organizing at the grassroots level, (5) building coalitions and maintaining strategic alliances, and (6) cultivating relationships with funders to sustain their work.

CVC coalitions are unique in their efforts to engage all health system stakeholders, including insurers, providers, employers, and hospitals as well as the faith community, small businesses, civic groups and community leaders.

The relationships generated in building and maintaining broad-based coalitions, revealed new possibilities and strengthened each member's influence—such clout will prove to be critical as the states face the massive task of implementing the Affordable Care Act.

In the midst of heated debates, the consumer coalitions proved their mettle, eking out state reforms in a treacherous economic environment, while pursuing national reforms by working with federal policymakers to represent the voice of consumers and share their health policy expertise.

RWJF funding helped the CVC coalitions in 18 states equip themselves for the battle, and the investment is paying off. While the paper goes into more detail, notable successes include:

- Tennessee Health Care Campaign expanded its reach with organizers spread out across the state who built relationships with more than 10,000 local advocates—including a potent band of small business owners—who can be called on to participate in local events and demonstrate support for specific policy objectives.
- The North Carolina Justice Center became a powerhouse in story-banking, using new media to showcase videos of real people telling compelling stories about their experiences in the health care system.
- The Washington Community Action Network built a small business coalition, so business and consumer advocates worked together to become a powerful voice for change.

What CVC is building will endure. The advocates are gaining the knowledge, skills and experience necessary to improve on the advances they helped make, and to implement new laws. Hazard and opportunity loom in each area, and ongoing support to champion the needs of consumers is needed.

In the days ahead, the clear, strong voice of consumer advocates will be essential. Implementing the federal law will be a massive undertaking in the states. And there are still many decisions to be made that need the voice of



“ The states were tackling reform head on and in so doing were providing a game plan for what could be achieved at the federal level. The states were, and always have been, the incubators for real reform. ”

– **Andrew Hyman**, Team Director and Senior Program Officer  
Robert Wood Johnson Foundation

consumers to ensure that all Americans have stable and affordable health insurance.

The advocates have created a seat for themselves at the table. While they cannot outspend other interest groups, they established coalitions where they can continue to increase their numbers, educate their members, and effectively advance grassroots action and engage in the political process on issues that affect them. In addition, they are proving to be an indispensable resource for policymakers and regulators who now see state consumer advocates as equal partners at the table with other stakeholders.

Consumer advocates have always faced long odds, but with sufficient resources, they have achieved important gains. CVC proves that supporting networks of consumer advocacy is an effective way to ensure that the voices of real people are heard and their needs are considered in the policymaking process. From community centers to Capitol

Hill, the CVC coalitions are promoting a health system that works for everyone. Going forward, state advocates will be a critical link between the national law and its successful local implementation.

“The Foundation is very pleased with the dividends already being paid from our investment in consumer advocacy,” said Andrew Hyman, team director and senior program officer of the Robert Wood Johnson Foundation. “Therefore, we remain as committed as ever to the important role consumer advocates play in building a better health system, and we look forward to working in partnership with others to build on the strong foundation that CVC helped build.”

The investment is paying off.

# Introduction

**Seeing an opportunity to replicate the success of Massachusetts' comprehensive health reform legislation in other states, the Robert Wood Johnson Foundation joined with Community Catalyst to form Consumer Voices for Coverage (CVC). The program provided consumer organizations in states on the cusp of health care policy changes with much-needed funding and technical assistance to build coalitions and increase their capacity to inform state reform efforts.<sup>1</sup>**

With the skillful work of coalitions engaging diverse stakeholders and finding common ground, a number of states scored policy wins in the first months of the CVC program—expanding care for some of their most vulnerable citizens, eliminating onerous rules and regulations that throw up barriers to enrollment, and making health insurance more affordable for individuals and businesses.

Then in late 2008, financial meltdown threatened the U.S. economy and as the country sank into a recession, states were scuttling reform plans and eyeing previously sacrosanct programs in order to close unprecedented budget deficits. Meanwhile, at the national level, a highly partisan debate over federal health reform was reaching a fever pitch.

The CVC coalitions straddled two roles: maintaining their state-level work and providing important feedback to national leaders about the impact of proposed reform measures on consumers in their states. Community Catalyst provided strong support for advocates to have an impact in areas it identified as vitally important to consumers—making sure that health insurance was affordable to low- and middle-income people, and that consumers got the information they needed to successfully navigate any new health insurance system.

“It’s hard for one group to do it all, and as they say, many hands make light work,” Lori Grubstein, the program officer in charge of the CVC program at the Robert Wood Johnson Foundation, said. “When you have all these groups working together in an integrated advocacy system, they bring their different strengths, and that is a much more effective way of pushing a policy agenda.”

In the midst of heated debates, the consumer coalitions proved their mettle, eking out state reform policies in a treacherous political and economic environment, while working with federal policymakers—often for the first time—to hammer out details of national reform.

The CVC states were following a straightforward formula identified by Consumer Catalyst in its October 2006

report, *Consumer Health Advocacy: A View from 16 States*.<sup>2</sup> In order to be successful, consumer organizations—individually or as part of a coalition—must be able to:

- **Analyze complex legal and policy issues in order to develop achievable policy alternatives**
- **Build a strong grassroots base of support**
- **Design and execute communications strategies to build timely public and political support for reform**
- **Build and sustain strong broad-based coalitions and maintain strategic alliances with other stakeholders**
- **Develop and implement strategic health policy campaigns**
- **Generate resources from diverse sources to build organizational infrastructure**

This report describes the CVC coalitions’ work to date in each of these strategic areas. It is important to note that the “six capacities” work together synergistically. Incisive policy analysis goes nowhere without a strong, on-the-ground grassroots effort to educate the people who will be affected and the legislators who will be voting on key policy changes. Communications campaigns are only effective when there is a broad-based coalition of partner organizations to carry the messages



to their respective supporters and advocates. And, of course, policy analysis and policy campaigns, building coalitions, activating the grassroots, and communications—all of it depends on steady, dependable funding, in the good times and in the bad times.

Since the launch of CVC, Mathematica Policy Research has been tracking the work of the state coalitions—cataloging how their capacities have grown, mapping the strategies that have proven effective in moving reform forward, and evaluating what will be required to maintain a strong, ongoing infrastructure for championing consumer needs and viewpoints. A formal evaluation by Mathematica will provide more detailed information.<sup>3</sup>

In the days ahead, the clear, strong voice of consumer advocates will be

essential, perhaps even more so than when the political debate over health reform was at full-tilt. Implementing federal reforms at the state level will be a massive job. Enacting reform legislation does not automatically translate to improved health care; there are still many decisions to be made that need the voice of consumers to ensure that individuals and families benefit from the new policy. The good news: the consumer coalitions formed and strengthened through the CVC program are well-equipped and well-positioned to play key roles in making sure that reforms work as they were intended, and that our most vulnerable citizens get their full benefit.

“The ability of a strong advocacy community to identify sources of problems in the statute or in the

implementation of the statute is a resource that the state needs,” said Alan Weil, executive director of the National Academy for State Health Policy. “It is community-based organizations that are able to come to the states and say, ‘this process is not working,’ or ‘this form is unintelligible,’ or ‘we have people speaking a language that you are not serving.’ It is a quality improvement feedback loop that [we] do not have where there is not a strong advocacy infrastructure.”

In a health system, you need the permanent and institutionalized voice of consumers at the table at all times. In bad times vulnerable people get hurt the most and are the most at risk; in good times, advocates can actually make progress and move the system to another plateau.

<sup>1</sup> 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 Health Foundation, Foundation for a Healthy Kentucky and Georgia Health 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.

<sup>2</sup> Community Catalyst’s October 2006 report, *Consumer Health Advocacy: A View from 16 States*, funded by the W.K. Kellogg Foundation [www.communitycatalyst.org/doc\\_store/publications/consumer\\_health\\_advocacy\\_a\\_view\\_from\\_16\\_states\\_oct06.pdf](http://www.communitycatalyst.org/doc_store/publications/consumer_health_advocacy_a_view_from_16_states_oct06.pdf).

<sup>3</sup> Reports from the evaluation can be found on the RWJF web site at: <http://www.rwjf.org/pr/product.jsp?id=42449>



# The Devil is in the Details

**The “law of unintended consequences” is an old adage that says that any intervention in a complex system may or may not have the intended result.**

No system is more complex than the health system, and effective change must be grounded in legal and policy analysis. The CVC program focused on building this capacity in each state by honing the advocates’ skills in evaluating policy proposals and strategically combining multiple reforms to impact health care delivery. Some CVC grantees with less internal capacity used the network approach and built solid relationships with independent policy institutes in their coalitions or

as partners in research projects. And the CVC grantees worked to translate policy issues for the public to build awareness and support.

Each organization and coalition started with varied capacity in this area, and each state has a different environment for health advocacy efforts. In every state, however, other stakeholder groups such as hospitals, employers and other provider groups ensure their voices are heard, so consumer advocates must bring their unique—and important—perspective to policy debates. They represent people who have the least ability to fight back when policies threaten their well-being. They ground the policy

analysis in real experiences, and understand how people interact with the health system.

In 2008, New Jersey legislators were grappling with a health reform measure with good intentions—expanding the state’s health insurance program to cover all children 18 and under. But there was a sticking point, “The premium copayments being asked of low-income consumers were just too high and were a barrier to enrollment,” said Evelyn Liebman, director of organizing and advocacy at New Jersey Citizen Action.

Affordability had been a “sleeper” issue—something that up to that point

## Capacity #1

**Analyze complex legal and policy issues in order to develop achievable policy alternatives**

Successful coalitions must be able to:

- Understand the impact of health policy on consumers and identify galvanizing issues that can bring together a broad range of people, organizations and stakeholders.
- Provide data and facts that build a strong case for action.
- Develop winnable policy solutions that make an important difference in health care access and also mobilize key groups and build alliances with stakeholders.





“ The CVC Coalitions are strategic and smart and practical about who they think they need to partner with to make these sorts of policy changes in their own states and at the federal level. ”

– **Lori Grubstein**, Program Officer  
Robert Wood Johnson Foundation

policy makers and researchers had not addressed in a sustained way. The New Jersey CVC coalition enlisted the help of Community Catalyst policy experts to dig into the details of the pending legislation, understand its impact on families and fashion some workable alternatives.

Coupling in-depth policy analysis with compelling stories of real people, the coalition was able to make a strong case to legislators to “keep the good and eliminate the things that were really bad for consumers,” Liebman said. The bill signed into law July 8, 2008 made insurance premiums more affordable for low- and middle-income New Jerseyans and has resulted in some 20,000 more children having health coverage.

Working with Community Catalyst on the affordability issue helped the New Jersey coalition forge a relationship with a new partner, strong in policy analysis, that became a member of the coalition and now shoulders that essential work.

As a result of their more structured network approach to advocacy,

Liebman noted, “We are beginning to be seen as a resource for policy makers, legislators and regulators, which has highlighted that, yes, there is a consumer advocacy voice in New Jersey that is a force to be reckoned with.”

Their experience in expanding this capacity is emblematic of the transformation of all CVC coalitions, and of the critical role consumer advocates play in tying policies to on-the-ground experiences. Consumer advocates educated the public and state and federal lawmakers about making sure reform made health care affordable for families. Many coordinated with Community Catalyst and other national groups in a survey that served the dual purpose of allowing advocates to connect in their communities and provide real stories to share with policy makers.

### **Documenting the Impact and Creating a Feedback Loop**

As states struggle with budget issues, health programs are often on the chopping block.

“A lot of our work has been focused on clearly pointing out the impact of these cuts,” said Anthony Wright, head of Health Access, the leading coalition for health care consumers in California, “on families, on the health system we all rely on, and on the economy.”

CVC grantees make sure hard-hitting reports quantifying the impact of program cuts reach the desks of legislators as well as the media, and work to get a diverse group of people and organizations to rally around issues important to consumers. The CVC coalitions are mastering the art of finding policy solutions that are not only good for consumers, but winnable in tough political environments.

That ability will make the consumer coalitions valued partners in the hard task of implementing national health reform. “A lot of the programs are administered at the state level,” said Weil. “A well-funded and well-organized advocacy infrastructure helps promote more consumer-friendly policy, but it is also a great source of information to improve how programs are run.”

# Let's Get Organized

Campaign staff “were literally driving the wheels off our cars trying to reach all corners of the state.”

–**Tony Garr**, Executive Director  
Tennessee Health Care Campaign

**Grassroots organizing engages people at the local level, the arena in which uninsured and underserved people are most likely to experience the effects of health system breakdown.**

In the best cases, grassroots organizing directly informs the policy agenda. In the CVC states, grassroots

organizations have provided an effective and vocal base of popular support for significant health policy changes and played important advocacy roles. Now, as the focus turns to implementing the national law, the voice of consumers is being directed toward making sure the changes work for those who are most affected.

## Capacity #2

### Build a strong grassroots base of support

Strong grassroots organizations:

- Build support for reform among people directly affected by policy decisions, including people of color, the uninsured, and others disproportionately affected by disparities in health access and care.
- Influence key decision-makers in local and regional settings.
- Ensure that advocacy addresses the needs of people who use the health care system.





Grassroots organizing has been key to the statewide Tennessee Health Care Campaign (THCC). CVC funding enabled the coalition to hire organizers to cover sections of the 42,000 square-mile state; before campaign staff “were literally driving the wheels off our cars trying to reach all corners of the state” director Tony Garr said. With organizers spread out across the state, THCC built relationships with hundreds of local advocates—from seniors to young adults to small business owners to consumer advocates—who participate in local events and rally behind specific policy objectives.

The organizers recruit volunteers into local organizing groups. These volunteers attend monthly local meetings and statewide conference calls to discuss policy issues. They help implement THCC’s work by taking leadership roles in their communities as

local spokespeople, and by planning activities such as public forums and press events.

### **A Citizen Army of Advocates**

By connecting with community organizations, churches and synagogues, small businesses, and civic groups, CVC coalitions across the country recruited citizen armies of people passionate about health care. These people put a face to the issues and can be quickly mobilized to respond when important policies are on the line.

The Pennsylvania Health Access Network established a strong grassroots and grassroots network, culminating in a march from Philadelphia to Washington, D.C., in support of health reform. The “March to the Finish Line for Melanie” honored

advocate Melanie Shouse, who lost her battle with breast cancer after missing out on critical treatment because she could not find affordable insurance.

In Illinois, CVC funding helped the consumer coalition to organize its already vibrant faith-based caucus into a force to be reckoned with. In early 2009, when the future of health reform was uncertain, coalition members gathered in a church in downtown Chicago. The mood was grim until a pastor, a member of the caucus, rose to his feet with a challenge.

“He talked about the civil rights movement,” Jim Duffett, head of the Illinois coalition, who was in the audience that day, recalled. “He said, ‘Did Rosa Parks settle for new seats or cushions in the back of the bus?’ He then challenged the faith community to focus on health reform.”

# Are They Getting the Message?

**The ability to use media and communications is essential to building and maintaining timely public and political support and countering opposing misinformation. The CVC states expanded this capacity significantly, in some cases almost from scratch. Consumer coalitions paired compelling stories with data to break through the roar of better-funded opposition media campaigns. And in many cases, important policy decisions turned on the effectiveness of strategic communications efforts launched by consumer groups.**

## The Power of a Story

Harnessing the power of consumer stories was one potent strategy the CVC coalitions used to build public and political support for health reform. The days were numbered for the General Assistance Medical Care (GAMC) that provided health care to some 70,000 low-income Minnesotans, such as Robert Fischer, a 51-year-old left homeless by a failed business and chronic health problems. With GAMC support, he has slowly been rebuilding his life.

At a committee meeting, Liz Doyle, policy director of TakeAction Minnesota, heard Fischer talk about marking the last day he would get benefits on his calendar and weaning himself off medications so it wouldn't be such a shock when he could no longer afford them.

"He was a natural speaker," Doyle recalled. She recruited him to be a key spokesperson and member of the strategy team in TakeAction's campaign to rebuild the GAMC program.

After some training, Fischer appeared at major public events, legislative hearings, and in YouTube videos. He also participated in a phonebank—calling people in targeted legislative districts to tell his story.

Seeing and hearing the "human face" of the GAMC predicament made an impact, legislators told Doyle, who reached a deal that restored some funding for GAMC, as well as instituted some program reforms.

"The press speculated that this program's elimination would largely go unnoticed," Doyle said. "Very low-income people—many who are homeless and have significant mental illness—are not in a good position to get organized to defend their health coverage. Robert is a good example of how a community member can—with support and training—become an effective, articulate advocate for health reform."

"We worked hard to gather personal stories," said Carrie Fitzgerald, senior health policy associate at the Child and Family Policy Center, which partnered with the Iowa Policy Project to educate national legislators. "We interviewed a small business owner about the difficulty and cost of providing coverage to employees.

We covered the story of a rural family and their difficulty getting an individual policy on the private market. We spoke with many people with pre-existing conditions who were excluded from coverage. These stories were combined with data and facts to support positive policy change."

## Harnessing New Media to Get the Message Out

With CVC coaching and support, many coalitions significantly upgraded their web presence and harnessed the power and reach of new media such as Facebook, YouTube and blogging.

"Using new media made it possible for CVC grantees to reach a wider audience—and new people. With small staffs and small budgets, learning how to use new media meant they could expand their reach, giving people across their states more information, and more opportunities to share their stories," said Susan Sherry, director of the CVC program at Community Catalyst.

The North Carolina CVC grantees built a video editing suite so they could edit short videos to post on their Web site—including commentary, interviews and personal stories from North Carolinians—focusing on issues related to national health reform. Adam Searing, director of the Health Access Coalition and Adam Linker, policy analyst, both with the North Carolina Justice Center, post blogs on the Progressive Pulse Blog informing both the public and journalists about national health reform issues.

## Capacity #3

### Design and implement communications strategies to build timely public and political support for reform

Communications capacities contribute to advocacy success by:

- Effectively framing issues.
- Describing problems in ways that are accessible and create demand for solutions.
- Making a strong public case for policy change and critiquing oppositions' positions.
- Getting the right data and information to legislators, policymakers and stakeholders at the right time.
- Building broad editorial and op-ed support and obtaining other media coverage at critical junctures.
- Developing communications strategies for conveying timely information to supporters.
- Ensuring advocacy addresses the needs of people who use the health care system.

#### The Right Audience, the Right Message, the Right Time

The consumer coalitions also quickly learned to rethink and reshape their messages as the economic and political landscape shifted beneath them. In difficult economic times in 2009, the New York CVC coalition refocused its advocacy communications around the importance of “crisis coverage,” which they defined as simplifying public insurance eligibility and enrollment, and extending COBRA from 18 to 36 months under a proposed New York “mini-COBRA” statute.

“These were tough economic times, in which it was important to focus on helping people by making it easy—not hard—to get insurance coverage,” campaign director Elisabeth Benjamin said. “We were fortunate in being able to get the policymakers to frame the message around that goal.”

Equally important to reaching policymakers, is getting accurate, clear information to the communities who

benefit from policy change. Following a state Medicaid expansion, the Maryland Health Care for All! Coalition undertook an outreach and enrollment campaign.

“We had a special campaign in Baltimore City to educate newly eligible residents about the program in partnership with Governor O’Malley and Baltimore Ravens star Ed Reed,” said Suzanne Gilbert of the Maryland Health Care for All! Coalition. “Thanks to the campaign’s media, hotline and community outreach work, residents enrolled, gaining free access to comprehensive medical care, substance abuse treatment and preventive health care services.” Based on its success, they extended the scope of the campaign to additional counties.

Grantees learned new ways to deliver old messages, to frame public discussion, to develop unique tactics particular to the appropriate audience and to use stories combined with facts to make compelling cases. CVC support enabled the coalitions to make

media and communications strategies an integral part of their campaigns, to ensure that the right information got to the right people at the right time—and that the groups working together were all “on message.”

Making sure that the consumer voice is heard often means going up against well-funded interest groups that know how to command the news cycle. The CVC coalitions demonstrated they can be facile and spearhead dynamic communications campaigns that are on target and effective. As the national law is implemented at the state level, the communications task will be even more crucial.

“As in many other states, the Utah Legislature is working to reject all or some pieces of national reform,” Judi Hilman, head of the Utah coalition said. “Utah will need a voice to try to counteract this movement and educate policymakers about how they can work within the new federal parameters to implement the reforms in ways that uphold positive Utah values.”

# We Can Do This Better Together

## *For Advocates, A Broader Coalition Means Broader Impact*

**Advocacy groups march for issues they hold dear, even if others fail to join the cause. But health reform touches everyone—from the low-income mother to the small business owner to the county hospital—and the CVC coalitions found that addressing the health system’s deficiencies was the kind of big tent into which a diverse array of organizations and stakeholders would congregate.**

CVC support enabled grantees to expand their coalitions beyond the “usual suspects” and find common ground to create more broad-based coalitions with greater impact. Some of the states had long histories of working collaboratively with other groups

around specific issues and used these connections to rally strong support for health reform campaigns. Others found commonality with groups they had never worked with before, presenting an unusually diverse united front on specific health policy issues.

The advocates built effective coalitions coordinating the activities of a core group that included grassroots organizations, state advocacy organizations and legal services groups. They forged lasting alliances with other stakeholder allies in the health system, including hospitals, unions, tobacco control organizations, physician groups and health organizations, such as the American Cancer Society and the American Heart Association. All played different roles, and all contributed to achieving success.

## **Health Reform Means Business**

Several states for the first time built strong partnerships with small business owners. In Washington state, the small business coalition grew to some 2,000 members, all of them working together for quality, affordable health care. Members testified and spoke at an array of venues from the state capitol to the White House. “Never before have business voices stood with consumer advocates on health reform issues,” said Will Pittz, head of the Washington Community Action Network and Research Fund. “This coalition has become a powerful voice for change.”

A number of state coalitions recruited hospitals and provider groups into their ranks. More than 1,000 health care

## Capacity #4

### **Build and sustain strong, broad-based coalitions and maintain strategic alliances with other stakeholders**

The most effective coalitions:

- Have strong personal and organizational relationships built and strengthened through past collaborative work.
- Maintain communications and share information between collaborative campaigns.
- Utilize specific issue campaigns to increase membership and strengthen their capacity to affect the outcomes of other policy decisions.
- Bring together advocacy organizations and stakeholders that have different capacities, missions, constituencies, and strategies to work collaboratively toward a common goal.

“ We’ve been able to forge alliances with many consumer groups that often come in with a single issue. You have disease-specific groups, labor unions, faith-based groups, all focused on lots of different issues. We have been able to bring these partners together and speak with one effective voice.”

– Kathleen Gmeiner, Project Director  
Universal Health Care Action Network of Ohio

providers, including 562 physicians, joined the CVC coalition headed by the Utah Health Policy Project. Calling themselves the Utah White Coats, the group sent letters, took out ads, manned phone banks, and held press conferences to signal to Utah representatives in Washington their belief in the importance of getting started on national health reform.

### The Broader, the Better

Broad coalitions helped reinforce the notion that health reform is something that people across the political spectrum and with diverse agendas can embrace. Perhaps nowhere was this more evident than in the state of Texas.

So large and diverse is the state that consumer advocacy groups tended to operate independently and regionally, rarely joining forces to support specific statewide or national policy agendas. So the CVC project, Texas Voice for Health Reform, built a network—a neutral ground where groups could share information, strategize and collaborate, as they saw fit.

The groups participating in weekly phone planning sessions ran the gamut—faith-based groups, labor, low-income community organizers, national networks, and traditional grassroots allies such as social service and health care providers.

The network’s open-door policy made it possible for groups as diverse as Planned Parenthood and the Texas Catholic Conference to sit together and discuss the areas of health reform on which they were in agreement.

“They do not sit together at a table anywhere else,” Kymberlie Quong-Charles, the coordinator of the CVC network, said. “It was helpful to be able to say, ‘look, we have all these groups, including some groups that are diametrically opposed on some issues, and they are able to sit with us and share in the conversation.’”

### New Possibilities

Though at times challenging to manage, broad coalitions opened up new possibilities and strengthened their legitimacy and influence with

policymakers—important clout to have as the massive task of implementing the new law over several years.

The CVC program allows advocates to expand what is politically possible. Forming coalitions is fundamental to the project, and brings in a different set of actors than those who were part of the health care conversation in the past.

“When enough stakeholders say, ‘There are some things we agree on and it makes sense to go after them together,’ that’s how you make change. It requires time and effort to build working relationships with all of those interest groups. You’ve got to have somebody whose job it is to build those relationships, to be constantly talking and constantly seeking that common ground,” explained Sherry.

The CVC coalitions have put in the time and effort, and had an impact on health policy in their states and the nation. Now, in addition to continuing to push for progress, these coalitions will ensure that the new law is implemented effectively.



# In This Environment, the Best Offense May Be Defense

**Mounting a successful health policy campaign requires equal parts imagination, organization and laser-like focus. Once you've gathered your troops and trained them, you need to give them clear marching orders. The CVC coalitions greatly expanded their capacity to lead effective policy campaigns, and did so in the midst of shifting conditions on the ground.**

"It's really important to have the advocacy groups out there in good times and in bad times to fend off cuts and also to keep pushing for more and more coverage," said Grubstein.

When the CVC coalitions started their work, health reform was moving forward in a number of states. By the end of 2008, the country was in a recession and many advocates were learning the fine art of defense, rallying

to save health programs for the most vulnerable, and fighting to counter the lobbying and media machines of well-heeled interest groups.

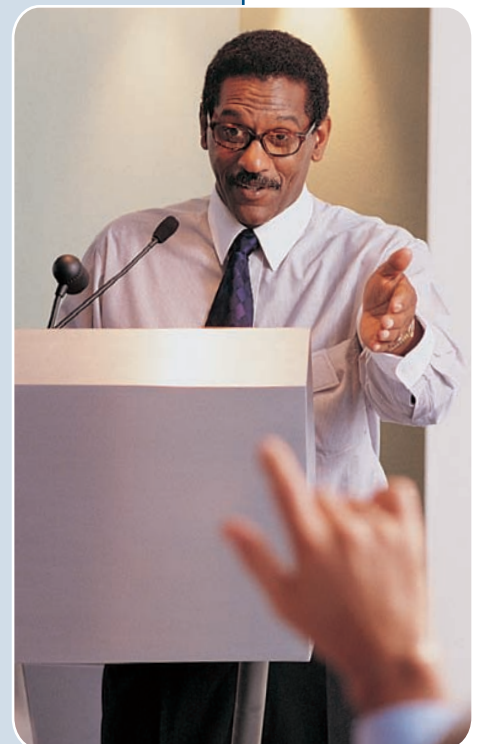
In the beginning of 2007, the Ohio CVC coalition, Universal Health Care Action Network of Ohio (UHCAN Ohio), was in the thick of a campaign supporting the Governor's effort to develop a plan to expand coverage for half of the state's 1.3 million uninsured. A year later, Ohio

## Capacity #5

### Develop and implement strategic health policy campaigns

Consumer advocates must be able to:

- Identify decision-makers who can function as "champions" for the policy goals.
- Build and maintain alliances to expand support and reduce opposition.
- Orchestrate the involvement of campaign partners and allies so they do the right thing at the right time in decision-making processes.
- Closely track the policy process for intervention opportunities, then move quickly to take advantage of them.
- That have different capacities, missions, constituencies, and strategies to work collaboratively toward a common goal.





legislators were scrambling to plug huge deficits in the 2009 state budget.

It was a common refrain across the country, as many states took their planned reform initiatives off the table entirely. The consumer advocates, no strangers to a changing political and economic realities, quickly regrouped and swung into action to focus on reforms that would protect consumers, yet not cost states anything. Despite the grim prospects, they produced some policy “wins,” many of which foreshadowed provisions in the national law.

In Ohio, the consumer coalition created policy campaigns to:

- Require insurance companies to lower what they charge people with pre-existing conditions.
- Expand the age that young people can be covered on their parents’ insurance.
- Require employers that don’t provide insurance to create “cafeteria plans,” so that their employees can purchase health insurance on the individual market with pre-tax dollars.
- Require insurance companies to have greater transparency in reporting the ratio of medical expense to revenue.

To push these policy changes, the coalition went into full-court press: meeting regularly with legislators to talk about the impact reform would have on their constituents, putting out bi-weekly policy briefs laying out the implications of the reforms, mounting postcard campaigns, and hosting advocacy days at the Capitol. Seasoned and inexperienced advocates teamed up to present their case and talk with legislators. In the end, despite opposition, each of the no-cost reforms was enacted.

### **Eking out Reforms**

Across the country, CVC coalitions mounted equally impressive health policy campaigns, and along the way, learned lessons that will be invaluable in the upcoming battles to implement—and defend—the new law.

For example, in their successful campaign to win passage of two major health policies, consumer advocates in Maine learned the importance of planning, building coalition support with traditional and non-traditional allies, and communicating effectively about policy measures. “We were able to be proactive,” said Joe Ditré, a leader

of the Maine Voices for Coverage coalition, “and set the terms of the debate by carefully focusing on high-leverage policies that would make a real difference for consumers and patients—and ones that even large businesses were unable to accomplish through their quality improvement work.”

With their hard-won experience, the CVC coalitions have found a ready ear among federal policymakers. “In national discussions about what needs to be done in the states after reform, we brought in state consumer advocates for the first time,” said Sherry. “They have not only the policy expertise, but also the political experience of working on these issues.”

The CVC coalitions gained experience in mounting local, statewide and national policy campaigns—often simultaneously. State advocates live in the real world with real people, so they did not have the luxury to walk away when times got bad. They figured out how to defend what needed defending, and found opportunities to make policy gains. They approached their policy campaigns with energy, imagination and pragmatism.

# Now Comes the Hard Part

**If achieving health reform is like a marathon, then a primary goal of Consumer Voices for Coverage was to make sure that consumer advocates were “in the race.”**

“We noticed that other stakeholders had a lot more resources and political clout,” said Grubstein. “We wanted consumer advocates to be on more equal footing with these groups that have a major influence on the outcomes of health care debates at both the state and the federal level.”

“RWJF funding helped the CVC coalitions equip themselves for the battle, and the investment is paying off,” Grubstein said. “They have immediate, trusted access

to consumers—especially those populations who will benefit the most from the legislation. They established working coalitions and relationships with stakeholders, state agencies and legislators. They have the knowledge, skills and experience to take health reform forward.”

Now consumer advocates find themselves at about the 19-mile mark of the marathon—in a position to play a crucial role in state implementation of the federal law. But they’re wondering:

## Capacity #6

**Generating resources from diverse sources for infrastructure, core functions and campaigns is critical because:**

- Investment in advocacy infrastructure and capacity makes all the difference.
- Support for policy research brings important issues to public attention.
- Funders can uniquely bridge and convene stakeholder groups.
- Local foundations are valuable partners because they know what is happening on the ground.



“This is our time in history, a time when legislators voted for bold and big changes. Our ability to succeed with those changes, to show positive and concrete results is in large part a statement about government’s ability to work well.”

– Ellen Pinney, Executive Director  
Oregon Health Action Campaign

Do we have enough resources to finish the race?

### **Health Reform Implementation: Danger and Opportunity ‘Round the Bend**

The road ahead for consumer advocates involves at least three large areas of work—defending against efforts to repeal all or parts of the health reform law, implementing it on the state level, and educating consumers about how the new law will affect them. Hazard and opportunity loom in each, and on-going support to champion the needs of consumers will be needed.

“In all states—particularly ones without supportive state policymakers—strong local advocacy will be necessary to make sure implementation goes smoothly, and we see the benefits to the people in our communities who most need reform,” said Sue Berkowitz director of South Carolina Appleseed Legal Justice Center. “We will have to prove that the new law is good for our families and our state.”

“A significant amount of time and resources will be needed to implement federal reform initiatives on the state level to create the best possible

systems for Colorado,” said Dede de Percin, executive director of the Colorado Consumer Health Initiative.

In implementing reform, state policymakers and advocates will be intimately involved in every step. States that have already achieved deep reforms in their health systems will be in a position to be model states for the implementation process. Other states will need to carefully analyze how programs that have worked in one state can be fitted to their unique circumstances.

“We have created a climate where our legislature is prepared to implement key elements of reform quickly,” said Pittz. “We are equipped with the advocacy capacity to both push for implementation and monitor progress to ensure success. Investing in our work to develop models and best practices for health reform will be critical to the success of health reform throughout the nation.”

Several state consumer groups said their crucial work during implementation will be in the area of consumer assistance—making sure that people have the information and resources they need to navigate

through a health system where the rules and processes have changed.

“Consumer engagement and navigation work will be important for translating the reform provisions into meaningful access to care and financial security for Utah families and small businesses,” Hilman said. “This, too, will generate positive public pressure to sustain and build on the reforms.”

The coalition-building and health policy work gives consumer advocates the opportunity to engage organizations that do not have the capacity in health reform. The coalition brings stakeholders together, and the advocates’ policy expertise gears those organizations toward meaningful activities to change health policy. CVC coalitions have a strong foundation for advancing a consumer agenda on health care.

In addition to serving as the voice of consumers, the coalitions are a resource for policymakers, legislators and regulators who now see state consumer advocates as a force to be reckoned with.

The advocates have created a seat for themselves at the table, bringing

“ If consumer interests need to have a seat at a table, then that capacity to be at the table needs to be institutionalized. That’s where you need infrastructure. The hospital association is funded to represent hospitals at the table. They have an infrastructure to do it. The medical society has that too. And so do insurers. Consumers certainly deserve no less. ”

– Susan Sherry, National Program Director  
Consumer Voices for Coverage

strength in numbers. While they cannot outspend other interest groups, they established coalitions where they can continue to increase their numbers, educate their members, and efficiently move people to take grassroots action and engage in the political process on issues that really affect them.

### **The Wind at Their Back: The Role of Philanthropy**

One of the unfortunate fallouts of a struggling economy is that sources of funding have become even more challenging to find. The cutbacks have put a number of the consumer advocacy groups in jeopardy.

“Survivability is key. All the capacity that we have been able to build—there is knowledge there—but it is very fragile,” Duffett said.

A number of leaders in the field have called for creative solutions that would ensure ongoing support for consumer advocacy groups. “There is a lot of talent on the ground. Sustained funding frees up good advocates to

do the work. These coalitions are really struggling,” Kathleen Stoll of Families USA said. “They know how to fundraise. There just aren’t many pots to dig in.”

Indeed, as reported in *Consumer Health Advocacy: A View from 16 States*, the states with the highest levels of advocacy capacity also had the highest levels of funding support. Consumer advocates need not just funders, but true partners.

“State advocacy capacity is strongest where funders engage in regular dialogue with advocates and are ‘on the same page’ with regard to understanding opportunities to impact policy through consumer advocacy,” the report stated.

### **What’s Next?**

Consumer advocates have always faced long odds. But with sufficient resources, they have achieved important gains for people in need. Investment in consumer advocacy coalitions will ensure that consumer

needs drive change and build a health system that holds both the promise and reality of access to affordable, quality health care for all.

CVC proves that supporting networks of consumer advocacy is an effective way to ensure that the voices of real people are heard and their needs are considered in the policymaking process. From community centers to Capitol Hill, the CVC coalitions are promoting health reform efforts to make high-quality care available for everyone. Going forward, state advocates will be a critical link between the national law and its successful local implementation.

“The Foundation is very pleased with the dividends already being paid from our investment in consumer advocacy,” said Hyman. “Therefore, we remain as committed as ever to the important role consumer advocates play in building a better health system, and we look forward to working in partnership with others to build on the strong foundation that CVC helped build.”



