# Building State-Level Advocacy Networks: CVC After Two Years

Consumer Voices for Coverage Evaluation

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#### **EXECUTIVE SUMMARY**

In 2007 several states appeared to be on the verge of adopting or fully implementing public policies to provide comprehensive health insurance coverage to their residents. To increase the odds that these public policy changes would come to fruition, support similar trends in other states, and increase the voice and role of consumer advocates in the policy development process in these and other states, the Robert Wood Johnson Foundation (RWJF) launched a new program, Consumer Voices for Coverage (CVC), aimed at building single, integrated consumer health care advocacy networks in 12 states. This strategy was based on a study showing that such networks could be effective in changing state health policy if they possessed specific advocacy capacities, which the program was designed to enhance (Community Catalyst 2006).

RWJF contracted with Mathematica Policy Research to evaluate CVC. The Foundation wanted to learn (1) how the advocacy networks were structured and operated, (2) whether their advocacy capacity increased over the life of the initiative and (3) how they influenced state health coverage policy.

This report describes the progress made by CVC participants during the first two years of the initiative. It synthesizes information from (1) a review of status reports filed by grantees in 2008 and 2009, (2) semistructured interviews held with grantee project directors and group interviews with leadership team members in 2009 and (3) focus groups with participants attending the CVC annual conference in September 2009. Several key findings have emerged from our analysis.

### **Evaluation Findings**

Successful consumer coalitions maintain ongoing infrastructure rather than pulling together episodically around particular issues (Community Catalyst 2006). CVC was designed to foster and/or strengthen consumer advocacy systems or networks, including building the network around a core leadership team. The composition of leadership teams was similar across states, though teams varied in size and how they were formed. Many team members had worked together prior to CVC. Prior relationships presented advantages and disadvantages, and were not as important as frequent communication in predicting teams' abilities to coordinate their decision-making and engage in joint advocacy. Participants appreciated the advantages of having leadership teams, but also suggested that more initial support to build cohesion would be helpful in future initiatives.

After grantees were selected and just two months before CVC funding began, the economic conditions facing states began to change dramatically, as the United States entered a recession. States' downward fiscal trajectory reduced opportunities for supporting comprehensive coverage in 2008 and 2009 at the state level. Despite these conditions, legislatures in many states in which CVC operated rejected proposed cuts to Medicaid or safety net public programs and even managed to expand coverage for families and children through federal stimulus efforts and program reauthorizations. CVC networks participated in these debates and advocated proactively for private insurance reforms favorable to consumers, which were adopted in numerous states. They also advocated for federal reform in 2009, building on the relationships and capacities they had established through their CVC-related work.

v Consumer Voices for Coverage Evaluation

Effective consumer advocacy on health policy requires the analysis and development of policy alternatives, outreach to media and grass roots organizing, and strong communications capabilities. To address the state- and federal-level policy issues they faced, CVC grantees and their partners produced quick-turnaround analyses and talking points on proposed legislation or budget cuts; collected and analyzed data; or produced or commissioned reports on topics such as insurance affordability, insurance needs of small businesses, or health coverage for immigrants. They also developed some policies and proposals themselves. Grantees reached out to traditional media through press releases, rallies and protests, or direct contacts with journalists or editors. Some also experimented with blogs and social media. CVC networks operated story banks to provide personal testimonies as a counterweight to humanize the complex health care debate. They engaged, organized and trained grass roots activists, often for the first time or on a larger scale than they were able to do prior to CVC. They also reached out directly to policy-makers and their staff members, especially in debates over federal health care reform in 2009.<sup>1</sup>

As part of the evaluation, we asked grantees and leadership team members how CVC influenced their capacities, activities and plans for the future. Participants felt that CVC positively affected their advocacy networks in several important ways. First, because it came from a well-known and respected foundation, the grant boosted credibility for the consumer advocacy networks, increasing their visibility and facilitating their health advocacy efforts with key stakeholders and decision-makers. Second, they reported that the initiative enhanced their advocacy capacities—especially in communications, grass roots organizing and policy development and analysis. CVC also set the stage for their involvement in federal health care reform in 2009.

#### **Key Outcomes**

At this stage in the evaluation, we cannot comment on how much the networks have influenced state policy outcomes, or on the effectiveness of particular advocacy approaches or leadership team structures. However, the evaluation shows that CVC networks have made progress on a number of fronts.

**Building strategic alignment.** CVC grantees and leadership teams built on or improved their initial relationships and decision-making approaches, improving coordination and conducting joint advocacy activities. To build their networks, leadership teams reached out to traditional and nontraditional consumer allies.

Addressing state health coverage policy. CVC networks involved themselves in health insurance coverage and related policy discussions, adding the consumer's voice to important policy debates in their states.

<sup>&</sup>lt;sup>1</sup> None of the CVC funding from RWJF was permitted to be used by grantees to support lobbying activities. RWJF funds were used to support unrestricted policy related activities. Some of the activities described in this report may have involved funds from other sources.

**Building advocacy capacity.** CVC helped build capacities among grantees and some network members, especially in the areas of communications and media, policy analysis and grassroots organizing. However, two years into the grant, participants were still uncertain how to cultivate financial resources to sustain their activities after CVC, suggesting that more technical assistance is needed in this area.

Overall, we suggest there are two main factors that will influence the degree to which the Foundation is able to realize its goal of establishing durable, core networks of consumer health advocates in participating states through CVC. The first factor is participants' ability to identify and secure ongoing funding to support coordination and joint advocacy at a meaningful level. Participants suggested ways the Foundation might be able to assist their efforts, and Community Catalyst may also play an important role in identifying and accessing sources of support. The second factor is the degree to which network members—especially grantees and their leadership teams—have been able to form strong bonds—either interpersonal, organizational, or through shared infrastructure. This will influence whether the networks continue in any form, with or without funding. It may or may not be realistic to expect such bonds to form in a short period of three years.

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#### I. INTRODUCTION

In 2007 several states appeared to be on the verge of adopting or fully implementing public policies to provide comprehensive health insurance coverage to their residents. The governors of California, Illinois, Pennsylvania and New York (among others) were strongly supporting expanded coverage, though the progress of their proposals had not been smooth. In 2006 Massachusetts and Vermont had passed laws intended to achieve near-universal coverage and were proceeding with implementation; Maine had established a state-sponsored coverage plan in 2003 but eligible participants still remained uncovered due to insufficient financing (Lipson et al. 2007).

To increase the odds that these public policy changes would come to fruition, to support similar trends in other states, and to increase the voice and role of consumer advocates in the policy development process in these and other states, the Robert Wood Johnson Foundation (RWJF or "the Foundation") launched the Consumer Voices for Coverage (CVC) initiative. CVC was aimed at building single, integrated consumer health care advocacy networks—made up of a close-knit coalition consisting of a grantee organization and "leadership team" partner organizations, plus other allies to advocate for increased coverage in selected states. This strategy was based on a study showing that such networks could be effective in changing state health policies if they possessed specific advocacy capacities, which the program was designed to enhance (Community Catalyst 2006). The Foundation made three-year grants to 12 state-level coalitions (Table I.1).

Advocacy aims to shift public policy. It comprises "the strategies devised, actions taken, and solutions proposed to inform or influence local, state, or federal decision-making" (Weiss 2007). Advocates may seek to influence any of the four stages of policy-making: (1) setting the agenda (defining issues to be addressed); (2) specifying alternatives from which a choice is to be made; (3) choosing among specified alternatives; and (4) implementing a decision. Foundations are increasingly supporting advocacy to expand health insurance coverage and to achieve other social goals (Alliance for Justice 2007; Egbert and Hoechstetter 2006; Guthrie et al. 2005).<sup>2</sup> Though supporting organized consumer advocacy was new to RWJF's grantmaking agenda, developing policies and programs to expand health coverage has been a goal of the Foundation since it was founded in 1972.<sup>3</sup> When the Foundation launched CVC, it was estimated that up to 46 million people in the United States lacked health insurance coverage (DeNavis-Walt et al. 2008).

#### A. The Initiative: Consumer Voices for Coverage

CVC is designed to strengthen state-based consumer health advocacy networks, elevate the consumer voice in health care reform debates and advance policies that expand health coverage.

<sup>&</sup>lt;sup>2</sup> None of the CVC funding from RWJF was permitted to be used by grantees to support lobbying activities. RWJF funds were used to support unrestricted policy related activities. Some of the activities described in this report may have involved funds from other sources.

<sup>&</sup>lt;sup>3</sup> Some earlier Foundation programs, such as anti-smoking or children's health insurance enrollment initiatives, had supported grantees that advocated for policy changes as one part of their activities.

RWJF hoped to develop durable health care advocacy networks that could lend ongoing support to state and federal coverage reforms during and after the three-year grant period (Robert Wood Johnson Foundation 2007).

State	Grantee	CVC Network
California	Health Access Foundation	It's Our Health Care
Colorado	Colorado Consumer Health Initiative	Colorado Voices for Coverage
Illinois	Campaign for Better Health Care	Health Care Justice Campaign—Health Care for All
Maine	Consumers for Affordable Health Care Foundation	Maine Consumer Voices for Coverage
Maryland	Maryland Citizens' Health Initiative Education Fund, Inc.	Maryland Health Care for All!
Minnesota	TakeAction Minnesota Education Fund	Minnesota Affordable Health Care for All
New Jersey	New Jersey Citizen Action Education Fund	New Jersey Consumer Voices for Coverage
New York	The Community Service Society	Health Care for All New York
Ohio	Universal Health Care Action Network of Ohio, Inc.	Ohio Consumers for Health Coverage
Oregon	Oregon Health Action Campaign	Consumer Voices for Coverage
Pennsylvania	Philadelphia Unemployment Project/Unemployment Information Center	Pennsylvania Health Access Network
Washington	Washington Community Action Network Education and Research Fund	Secure Health Care for Washington

Table I.1 Consumer Voices for Coverage States, Grantee Organizations, and Networks

Note: In 2008 RWJF added a second round of smaller, two-year CVC grants focused exclusively on federal reform. These grants were not included in the evaluation.

To help design the initiative, administer it and provide or coordinate technical assistance to the networks, RWJF engaged Community Catalyst. Community Catalyst is a national advocacy organization that works with foundations, policy-makers and state and local consumer groups on strategies to improve access to high-quality, affordable health care and health coverage in the United States.

## B. The Grantees

In 2007, applicants from 40 states submitted CVC grant proposals to RWJF. A national advisory committee established by the Foundation evaluated applicant organizations' experience in state health care reform efforts and the involvement of grassroots organizations in their efforts. Applicants had to demonstrate leadership in developing and coordinating a statewide network of consumer advocacy organizations. They had to identify a capable leadership team of allied organizations that would guide decision-making and form the core of the consumer network. The

advisory committee and Foundation decision-makers also assessed state contexts and policy environments. They considered whether windows of opportunity existed for pursuing increased health coverage. They also weighed the potential for grantees and leadership team members to develop strategic alliances with a range of stakeholders including business, government officials, labor, payers and providers. After deliberating on the recommendations made by its advisory committee, the Foundation awarded grants to applicants in 12 states beginning in February 2008.

## C. The Evaluation

In 2007 RWJF contracted with Mathematica Policy Research to evaluate CVC. The Foundation wanted to learn (1) how the advocacy networks were structured and operated, (2) whether their advocacy capacity increased over the life of the initiative and (3) how they influenced state health coverage policy. The Foundation was particularly interested in developing lessons applicable to funding advocacy efforts in the future. To address these questions, Mathematica is conducting a mixed-methods evaluation.<sup>4</sup> Qualitative methods being used are focus groups with network participants; semistructured interviews with policy-makers, grantees and leadership team members; and reviews of monthly activity reports filed by grantees. Quantitative methods include scales Mathematica developed to measure advocacy capacity (Gerteis et al. 2008), and social network analysis, which is being used to examine the structure of the leadership teams as well as their connections to state policy-makers.

## **D. Key Findings**

At this stage in the evaluation, we cannot yet comment on how much the networks have influenced state policy outcomes, or on the effectiveness of particular advocacy approaches or leadership team structures. However, as this report will show CVC networks have made progress thus far on a number of fronts.

**Building strategic alignment.** CVC grantees and leadership teams enhanced their initial relationships and decision-making approaches improving coordination and conducting joint advocacy activities. Leadership teams with more frequent communication showed stronger strategic alignment early in the grant period. Leadership teams also reached out to traditional and nontraditional consumer allies to develop both ongoing and occasional alliances to strengthen consumer voices. Participants appreciated the advantages of having leadership teams, but suggested that more initial support to build cohesion would be helpful in future initiatives.

Addressing state health coverage policy. CVC networks participated in discussions about health insurance coverage and related policy, adding the consumer's voice to important policy

<sup>&</sup>lt;sup>4</sup> Mixed methods are well-suited to advocacy evaluation due to the lack of a single outcome measure and the consequent need to capture multiple measures and perspectives (Campbell and Fiske 1959; Webb et al. 1966), the inability of any single method to capture the complexity of advocacy (Greene et al. 1989; Doyle et al. 2009) and the need in this case to capture both what happened and why to generate lessons for future efforts (Sosulski and Lawrence 2008). Most important, mixed methods were needed because there were multiple evaluation questions; no single method would adequately address all three (Creswell and Plano Clark 2007; Sale et al. 2002).

debates in their states. With changes in state political environments and tightening fiscal constraints, no state was able to establish comprehensive insurance coverage. Instead, the networks focused on emerging issues such as defending existing public insurance programs against proposed state budget and program cuts. However, they also took a pro-active approach by advocating for private insurance reforms that would not require public funding. Networks also responded to options for expanding coverage for families and children that resulted from federal stimulus efforts and program reauthorizations. Advocates deployed their skills developed through CVC to advocate for federal reform. Grantees felt that CVC ideally positioned them to do this and the timing of federal reform was favorable, occurring at the end of many state legislative sessions.

**Building advocacy capacity.** CVC helped build capacity among grantees and some network members, especially in the areas of communications and media, policy analysis and grassroots organizing. It did so through several mechanisms. First, CVC funding enabled grantees to add specialized communications staff and organizers or build new infrastructure such as systems for grassroots organizing. Second, the initiative provided training and technical assistance to improve skills (such as media advocacy) and tools (such as grantee Web sites). Third, it provided targeted assistance such as ongoing help with policy analysis and strategy formulation from Community Catalyst and a training session on Congressional outreach. However, two years into the grant, participants were still uncertain how to cultivate financial resources that would be needed to sustain their activities, suggesting that more technical assistance is needed in this area in 2010, the final year of the CVC initiative.

Overall, we suggest there are two main factors that will influence the degree to which the Foundation is able to realize its goal of establishing durable, core networks of consumer health advocates in participating states through CVC. First is the ability of participants to identify and secure ongoing funding to support coordination and joint advocacy at a meaningful level. Participants suggested ways the Foundation might be able to assist their efforts, and Community Catalyst may also have an important role to play in identifying and accessing sources of support. Second is the degree to which network members—especially grantees and their leadership teams—have been able to form strong bonds—either interpersonal, organizational, or through shared infrastructure. This will influence whether the networks continue in any form, with or without funding. It may or may not be realistic to expect such bonds to form in a short period of three years.

## E. Purpose and Organization of the Report

The main purposes of this report are to describe the progress made by CVC participants during the first two years of the initiative and help RWJF assess the CVC program model. The report synthesizes information from several primary data sources. These include (1) a review of status reports filed by grantees in 2008 and 2009; (2) semistructured interviews held with grantee project directors in mid-2009; (3) focus groups with grantees, leadership team members and other participants attending the CVC annual conference in September 2009; and (4) semistructured group interviews with leadership team members in November 2009. It also incorporates selected data and findings from baseline evaluation data and reports.

The report is organized as follows: Chapter II discusses how the grantees and leadership team members worked together and their efforts to build broad consumer advocacy networks in their

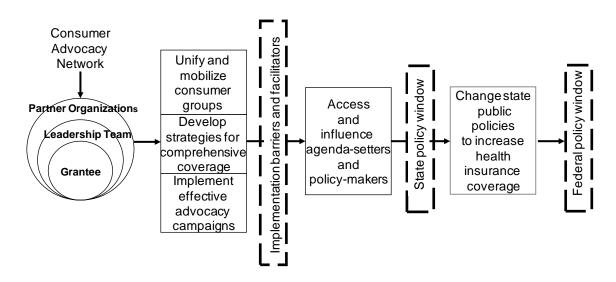
states. The state-level policy debates CVC networks have faced since receiving their grants are described in Chapter III. Chapter IV discusses how the networks conducted advocacy during 2008 and 2009, the first two years of the program, including their involvement in federal reform debates that occurred in 2009. Chapter V describes how CVC has so far affected participants.

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#### **II. BUILDING THE CONSUMER ADVOCACY NETWORK**

In its 2006 report, Community Catalyst found that successful consumer coalitions maintained ongoing infrastructure rather than pulling together episodically around particular issues. This infrastructure typically included a core group that coordinated its activities and maintained communications and information sharing even in the absence of ongoing collaborative campaigns. The report recommended strengthening consumer health advocacy by developing these types of sustainable health advocacy systems.

CVC was designed to foster and/or strengthen advocacy systems, called consumer advocacy "networks," including building the network around a core leadership team. The theory of change behind the CVC design was that leadership teams would set the strategic direction for consumer advocacy and draw additional partners into their coalition (Figure II.1).<sup>5</sup> Supported by Foundation-provided funds and technical assistance resources, these networks would strengthen their capacities to undertake advocacy activities: developing comprehensive coverage strategies, mobilizing consumers and unifying stakeholders and implementing advocacy campaigns. Through these activities, networks would access relevant agenda-setters and policy-makers and influence them to change public policies in their states so as to increase coverage. Eventually, progress among states might help spark momentum for federal action; in addition, if federal reform developed, the grantees would be well-prepared to advocate for its passage. Regardless of the pace of policy progress, an important outcome desired from CVC was that a core network of consumer advocacy organizations would continue beyond the grant period to advance health care coverage.



#### Figure II.1. Consumer Voices for Coverage Theory of Change

<sup>&</sup>lt;sup>5</sup> Grantee organizations were part of the leadership team. They had additional responsibilities as fiscal agents for the grant and points of contact with Community Catalyst, the Foundation, and providers of technical assistance made available as part of CVC.

This chapter examines the CVC networks in each state, with an emphasis on the structure and operation of the leadership teams. What was the composition of the leadership teams? How did they make decisions? Did participants view the required leadership team as a useful structure to build an advocacy network? What other partners did they engage?

## A. Leadership Teams Had Similar Types of Members but Varied in Size and How They Were Formed

By design, CVC leadership teams were composed of a group of core partners who agreed to collaborate and contribute to the advocacy effort led by the grantees. The leadership teams ranged in size from 4 member organizations in Colorado, which used a "coalition of coalitions" model, to 25 in Illinois. Half of the CVC grantees formed leadership teams with eight or fewer key partners.

The composition of leadership teams was similar across states. Most leadership teams included representatives from labor organizations, religious organizations and groups organized around particular constituencies such as minority groups, immigrants, or children, or focused on a particular disease, such as the state chapter of the American Cancer Society. Less common were leadership team members from AARP (two states), ACORN (two states), the Children's Defense Fund (two states), or business groups (two states). The annual budgets of leadership team organizations varied; one quarter had annual budgets under \$400,000 and half had budgets of \$1 million or more (Table II.1).

Variable	N	Percentage
Annual Budget (Quartiles)		
Less than \$400,000	22	23
\$400,000 to \$999,999	23	24
\$1,000,000 to \$2,999,999	24	25
\$3,000,000 or more	23	24
Health Policy Focus		
One of several policy areas	66	69
Most important of many policy areas	14	15
Only policy area	12	13
Years of Health Care Experience		
Fewer than 2 years	7	7
2 to 5 years	13	14
6 to 9 years	13	14
10 or more years	63	66

Table II. 1. Characteristics of Organizations Participating in CVC Leadership Teams

Source: 2008 CVC Network Survey, Mathematica Policy Research.

Note: N = 96 organizations. Percentages may not total to 100 percent due to rounding. Four respondents did not report their annual budget or respond to the question on health policy focus.

Leadership team member organizations had considerable experience with—but not an exclusive focus on—health coverage issues. All of the leadership team organizations included health policy as one focus of their organizational agendas, but 15 percent indicated it was the most important of the policy areas on which they focused, and 13 percent of respondents said it was their only policy focus. This may reflect instructions in the Foundation's Call for CVC Proposals to develop relationships with a range of stakeholders, not just health-focused groups. Still, 66 percent of the organizations had been involved in heath care issues for 10 or more years.

Although the leadership teams represented new, formal structures for advocacy, most were not created from scratch. In California, the CVC grant enabled a coalition that had worked together to support proposed state reforms to continue collaborating when the reform package, which had strong support from the governor, failed in the state legislature. Several states formed new coalitions, although often the leadership team partners had worked together previously. For example, the Illinois leadership team was composed of members who had worked as a steering committee prior to CVC for the Illinois Health Care Justice Campaign. In a few states, such as New Jersey and Colorado, the CVC leadership team brought many groups together for the first time.

In a survey of leadership team members conducted in 2008, Mathematica asked respondents about their initial relationships, communication patterns and participation in shared decision-making and advocacy activities.<sup>6</sup> Even in newly formed leadership teams, some members had relationships that pre-dated CVC (Figure II.2). More than forty percent of the organizations belonging to the leadership teams in New Jersey and Colorado had worked with one another prior to the grant. All organizations in the Secure Health Care for Washington leadership team had worked together prior to receiving the grant, some for more than 20 years.

Shared histories presented advantages and disadvantages. Among states where leadership team members had longer shared histories, members reported that it was easy to work together on CVC; it was a natural extension of the type of work on which they had previously collaborated. At the same time, some leadership team members noted that having a shared history could work against groups, if issues from the past had not been resolved between organizations. Another disadvantage to a lengthy shared history mentioned by leadership team members from two states was that their teams may have been so comfortable working together that they did not reach out to other groups in the state that might have added to the team's diversity or expertise.

### B. Coordination and Alignment Varied Across the Networks

To work together effectively and to create momentum to sustain their relationships, resources and efforts, consumer advocacy networks need to develop strategic alignment among their members (Community Catalyst 2006). Put simply, strategic alignment means "everyone rowing in the same direction" by creating a shared vision for the network that is aligned with the goals of its members. Greater alignment can lead to more efficient use of network resources, increased speed in executing plans and a keener sense by members of the importance of their contributions. At the same time,

<sup>&</sup>lt;sup>6</sup> We will conduct a follow-up survey in 2010 to describe how the leadership teams have developed.

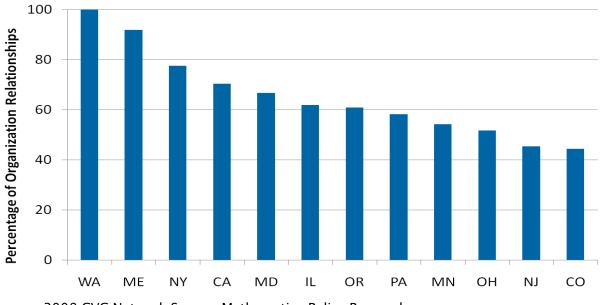


Figure II.2 Proportion of Leadership Team Member Organizations that Worked Together Prior to CVC

Source: 2008 CVC Network Survey, Mathematica Policy Research.

Note: A score of 100 percent would mean all leadership team members had worked together prior to CVC, while a score of 0 percent would indicate that no team members had done so (no states were in this category).

achieving strategic alignment can be challenging, since different partners may have diverse, and possibly even conflicting, organizational and policy interests. To examine the degree of alignment leadership teams achieved and factors that affected their progress, we combined data from the leadership team survey and interviews and focus groups with participants to examine coordinated decision-making and advocacy activities.

Leadership teams were somewhat aligned as CVC began. To apply for a CVC grant, grantees had to identify leadership team members who agreed to participate, indicating some degree of initial alignment with one another around the broad goals of CVC. In addition to strengthening this alignment over the three-year initiative, CVC networks had to come together quickly to address pressing health coverage issues in their states. They had to work out decision-making processes for the network and begin to collaborate on advocacy efforts.

One strategy for integrating leadership team members in the CVC project was shared funding. Eleven of the 12 CVC grantees distributed a portion of the grant funds to some (and sometimes to all) leadership team member organizations. However, satisfaction with this approach differed. Some teams that took this approach felt it enhanced accountability. Respondents in Maine, for instance, said that sharing funds with leadership team organizations was an advantage because having a contractual relationship raised the bar on accountability and ensured that members were vested in the work. In contrast, some states encountered problems with shared funding. Pennsylvania initially distributed funds to leadership team members, but found that in the second year, some of the

organizations were no longer focused on state health reform issues or had reduced their CVC activity levels due to staff departures. Thus, the grantee revised the terms of its financial arrangements with leadership team members in 2009 to hold leadership team member organizations more accountable for their work in exchange for CVC funds.

**Decision-making approaches varied.** With three different entities forming the CVC network—the CVC grantee, the leadership team and additional partners—states adopted different styles of decision-making. In 10 of the 12 CVC states, the leadership team formulated policy goals and action strategies that the entire network implemented (that is, the grantee, the leadership team and other partners and allies combined). In some states, this process was executed in a formal, structured manner. For example, the Maine Consumer Voices for Coverage<sup>7</sup> leadership team held an annual retreat to consider alternative policy initiatives and strategies. Team members voted on their agenda for the following year. In other states, the decision-making process was more flexible, with more give-and-take between leadership team members and the larger network of partners in setting the CVC policy agenda and strategies.

In some states, the leadership team's direction went beyond policy or strategy formulation. In Illinois the leadership team set priorities for undertaking state and federal policy initiatives. It then developed a communications strategy to ensure network members and workgroups were informed about the priorities and used consistent messaging throughout their related network efforts.

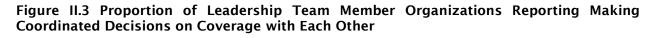
Some teams encountered challenges deciding how to operate. Other teams struggled to reach agreement about their "CVC message." For example, one leadership team member noted that messaging was something that each leadership team organization previously had tailored to its own constituencies and that, as a group, they initially had trouble building momentum around a shared message and using it consistently. However, by the second grant year, leadership team members and grantees reported that the teams were functioning more smoothly.

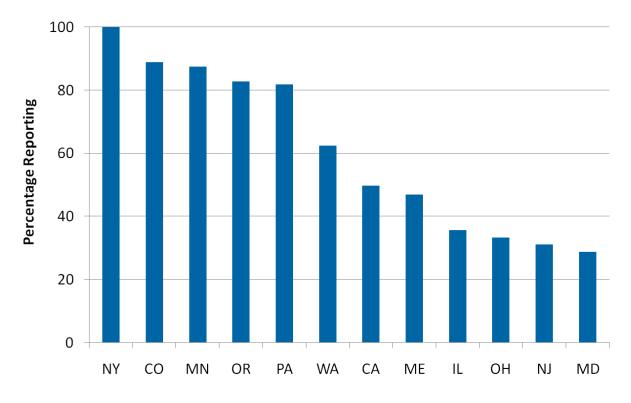
Some leadership team members reported that they did not discuss from the beginning how they would operate and make decisions, causing tensions within the team. For example, in Maine, it was only when the leadership team members and the grantee approached the second year of the CVC project—and renewal of their CVC subcontracts—that they formally agreed on how to make decisions. In contrast, New Jersey Consumer Voices for Coverage spent the early months of the grant ironing out decision-making processes, with contributions from all leadership team members under the grantee's leadership. Although some initially felt this step delayed working on CVC issues, in the end, they agreed they needed to establish and concur on their processes in order to work together effectively.

The leadership team survey asked CVC network members whether their organizations coordinated their decisions on health coverage with other members (Figure II.3). In New York, all

<sup>&</sup>lt;sup>7</sup> Several of the CVC networks incorporated "Consumer Voices for Coverage" into their names. When referring to the overall initiative or to CVC networks in general, we use the acronym, but when referring to these specific networks we do not.

respondents reported making coordinated decisions among leadership team members. At the other end of the spectrum, few Maryland respondents reported coordinated decision-making. The latter result was consistent with Maryland's initial leadership team model, in which decision-making was not their planned role.<sup>8</sup>



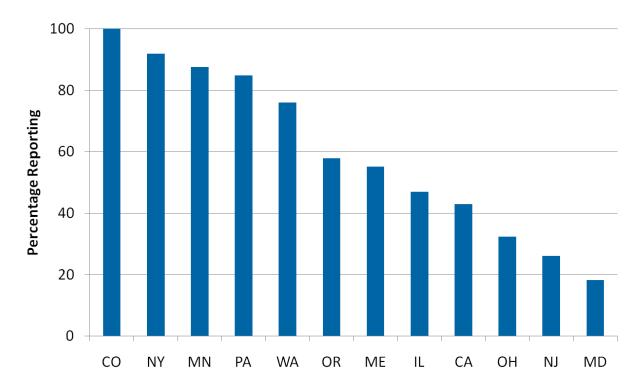


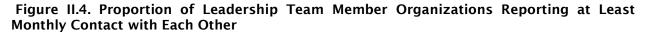
Source: 2008 CVC Network Survey, Mathematica Policy Research.

Frequent communication was more important than prior relationships to coordinated decision-making and joint advocacy. In statistical analyses, prior relationships among leadership team members were not associated with groups making more coordinated decisions. However, the frequency of communication during the first six months of the grant was strongly correlated with higher levels of coordinated decision-making (Honeycutt 2009; Honeycutt and Strong, forthcoming). Frequency of communication during the first six months of CVC was also correlated with joint advocacy activities, such as meeting with policy-makers or attending hearings together (Honeycutt and Strong, forthcoming). In 7 of the 12 states, more than half of the leadership team members reported at least monthly contact among leadership team members (not counting

<sup>&</sup>lt;sup>8</sup> Maryland later expanded the role of the CVC leadership team.

leadership team meetings) (Figure II.4). In Illinois, California, Ohio, New Jersey and Maryland, contact among leadership team members was less frequent in the first six months.





Source: 2008 CVC Network Survey, Mathematica Policy Research.

Moreover, leadership team members in the five states with less contact (Illinois, California, Ohio, New Jersey and Maryland) communicated mainly with the grantee, and less with one another as indicated by their communication diffusion scores (Table II.2). The "communication diffusion score" is a measure of the extent to which communication is dispersed among all group members. If all members talked with each other, the score would be 100 percent, while a score of 0 percent would indicate that members only reported communicating with the grantee organization. Low diffusion scores do not necessarily indicate a problem. Low scores—especially early in the initiative—may indicate that the leadership team was large and so it needed more organized communication (such as in Ohio and California). In Maryland the leadership team was not initially constituted as a decision-making group; rather its main role was to advocate for issues and positions addressed by the grantee organization, which had a large advisory committee of its own. In this model, leadership team members mainly required contact with the grantee. Low scores may also indicate that the team had not yet had time to come together (such as in New Jersey).

State	CVC Network	Communication Diffusion Score (Percentage)	Agreement On Coalition Operations (Range: 1-5)
California	It's Our Health Care	46.1	4.3
Colorado	Colorado Voices for Coverage	100.0	3.6
Illinois	Health Care Justice Campaign—Health Care for All	65.7	4.3
Maine	Maine Consumer Voices for Coverage	72.3	4.1
Maryland	Maryland Health Care for All!	12.5	4.6
Minnesota	Minnesota Affordable Health Care for All	77.8	4.1
New Jersey	New Jersey Consumer Voices for Coverage	22.2	3.9
New York	Health Care for All New York	91.7	4.6
Ohio	Ohio Consumers for Health Coverage	44.6	3.7
Oregon	Consumer Voices for Coverage	73.5	4.3
Pennsylvania	Pennsylvania Health Access Network	85.7	3.3
Washington	Secure Health Care for Washington	68.7	3.6
Median		70.50	4.1

#### Table II.2. Communication Diffusion and Agreement on Operations in CVC Leadership Teams

Source: 2008 CVC Network Survey, Mathematica Policy Research.

As a broader measure of alignment, we asked survey respondents whether they agreed or disagreed with several statements about collaboration and decision-making, on a scale of 1 (strongly disagree) to 5 (strongly agree). We then created a composite measure of how the leadership team operated during the first six months of the grant, based on five survey items:

- Coalition leadership members willingly collaborate with one another on coverage issues
- The coalition leadership follows a set of agreed-upon principles for making decisions related to health coverage
- The decision-making process used by the coalition leadership is open and clear
- The coalition leadership members are forthright in their dealings with one another
- The coalition leadership's decision-making process on policy issues is timely

Despite the contrasts mentioned above in the degree of coordinated decision-making between the leadership teams in New York and Maryland, the teams in these two states reported the highest levels of agreement on leadership team operations, showing that different types of leadership styles can work in different environments.

## C. Leadership Teams Have Evolved Due to the Economy or Changing Policy Landscapes

Regardless of their prior history, all of the leadership teams have evolved in some way since CVC began. Some lost or gained members. One leadership team member in Colorado left the team, deciding it could more effectively pursue its agenda outside the leadership team structure. Illinois, Maine, New York and New Jersey all lost some team leadership members when member organizations experienced financial or other setbacks such as loss of staff and could not continue to participate. Some of these teams have been able to replace members; for example, Illinois, Maine and New Jersey were able to bring other key allies onto their teams (and, in fact, the teams in Illinois and New Jersey are now larger then when CVC began). The Health Care for All New York leadership team doubled from the original 8 members to 16.

Changing priorities have also led to changing leadership team structures. For example, Minnesota and New Jersey created separate leadership teams to focus on a specific state policy problem; the first team (the core CVC team) remains focused on state-level health reform. In Illinois, in response to the political environment and the economy, the leadership team divided into three subcommittees to focus on specific policy priorities, such as insurance reform.

In addition to changes in membership and structure, by late 2009 leadership team members reported that many of the initial challenges of working together had been overcome (Lipson 2009). In part this occurred because team members had needed time to work out decision-making and operating procedures. Teams also began collaborating in a more integrated way once they turned to addressing urgent state-level policy issues, described in the next chapter.

## D. Leadership Teams Were Useful but Presented Challenges

Mathematica will use data from a follow-up survey of leadership teams, planned for 2010, to assess changes in communication, decision-making and shared advocacy activities over time, as well as to measure relationships and communication patterns and their associations with network operations in comparison to the baseline assessments discussed here. These assessments will be combined with evaluation data from other sources to describe the strength of the leadership teams and their broader network, and the potential for sustaining their collaboration beyond CVC. Meanwhile, we asked participants for their impressions of the usefulness of requiring a formal leadership team structure, as part of the CVC program model.

**Participants believed the leadership team requirement was useful.** In discussions with us, leadership team members identified advantages of the leadership team mandate. It required the inclusion of a variety of participants with different skills and expertise, allowed participants to develop a shared agenda and gave them flexibility to pursue the right agenda for their state. According to one leadership team member, "It really created an opportunity for organizations to work together in a way that they hadn't coherently [worked together] in the past."

At the same time, some leadership team members noted that there were challenges to being on leadership teams. One challenge for leadership team members representing local chapters of national organizations (such as union groups, AARP, or disease-specific advocacy or research organizations) were not permitted by their national organizations to speak out on particular issues. When they spoke as leaders of their CVC networks, the media often misidentified them as speaking for their own organizations, or vice versa. This made it appear that the individuals had conflicts of interest, taking different positions than their CVC network or their national organizations.

Another challenge to working on the leadership team was creating-and keeping-cohesion among team members when their interests or goals differed. Some teams learned that, to keep the team functioning, they had to agree to trade-offs in the policy positions they championed, such as advocating for a general principle many groups could support (such as quality, affordable health care for all) versus specific approaches that were not supported by all leadership team members (such as a single-payer system or providing coverage for undocumented immigrants, which are controversial in some states). In our calls with leadership team members, some said they had adopted "agree to disagree" as an operating principle of their leadership team, so that disagreement would not prevent or derail progress. For example, one leadership team member noted that another leadership team member in the state was opposed to soliciting the state's teachers' union to support certain state health reform bills. Although the individual leadership team members differed on the issue, the entire team agreed that the organization that supported pursuing the teachers' union could do so independently and the leadership team could pursue other avenues of support the members agreed on. Members of this leadership team reported that this method of operating has not only allowed their CVC work to make progress on reform issues, but also built trust among the participating organizations.

Future advocacy coalitions might benefit from organizing help at the outset. Based on their experiences, some leadership team members said that if they were forming leadership teams today, they would recommend technical assistance at the outset on collaboration, including a review of different leadership styles, group organizing approaches and decision-making models. As one leadership team member noted, such advice at the beginning "...could help groups expedite or overcome the issues of how to work together."

# E. Beyond the Leadership Teams: Network Partners Included Traditional and Nontraditional Consumer Allies

To expand their advocacy capacity and influence, CVC leadership teams added other partners to their networks. Leadership team and grantee organizations reached out to some of their traditional allies to be part of their CVC coalitions. Eight of the 12 CVC networks reported that outreach to faith-based organizations was a main strategy. Half conducted substantial outreach to ethnic, cultural or immigrant groups. For example, the Oregon coalition formed many alliances with ethnic and intercultural groups to support its focus on equity in health reform. CVC networks also reached out to nontraditional allies. Seven CVC networks recruited businesses, especially small businesses, which became key partners in these states. For example, from the beginning of CVC, Secure Health Care for Washington focused on drawing small businesses into the network. Its efforts have led to the involvement of a large and diverse group of small business owners throughout the state, including development of a 2,000-member small business coalition.

The CVC leadership teams and grantees have also tried to find common ground with groups often opposed to consumer agendas, such as health care providers and private insurers. For example, in Ohio, the CVC network was able to gain the medical association's support for initiatives targeting insurance reform and creating 12-month continuous coverage in the Medicaid program. Leadership team members believed they were able to garner providers' support for two key reasons. First, providers supported the reforms for medical reasons; for example, 12-month continuous coverage leads to improved continuity of care. Second, providers realized that the CVC coalition was a worthy partner in the state on matters of health reform.

CVC coalitions realized that outreach to nontraditional groups could be difficult and may involve trade-offs. Partnerships with nontraditional groups were often limited to specific issues, because these nontraditional allies typically did not support the entire CVC agenda. For example, Oregon Consumer Voices for Coverage worked closely with a provider group that was very supportive of preserving programs (such as preventing cuts to Medicaid), but opposed immigrants' rights to health care. Some CVC states found it was worth forming partnerships when opportunities arose, as they increased the chances of consumer network voices being heard. However, where there was too little common ground even temporary, opportunistic partnerships were beyond reach. In addition some partnerships were simply viewed as unwise, since they risked diluting the consumer message or lending credibility to views or policies contrary to values articulated by the CVC networks.

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#### **III. STATE POLICY ISSUES ADDRESSED BY CVC NETWORKS**

When CVC grants were awarded, many states seemed poised to enact or expand comprehensive health insurance coverage programs and others showed promising progress toward similar actions. Yet, just two months before CVC funding started, the economic conditions states faced began to change dramatically. In December 2007, the United States entered a recession that still has not officially ended.<sup>9</sup>

The recession hit states hard. Revenues fell and the growth of state spending slowed in most states during fiscal 2008. By December 2009, a survey of state budget officers reported, "States are currently facing one of the worst, if not the worst, fiscal periods since the Great Depression" (National Governors Association and National Association of State Budget Officers 2009). Federal emergency funding provided through the American Recovery and Reinvestment Act of 2009 (ARRA), and additional Medicaid funding available from increased Federal Medical Assistance Percentage rates and the State Fiscal Stabilization Fund, helped states avoid draconian cuts to state services and maintain critical funding for education and health and human services. Yet, even with this assistance, states were forced to cut programs and raise some taxes and fees.

The downward fiscal trajectory closed the policy window in most states for state-supported comprehensive insurance coverage and strongly influenced the options facing CVC coalitions in 2008 and 2009. Most CVC networks found themselves defending against cuts to existing health and coverage budgets and programs, rather than advocating for expansions, as initially hoped.

In another dramatic change, the election of Barack Obama as president in November 2008 brought heath coverage reform to the forefront of the federal policy agenda. For much of 2009, and especially during the Congressional summer recess when representatives went home to their districts to hear from constituents, CVC networks became involved in federal reform.

This chapter describes the state-level heath-related policy issues that engaged CVC networks in 2008 and 2009. Although we cannot draw conclusions about the impact of CVC networks on policy outcomes, the data show that CVC networks were highly active in health insurance coverage and related policy discussions, adding the consumer's voice to important policy debates in their states. Two issues were top priorities as networks responded to fiscal constraints in their states: (1) defending cuts to public insurance programs and (2) supporting private insurance reforms that would expand coverage or choice, with all CVC networks addressing the latter (Table III.1).

<sup>&</sup>lt;sup>9</sup> The National Bureau of Economic Research (the official arbiter of recessions) declared in December 2008 that a peak in economic activity occurred in the U.S. economy in December 2007. The peak marked the end of the expansion that began in November 2001 and hence the beginning of a recession (*Wall Street Journal* 2008; National Bureau of Economic Research 2008).

	States												
Policy and CVC Position or Action	СА	со	IL	MD	ME	MN	NJ	NY	он	OR	РА	WA	Total
Cutbacks in Public Insurance Programs	x			x	x	x	x	x				x	7
Opposed cuts or premium													
increases	X			X	X	X X	X	X				X	7
Opposed privatization Reforms to Private						^							1
Insurance	x	x	x	x	x	x	x	x	x	x	x	X	12
Supported keeping young adults on parents' coverage			x					x	x	x			4
Supported reform or regulation	x		х	х	х		x	x		х	х		8
Supported rate reform		Х				х		X	Х	х	Х	х	7
Opposed premium increases					х					х			2
Expansions in Public Insurance		x		x		x	x	x	x	x	x	x	9
Supported coverage expansion for children		х				х		x		х		х	5
Supported reductions in premiums							x						1
Supported coverage													I
expansion for families or adults		x		x			x	x	x	х	x		7
Provision of		~								~	~		
Comprehensive Health Coverage and/or Health													
Care	x			x		x				x		x	5
Advanced specific proposal or plan				x		x							2
Set as goal	х									х		х	3
Supported Increases in Existing Coverage				x				x		x		x	4
Changes in State Revenue and Tax Policy		x			x								2
Supported new revenue sources to finance health													
care or coverage		Х			Х								2
Supported removal of revenue limits		x											1
Expansion or Protection of Health Care		x		x	x		x			x		x	6
Supported maintaining or increasing access to care		x		x			x			x		х	5
Supported consumer rights					х		_			-			1
Regulation of Provider Practices	x			x			x	x					4

Table III.1. State-Level Policy Issues Addressed By CVC Networks in 2008-2009

## A. CVC Networks Defended Existing Coverage

To plug budget gaps, governors proposed cuts or changes to state-supported public health insurance programs. Some states proposed increasing premiums to help sustain programs, but at the risk of pricing out some participants. Responding to such threats was a major focus for CVC grantees and networks during 2008 and 2009 (11 of the 12 networks defended against public insurance cuts); it may remain a major focus until state fiscal situations improve.

CVC networks helped build opposition to proposed state budget cuts or changes threatening public insurance programs. Minnesota Affordable Health Care for All opposed the redirection of \$250 million from the fund that supported MinnesotaCare, the state's Medicaid program, proposed by the governor to help cover the state's budget deficit. The amount ultimately redirected was \$50 million. The network also opposed attempts to privatize MinnesotaCare. In 2008, the California governor's budget proposed large cuts in the state's Medicaid program, Medi-Cal, which the CVC network (It's Our Health Care) opposed. The final budget included substantially reduced cuts. It's Our Health Care and other consumer advocates also objected to substantial Medi-Cal cuts proposed the following year that would have required a federal waiver to enact. Their opposition included outreach to federal policy-makers whose support would have been needed for the waiver.

Maine Consumer Voices for coverage advocated in 2008 to maintain Medicaid eligibility for single adults up to 100 percent of the FPL; eligibility was maintained. In 2007, Maryland Medical Assistance for Families had expanded Medicaid eligibility for adults up to 116 percent of the federal poverty level (FPL). In 2009, this expansion was threatened with major cuts, which Maryland Health Care for All! opposed. The cuts were eventually averted, although full funding for the expansion of benefits for childless adults was not included in the proposed budget. New Jersey Consumer Voices for Coverage advocated against cuts in the state budget to NJ Family Care, the state's Children's Health Insurance Program (CHIP). The proposed funding cuts were avoided. Secure Health Care for Washington advocated against enrollment cuts in the state's Basic Health Plan, a subsidized program to help make health insurance affordable to working people and others who lack health coverage. Enrollment was maintained, although the state enacted rate increases instead.

Networks also defended safety net medical care programs for children and adults. Secure Health Care for Washington opposed cuts in General Assistance Unemployable, a state-funded program that provides cash and medical benefits for people who are physically and/or mentally incapacitated, unemployable and ineligible for TANF, SSI or other types of assistance. Similarly, Minnesota Affordable Health Care for All opposed cuts to General Assistance Medical Care, a state-funded program for low-income adults, ages 21-64, who have no dependent children and do not qualify for federally funded health care programs. Cuts were averted.<sup>10</sup>

<sup>&</sup>lt;sup>10</sup> People enrolled when funding ends will automatically receive MinnesotaCare coverage. Counties will pay MinnesotaCare premiums for these enrollees until their next six-month renewal. When enrollees renew their eligibility, they will then have to pay their own premiums to keep their coverage.

Two CVC states opposed co-payments or premium increases for Medicaid. New Jersey Consumer Voices for Coverage challenged proposed Medicaid co-payments and defended previous eligibility expansions that had been threatened. Health Care for All New York opposed premium increases for a Medicaid buy-in program for working adults with disabilities as well as Child Health Plus premium increases. Both proposals were defeated.

Many cuts were reduced or averted, but threats to some programs continued. In Washington, the governor's 2010 budget again proposed eliminating the Basic Health Plan. Plans to end General Assistance Medical Care in Minnesota in 2010 remain an important focus of the CVC network's advocacy. With continued or worsening gaps between revenues and expenditures in many states, CVC grantees expect that efforts to maintain existing coverage will remain a high priority for their networks during the final year of the grant.

## **B. All CVC Networks Advocated for Private Insurance Reforms**

Besides resisting proposed health coverage budget and program cuts, CVC coalitions sought opportunities for proactive advocacy. Facing fiscal constraints along with shifting political environments in some states that reduced support for comprehensive state coverage plans, all CVC networks reported advocating for private insurance reforms during 2008 and 2009. Reforms were designed to expand coverage (usually to young adults), protect and improve choices for consumers, or reduce or control premiums.

**CVC** networks in Pennsylvania, Ohio, New York and Illinois supported options to keep young adults on their parents' coverage. Pennsylvania passed legislation to provide dependent coverage up to age 29; Ohio Consumers for Health Coverage supported enabling dependents up to age 28 to be covered by family health insurance policies at no cost to employers if they have been continuously covered. New York raised the age limit for coverage under parental insurance to 29 years. Illinois expanded coverage on parents' health plans for dependents up to age 26, or up to age 29 if the dependent met military service requirements.<sup>11</sup>

Networks advocated to reform practices, though progress was mixed. In California, It's Our Health Care advocated strongly for reforms to limit "junk insurance"—plans that provide minimum benefits and do not limit out-of-pocket expenses. Lawmakers also proposed to split private health plans into defined tiers for easier price comparisons. These reforms, introduced in legislation in 2008 and 2009, did not pass.<sup>12</sup> Reforms were also proposed to the state's high risk pool, such as eliminating annual benefit caps, preventing emergency physicians without contracts with a patient's insurer from directly billing the patient, setting a minimum medical loss ratio and requiring insurers to spend a fixed percentage of premiums on patient care. The CVC network had advocated

<sup>&</sup>lt;sup>11</sup> While the legislature rejected the policy, Governor Blagojevich enacted it through veto powers (an "amendatory veto") that allows the governor to change the wording, but not the fundamental purpose, of a bill; Illinois is one of six states whose governor has such a veto power.

<sup>&</sup>lt;sup>12</sup> The reforms were originally part of Governor Schwarzenegger's health care expansion proposal, which failed to win approval in the state senate in 2007.

for such reforms, which were contained in legislation passed by the state assembly and senate but vetoed by the governor. However, California's CVC network also supported a package of private insurance reforms and consumer protections that were signed into law in 2009, including imposing insurer penalties for improper rescissions (retroactive cancellation of approved insurance coverage), preventing direct patient billing by emergency departments without insurance contracts and outlawing bonuses to insurance company employees for rescissions.

In Illinois, a bill to reform the private insurance market by requiring guaranteed issue, adjusted community rating, limitations on exclusion for pre-existing conditions, increased transparency for insurers and targeted reinsurance to low-income people and small businesses—all policies supported by the Health Care Justice Campaign—was considered by the legislature in 2009, but only a watered-down version that excluded reforms such as providing guaranteed issue (health insurance plans that are available to people who do not qualify for standard full coverage major medical insurance such as due to pre-existing conditions) and community rating (charging a common premium to all members of a heterogeneous risk pool who may have widely varied health spending) was passed and signed by the governor in January 2010. Maryland passed reforms in 2009 supported by Maryland Health Care for All to limit exclusions for preexisting conditions for policies sold on the individual market. New Jersey legislation passed in 2008 (S1557) expanded Medicaid eligibility but also allowed insurers in the individual market to vary premiums by age only instead of community rating. The CVC network opposed this part of the legislation, then advocated for adding a rate band to protect older consumers, which was added to the legislation and so softened the change.

Health Care for All New York supported legislation to expand eligibility for COBRA from 18 to 36 months for those who lost jobs or had a reduction in hours, and to improve consumer protections for enrollees under managed care plans. While these reforms passed, legislation to restore the authority of the state's Department of Insurance to approve health insurance premium rates was not successful in 2009, but passed in 2010. In recognition for their work on these heath insurance affordability and access issues (including the extension of coverage under parental insurance mentioned above), representatives of Health Care for All New York were invited to attend and speak at the bill-signing ceremony. The Pennsylvania Health Access Network supported legislation to implement payment reforms and modest COBRA expansions (to businesses with fewer than 20 employees), which passed in Pennsylvania. In 2008 they also supported reforms to the small group market embodied in HB 2005, a bill that passed in the state House but died in the Senate.

CVC Networks in Maine and Oregon campaigned strongly for transparency and other reforms. Making it easier for consumers to understand and compare the features, costs, and quality of health coverage plans was a goal for several CVC networks. Maine and Oregon Consumer Voices for Coverage gave priority to this issue. In Maine, transparency reforms supported by the network and enacted in 2009 required insurance companies to post top-selling individual and small business plans on an accessible website and make documents supporting proposed insurance rate hikes available to the public. The reforms required the Superintendant of Insurance to conduct examinations of health insurance companies at least every five years and also allowed the Superintendant to require companies who offer insurance plans to small business to standardize their plans, to facilitate comparisons. Under the reforms, the Maine Health Data Organization and Maine Quality Forum were directed to link health care cost and quality data in a format consumers

could use when purchasing health care services. In Oregon, stronger standards for insurance rate reviews included in HB 2009 required more disclosure of health insurance company administrative expenses, such as salaries, broker commissions, and advertising expenses. The law requires insurers to make rate request information available to the public, in addition to providing a public comment period on insurance rate requests.

Some CVC networks supported efforts to deny or limit increases to insurance premiums. Colorado legislators approved requiring insurers in individual and small group markets to submit annual data for rate reviews through the FAIR (Fair Accountable Insurance Rates) act. Components of the bill embodied policies strongly supported by Colorado Voices for Coverage, including authorization for the insurance commissioner to disapprove excessive or substandard rates and outlining the standards for evaluating rates. Pennsylvania Health Access Network supported unsuccessful efforts to give the state's insurance commissioner more authority to regulate health insurance rates, while new legislation in Washington authorizes the state's insurance commissioner to review premium increases in the individual insurance market for approval. In Oregon and Maine, the CVC networks advocated against proposed private insurance rate hikes; Oregon subsequently approved rate increases of 26 percent in 2008 and 14.7 percent in 2009, while in Maine the rate hike was denied and Anthem Blue Cross/Blue Shield filed a lawsuit to overturn the denial.

#### C. Some States Expanded Public Insurance Programs

Despite states' fiscal difficulties, opportunities did arise to expand public health insurance programs, mainly through funding available as part of several federal initiatives. For instance, under ARRA, the minimum Federal Medical Assistance Percentage rate was temporarily increased from 50 percent to 56.2 percent for FY 2009 and 2010.<sup>13</sup> The increase stimulated several states to consider or enact expansions in Medicaid eligibility. Reauthorization of CHIP in 2009 provided new funding for covering children and pregnant women through the program. CVC networks in nine states actively supported these expansions.

Six CVC states expanded coverage for children or cut premiums. Colorado Voices for Coverage supported expanding CHIP eligibility to children and pregnant women with family incomes up to 225 percent of the FPL, increased from the previous cutoff of 205 percent. The expansion was approved in 2008 but not funded. However the Colorado Health Care Affordability Act, passed in 2009, expanded Medicaid eligibility for children and pregnant women to 250 percent of the FPL. Minnesota's Make Health Happen network supported Cover All Kids, designed to remove barriers to public health care programs for children in Minnesota and expand access to MinnesotaCare, a subsidized health care program for state residents who do not have access to health insurance.

<sup>&</sup>lt;sup>13</sup> For information on the actual federal share for each state in 2009 and 2010 see, for example, [http://www.statehealthfacts.org/comparetable.jsp?ind=184&cat=4].

Oregon and New York expanded coverage to all children. Oregon extended coverage to 80,000 uninsured children under age 19 in families with incomes up to 200 percent of the FPL through Oregon Healthy Kids, making Oregon one of 12 states with universal coverage for children. A private market component, Healthy KidsConnect, offered low-cost coverage on a sliding scale for families with incomes up to 300 percent of the FPL; coverage at full cost was available for families with higher incomes. Similarly, New York expanded eligibility for the Child Health Plus program to virtually all children in the state in 2008. Coverage is offered on a sliding scale. Families with incomes less than 160 percent of the FPL pay nothing for the coverage, while others are offered coverage on a sliding scale. Those with incomes greater than 400 percent of the FPL can buy in by paying the full premium. Combined with Children's Medicaid, this made coverage available to all children in the New York. Secure Health Care for Washington supported successful proposals to keep children's health for Kids. In its 2009 state budget, New Jersey eliminated all premiums for Medicaid for children below 200 percent of the FPL, with active support from New Jersey Consumer Voices for Coverage.

Two of the states that expanded coverage for children plus Maryland, New Jersey, and Ohio expanded coverage for adults and families. The Colorado Health Care Affordability Act expanded Medicaid eligibility for children and pregnant women to 250 percent of the FPL, and for parents and childless adults up to 100 percent of the FPL. In addition, it provided a buy-in for children and people with disabilities to 400 percent of the FPL. The act also provided continuous eligibility for children on Medicaid. In 2009, the state removed waiting periods for both Medicaid and CHIP for legally present immigrants. Oregon supported the House Bill 2116, passed in 2009, which expanded coverage for uninsured children and low-income adults.

The Maryland CVC network advocated for expanding Medicaid eligibility for those aging out of foster care, a policy adopted by the state in 2009. New Jersey Consumer Voices for Coverage advocated for raising the income eligibility limit for New Jersey Family Care, the state's Medicaid program, from 133 to 200 percent of the FPL. This was part of a 2008 bill that also mandated that all children obtain health care coverage. The CVC network proposed a hardship amendment to this requirement, which also became law. Ohio Consumer Voices for Coverage supported a budget bill that extended the time period between recertification for Medicaid from 6 months to 1 year, a change expected to keep 100,000 parents on Medicaid.

Not all expansion efforts have succeeded (yet). In 2008, the Pennsylvania Health Access Network advocated for an expansion of adultBasic, a limited benefit health insurance program funded through Pennsylvania's settlement with the tobacco companies and contributions from the Pennsylvania Blue Plans, which had been signed into law and funded by tobacco settlement funds in 2001. A bill to enact the expansion was withdrawn from consideration in the state senate. HB1, which would permit 85,000 low-income adults to buy subsidized health insurance at low monthly premiums, passed in the state's house, but was never acted on in the senate. In 2008, the Health Care for All New York network supported the governor's 2009-2010 budget provision to expand Family Health Plus. This program is for adults with incomes too high to qualify for Medicaid and covers those with children up to 150 percent of the FPL and single adults and childless couples up to 100 percent of the FPL. The budget proposed submitting a federal waiver to cover adults with

incomes less than 200 percent of the FPL, which the state legislature approved, though federal approval is still pending.

# D. Five CVC Networks Helped Keep Comprehensive Reforms on State Policy Agendas, Despite a Harsh Economy

Changes in state political environments and increasing fiscal constraints ended promising initial scenarios for comprehensive coverage in CVC states such as California and Pennsylvania. In addition to being slowed by the recession, some states adopted a "wait and see" attitude toward comprehensive coverage during and after the presidential campaign, anticipating possible federal reform. Despite these conditions, five states made progress toward comprehensive coverage.

In Maryland and Minnesota, CVC networks kept or placed comprehensive coverage on the states' policy agenda. Maryland Health Care for All! released its Health Care for All plan in November 2008. Designed to give every adult resident access to affordable insurance coverage, the plan also covers all children. It was to be financed by a 2 percent payroll tax and increases in alcohol and tobacco taxes, though this approach may be modified in response to federal health care reform provisions). To implement the plan, lawmakers introduced the Health Care Affordability Act in the 2009 legislative session and considered it in the summer of 2009, but did not take action on it then. Minnesota Affordable Health Care for All developed a plan for universal coverage that was included in the Minnesota Health Security Act of 2009. The first phase of the plan would provide health coverage to all children by the middle of 2010 without co-payments or premiums. A second phase would ensure access to coverage for adults by 2012 and hold costs to no more than 5 percent of family income. By the end of 2009, the act had been passed by two state house health committees.

Three networks supported establishing a structure for broad health care reform or setting it as a goal. Oregon Consumer Voices for Coverage supported advocating for delivery system reforms and cost containment and setting a timeline and specific steps to achieve health coverage for all by 2015 through an insurance exchange, a public option and an essential benefits package. These reforms were embodied in HB 2009, the Health Authority Law, which was passed and signed into law in 2009. The law provides for assessments on health insurance premiums and a hospital tax to fund health care coverage for 80,000 children (as mentioned above) and 35,000 lowincome adults. It includes a blueprint to pursue future health care reforms including costcontainment mechanisms, uniform statewide standards for quality, a focus on preventive care and evidence-based medicine, ensuring a sufficient health care workforce and stronger standards for reviewing insurance rates and proposed rate increases. It's Our Health Care in California also urged policy-makers to set goals for health care and coverage reforms. In 2009, legislation was introduced requiring the state's Department of Health and Human Services to develop a plan for broad-based reforms to the state's health care system, including reforms supported by It's Our Health Care, for presentation to the state legislature in 2010. It was passed by the health committee and moved on to the appropriations committee, where it remained through the end of 2009. Finally, Secure Health Care for Washington supported Cover Everyone by 2014, 2009 legislation that asked lawmakers to establish the goal of working in cooperation with the federal government to secure quality, affordable health care for all Washingtonians by 2014. The law also directed the state to apply for a Medicaid waiver to cover all adults up to 200 percent of the FPL.

In addition to setting comprehensive reform goals, three CVC states increased health care or insurance benefits (though on a small scale) and one provided coverage for a new group, moves supported by the CVC networks in these states. New York increased funding for mammograms and colon screening for certain uninsured groups in 2009, while Maryland added prescription drug benefits for some groups. Through a variety of bills, Oregon added coverage for hearing aids for children, human papillomavirus vaccine for females between age 11 and 26, medically necessary evidence-based telemedicine services, routine costs of care in qualifying clinical trials, smoking cessation programs (for certain insurers), and medically necessary treatment for traumatic brain injury. In Washington, the CVC network had advocated strongly for establishment of the Health Insurance Partnership, an exchange to subsidize health insurance for employees of small businesses. The program was adopted in 2008 but not funded due to state budget shortfalls. However, in 2009 the state obtained funding for the program through a State Health Access grant from the U.S. Department of Health and Human Services.

Maine and Colorado networks focused on tax and revenue policies affecting their states' capacities to fund coverage programs. In 2008, Maine Consumer Voices for Coverage supported a new beverage tax to replace the Savings Offset Payment, an assessment of insurance companies that financed their Dirigo Choice Health Insurance Plan. Dirigo Choice is designed to help small businesses and employers with fewer than 50 employees, the self-employed and individuals afford health coverage. However, the beverage tax was later repealed by a ballot initiative strongly supported by the beverage industry. Colorado Voices for Coverage supported the elimination of sales tax exemptions on cigarettes and vending machine foods, and opposed the use of tobacco funds for non-health purposes. To more broadly address state revenue limitations, it advocated for repeal of Arveschoug-Bird spending limits passed by the state legislature in 1991 capping growth in the state's general fund. The limits were repealed in 2009, allowing the possibility of expanding public spending on health or other needs—an important intermediate step toward the coalition's long-term strategy to expand health coverage.

## E. Networks Also Addressed Access to Care and Provider Regulation

CVC networks not only focused on health coverage but also addressed broader health care issues that affected consumers. Maine Consumer Voices for Coverage supported a health care bill of rights, which passed into law (LD 1205) in 2009. Among other provisions it required insurance companies to provide more and better information in explanation of benefit documents that accompany payment or denial of insurance claims, and allowed the state's Bureau of Insurance to review possible ways to improve insurance availability and affordability for those who buy insurance in the individual market. It initially contained a requirement that insurers spend at least 85 cents of each dollar collected from premiums on health care, but this provision was removed before passage of the legislation.

In Colorado, Maryland, New Jersey, Oregon and Washington, the CVC networks supported policies to maintain or improve access to health care. In 2009, Colorado Voices for Coverage advocated against proposed cuts in funding for community health centers; although cuts ultimately occurred, they were less severe than initially proposed. Maryland Health Care for All! advocated for increased access to dental care for Medicaid-eligible children. An arm of the grantee organization drafted legislation to enact such increases, which was passed and signed into law in 2008. New Jersey Consumer Voices for Coverage supported establishment of a working group to address barriers to access for immigrant and minority groups and efforts to establish a medical home demonstration project in the state. Senate Bill 862, passed and signed into law in Oregon in 2009, established a limited number of community based health care programs to improve access to care for the uninsured. Early in the grant period, the Secure Health Care for Washington network led efforts to improve access to insurance and care for non-English speakers through provision of language assistance. In 2008 and 2009, the network built momentum for reforms requiring insurance companies to reimburse hospitals and other providers for translation services, and urged passage of language access legislation in the state.

Four CVC networks pursued reforms affecting providers. Policies they supported included requiring providers to offer free or reduced-cost care (i.e., charity care) to uninsured low-income residents or improvements in patient safety. For example, the Maryland network supported two laws that passed in 2009, one mandating charity care for hospital patients with incomes below 150 percent of the FPL and another requiring better data on hospital quality and costs and transparency in hospital charity care. The New Jersey CVC network advocated for a medical errors bill, also passed in 2009, requiring public reporting of patient safety indicators and prohibiting providers from charging patients for medical errors. New York supported strengthening charity care standards and increasing the state's charity care funding pools, while the California network supported legislation to increase fees on hospitals.

#### IV. HOW CVC NETWORKS PURSUED THEIR POLICY GOALS

Advocacy seeks to influence public policy by informing, educating and influencing the public, as well as agenda-setters and policy-makers. Effective consumer advocacy on health policy requires the analysis and development of policy alternatives, outreach to media and grassroots organizing, along with strong communications capabilities. Like other interest groups, advocates also interact directly with policy-makers as part of their advocacy campaigns—such as attending public hearings or meeting with legislative staff.

The CVC initiative was designed to enhance the capacity of CVC grantees and networks to conduct these activities—especially policy analysis and media outreach. Community Catalyst provided policy expertise and advice tailored to each state's needs. Grantees could also call on consultants under contract to Community Catalyst or the Foundation for help with messaging, media and communications, including Web site design. Community Catalyst advised the networks on advocacy strategies and approaches. The activities CVC networks pursued probably reflect (1) the tools available to them (for example, a network with partners strong in grassroots outreach would likely emphasize that strategy); (2) their perceived strengths; (3) their environmental context (both political and economic); and (4) what they thought they could reasonably achieve, given their resources and constraints.

Just as CVC grantees and leadership teams took different approaches to building their networks, the networks had different emphases and approaches to advocacy and received unique contributions from their members. As CVC got underway in 2008, grantees and other leadership team members ranked their organization's three most important roles for CVC. Across all leadership teams, most named grassroots organizing as their most important advocacy role on the leadership team (Table IV.1). They ranked their contributions to media and communications least important. Participants may have felt their organizations lacked capacity to conduct communication and media outreach. During interviews and focus groups in 2009, CVC participants from several states said that media and communications had been their weakest skills as CVC began (and, some believed, their most improved by 2009).

This chapter describes the advocacy activities undertaken by CVC networks during 2008 and 2009, with an emphasis on activities that were targeted to state-level issues.<sup>14</sup> The chapter is not a full catalogue of all the activities conducted by each CVC network and we have not assessed or compared the effectiveness of particular advocacy approaches. Rather, it describes the types of activities undertaken and provides examples to illustrate common activities and differing approaches.

<sup>&</sup>lt;sup>14</sup> Most of the data for this chapter were extracted from the status reports grantees file on a regular basis with Community Catalyst, with some additional details obtained during the semistructured telephone interviews conducted with grantees in 2009.

	Perceived Impo	ceived Importance of Organization's Role in CVC Coalition's Activitie				
Coalition	(Ranked from 6 [Highest] to 1 [Lowest])					
	Grassroots Support	Policy Analysis	Campaign Implementation <sup>a</sup>	Media and Communications		
California	3.9	4.4	3.8	3.2		
Colorado	3.5	4.0	4.0	2.5		
Illinois	3.9	4.0	4.3	3.0		
Maine	3.6	3.5	3.2	4.3		
Maryland	4.7	3.3	4.0	2.0		
Minnesota	4.7	4.7	3.5	2.0		
New Jersey	5.0	3.0	4.0	3.2		
New York	3.3	4.4	4.3	2.6		
Ohio	4.7	4.2	3.8	3.1		
Oregon	5.1	4.3	2.6	3.1		
Pennsylvania	5.4	2.4	3.4	2.0		
Washington	3.5	4.6	4.4	3.0		
Cross-site						
median	4.3	4.1	3.9	3.0		
Cross-site						
maximum	5.4	4.7	4.4	4.3		
Cross-site						
minimum	3.3	2.4	2.6	2.0		

Table IV.1. Leadership Team Organizations' Contributions to Advocacy Activities, at Baseline (2008), by Site

Source: 2008 CVC leadership team network survey, Mathematica Policy Research.

Notes: Individual respondents; N = 105.

<sup>a</sup>Campaign implementation includes contacts with policy-makers as well as other advocacy activities.

# A. Policy Analyses Ranged from Legislative Fact Sheets to Complex Coverage Plans

Conducting legal and policy analysis and research is one of the core advocacy capacities the CVC initiative supports and develops. This includes the ability to (1) analyze complex legal and policy issues, (2) conduct research and (3) develop winnable policy alternatives (Community Catalyst 2006). During the first two years of the initiative, CVC grantees engaged in a range of policy analytic activities of all three types.

Grantees and their partners produced quick-turnaround analyses. All CVC grantees reported analyzing and scoring state budget proposals, examining the impact of proposed legislation on consumers, and developing and circulating one-page fact sheets or talking points on policies, legislation, or proposed budget cuts. Most grantees had someone on staff who performed these quick analyses. When additional depth or expertise was needed, grantees sometimes turned to other leadership team members or to nonprofit law and advocacy organizations for assistance. Leadership team members often circulated fact sheets on health care topics to one another's constituencies to stimulate awareness and action.

Less frequently, CVC networks also responded to requests from policy-makers or media representatives for information or analysis. For example, when federal health reform was being debated, congressional staff members sometimes sought information from grantees on how federal reform might affect the state or consumers.

**CVC** networks also collected and analyzed data, or produced or commissioned in-depth reports. The Colorado and New Jersey networks conducted research on insurance affordability to inform and educate legislators and consumers. Because they hoped to bring small businesses on board with other consumers supporting coverage reform, CVC networks in Maine, Ohio and Washington surveyed small businesses to learn about their insurance coverage, needs and perspectives on reform. Several CVC networks published or helped sponsor reports on health insurance costs and practices. Advocates in Maine authored *A Call to Action on Health Care Reform in 2009: The Transparency Imperative*, a white paper they used to launch a campaign for greater transparency. New York's CVC grantee, The Community Service Society, reviewed state data on insurance quality and literature on racial and ethnic disparities in health outcomes, along with interviewing state officials, health plan representatives, and experts to produce two policy briefs on promoting equity, coverage and quality in the state's public insurance programs (Benjamin and Garza, 2009 a and b). The New Jersey Consumer Voices for Coverage grantee and leadership team funded "State Practices in Health Coverage for Immigrants: A Report for New Jersey," a report produced by the Center for State Health Policy at Rutgers University (Rosenthal 2009).

**CVC** grantees and network members developed policies and helped draft legislation. For example, several networks developed legislation addressing insurance reform (Minnesota, New York, and Washington) and transparency (Maine). Minnesota Affordable Health Care for All developed a plan for universal coverage that was included in the Minnesota Health Security Act of 2009. The Maryland Citizens' Health Initiative Education Fund (the CVC grantee) developed a detailed plan to finance and provide comprehensive coverage to adults and children in the state. It was released in 2008 and gathered key endorsements, then introduced in the 2009 legislative session through the Health Care Affordability Act.

## B. Networks Used Traditional and New Media

**CVC** networks emphasized different media approaches and honed their media skills to varying degrees. California aimed for a 'big media footprint' in the state to circulate its messages. Colorado emphasized writing letters to the editor and op-ed pieces, but after two years felt its capacity for working with the media still needed strengthening. In contrast, participants in Illinois felt their media capacity had grown the most of all the advocacy capacities since the beginning of CVC. They worked closely with The Herndon Alliance to develop a messaging strategy and increase their visibility.<sup>15</sup> The Maryland Citizens' Health Initiative maintained a constant agenda of media events and publicity, sometimes featuring high profile athletes or other well-known figures to call

<sup>&</sup>lt;sup>15</sup> The Herndon Alliance is a nationwide nonpartisan coalition of more than 200 minority, faith, labor, advocacy, business and health care provider organizations. It provides polling research and communications consulting.

attention to policy accomplishments or convey key messages. Ohio used its grassroots network to generate coverage in local media, including placing editorials and op-ed pieces in local newspapers.

**CVC** networks sought to inform and influence the public, policy-makers and agendasetters through traditional media. Outreach to traditional media included providing editorial background and content, developing earned media (favorable publicity gained through promotional efforts) and producing public service announcements. Two grantees reported producing videos or using paid advertising. In addition to strengthening this outreach, grantees also began making better use of their Web sites and some experimented with new media.

To influence or obtain editorial coverage, CVC networks held press conferences, sometimes in conjunction with groups such as AARP or with legislators. Five grantees reported meeting with editors or editorial boards. CVC networks also urged their constituents to submit letters to the editor. The Illinois grantee, Campaign for Better Health Care, implemented an online "letter to the editor builder" to help consumers draft and send individualized letters. In California, Maine, Oregon and Illinois, CVC funds helped provide media training to advocates, organizers, or grassroots participants to enable them to improve their outreach to the media and responses to media inquiries.

CVC participants also described their efforts to obtain earned media. Grantees and network members wrote press releases and media advisories, and often revised their media lists to ensure distribution to reporters currently on the health care beat. They updated their lists of media outlets and expanded them to include Spanish language or other media targeted toward particular ethnic or cultural groups. Grantee and network representatives participated in radio and television interviews and panel discussions. To gain media coverage, California CVC network members and their allies organized rallies and protests against proposed cuts in the state budget. Ohio Consumers for Health Coverage held a rally at the statehouse calling for the governor to make health care reform a top priority for his administration. In Oregon, the network coordinated the 100 Days Campaign and Health Action Day to advocate for health reform at the state capitol. In the "March for Health Care for All: Mothers Leading the Way" organized by the Washington Community Action Network, 5,000 people marched and rallied to support health insurance reform. In Illinois, consumers Honked for Health Care and participated in Take Action Tuesdays, and the network produced public service announcements. TakeAction Minnesota produced a video to show the impact on consumers of proposed budget cuts. Health Care for All New York held a day-long public hearing in the state capital with testimony from consumers they bused in from across the state.

**Grantees explored new media as well.** In addition to taking advantage of traditional media, some CVC grantees also used Twitter, Facebook, SocialVibe, or other new social media to quickly inform consumers or the public about policy developments, sometimes "scooping" traditional media. New media approaches were also used to advocate, raise money, or rally the grass roots.

Through support provided by CVC, grantees were able to launch or improve Web sites devoted to their organizations or CVC networks and campaigns. Most grantees worked with a consultant provided through CVC to update or redesign their Web sites, including adding blogs on which CVC project directors and others could comment on current policy debates or issues at the state and federal level. For example, the director of Health Access, the California grantee, set up a daily blog focusing on health care and coverage; the blog includes links and videos to heighten its impact and engage readers (see <u>www.health-access.org</u>). The Washington Community Action network provides information on Secure Health Care for Washington and features a health care blog on its Web site (<u>http://washingtoncan.org/wordpress/</u>), as do the Pennsylvania Health Access Network (<u>http://www.pahealthaccess.org/blog</u>) and Health Care for All New York (<u>http://www.hcfany.org</u>).

#### C. Grassroots Organizing Expanded Under CVC

The financial support provided through CVC enabled grantees to engage, organize and train grassroots people or groups, often for the first time or on a larger scale than before. Grantees described the direct and indirect approaches to grassroots organizing or field work they implemented—some of which stood out as distinct. However, for some networks, particularly those that were newly formed, grassroots organizing was not yet a high priority.

**CVC** grantees organized various events to recruit grassroots volunteers. Events intended to engage the public, such as rallies and protests to fight state budget cuts, also helped attract media attention by increasing awareness about health care or coverage issues and the need for reform. A faith-based CVC partner in Minnesota—ISAIAH—attracted some 4,000 people to Time to Believe: Faith in Democracy, a 2008 gathering in St. Paul where speakers addressed poverty, immigration reform, health care and other social justice topics.<sup>16</sup> The New York Immigration Coalition, funded through the CVC grant to the Community Service Society, held a rally in New York City for immigrant inclusion in health care reform. In March 2009, Illinois's Campaign for Better Health Care held Sound the Alarm for Health Care Justice, inviting congregations across the state to join together in prayer, to "sound the alarm" with a horn, bell or other instrument, or to send notes asking legislators to enact health care reform.

Conferences, retreats and documentary screenings also promoted both awareness and engagement in health coverage. The Pennsylvania Health Access Network organized a Getting Everyone Involved conference in March 2009. It brought together policy-makers, advocates, business owners and citizens to prepare them for advocacy supporting state and national health care reform. In October 2008 and again in 2009, Maine Consumer Voices for Coverage held policy retreats; in December of that year the New Jersey grantee held a similar retreat for its leadership team, and the Colorado grantee held a conference to discuss policy. CVC networks in Illinois, Minnesota, New Jersey and Pennsylvania brought groups together for screenings of documentary films as a way to stimulate discussion of the need for health care reform or broader social justice goals. Several grantees reported screening *Unnatural Causes*, a PBS documentary on socioeconomic and racial inequities in health that was first broadcast in spring 2008 and subsequently released on DVD (http://www.unnaturalcauses.org/video\_clips.php). A second PBS documentary, *Critical Condition*, described the struggles of four critically ill but uninsured Americans. It premiered September 30, 2008 (http://www.pbs.org/pov/criticalcondition/). The Deadliest Disease in America, a

<sup>&</sup>lt;sup>16</sup> ISAIAH is a nonprofit coalition of 90 congregations from various faith traditions working in the Minneapolis, St. Paul and St. Cloud regions and focusing on racial and economic justice. It is one of 60 similar organizations around the country affiliated with the Gamaliel Foundation in Chicago.

film about people experiencing racism when seeking medical care, included workshops aiming to reduce barriers in access to health care (<u>http://www.urutherighttobe.org/disease/deadliest.php</u>).

Grassroots participants received training on health care and coverage issues, advocacy skills, organizing and leadership. The Washington Community Action Network held health care parties to train local leaders. The network trained roughly 300 grassroots leaders on public speaking, organizing and campaign-building, along with giving them background education on health care issues. Health Care for All New York provided advocacy training on health care reform for people with disabilities and serious illnesses so that they could advocate with policy-makers. They also broadened the reach of advocacy by hosting "train the trainer" sessions on health reform and fundraising. Oregon Consumer Voices for Coverage also used "train the trainer" approaches.

Several organizing strategies stood out as distinct. The Illinois Campaign for Better Health Care organized congressional district committees to function as "local engines of advocacy." Networks of volunteers worked in each district on both state and federal reform and policy issues. These district committees fed into regional working groups, and the regional groups in turn fed into the steering committee, creating a well-organized hierarchy to coordinate advocacy. Minnesota's organizing approach targeted four geographic areas in the state. TakeAction Minnesota recruited participants through events and its Web site, assessed volunteers' interests, created "citizen teams" that shared interests and priorities and tailored activities to the interests and needs in each area. In 2009, the teams met with legislators for research visits in which team members asked the legislators questions about specific issues or views as a way to establish relationships with them. TakeAction Minnesota used the interview strategy as a comfortable way to open a conversation, to help relieve volunteers' anxieties about how to advocate. The Washington Community Action Network sent organizers into communities across the state to canvass for members, and operated phone banks to conduct outreach from its offices in Seattle. Memberships provided ongoing financing for the organization. In addition to maintaining this ongoing organizing strategy, Secure Health Care for Washington solicited grassroots participation by small businesses as a counterweight to the business lobby they felt often stifled reform. They hired a small business owner from the Pike's Place Market shopping area to lead these organizing efforts. By mid-2009 the small business coalition had grown to around 2,000 members across the state.

**Some CVC networks focused less on grassroots organizing.** In states with new leadership teams, such as Colorado and New Jersey, field work took a back seat to more urgent priorities, such as creating cohesion among leadership team members or responding in other ways to policy issues or opportunities that arose early on. In California, the grantee organization had reduced the number of organizers to 3 from a high of 10 in 2007, when state-based health coverage reform was high on the governor's agenda. The Maryland grantee focused mainly on obtaining endorsements for its health care plan; a key strategy was paying organizers based on the number of endorsements they obtained.

In some CVC networks, grantees added partner organizations that represented grassroots groups, rather than doing direct grassroots recruiting and organizing. Grantees and leadership teams reached out to organizations representing low-income, immigrant, cultural, or other groups. Some CVC networks took both approaches—engaging faith-based, business, immigrant, or other organizations when possible and also directly engaging individuals.

#### D. Networks Coordinated Campaigns to Reach Policy-Makers

CVC networks conducted or coordinated three main types of additional activities to advance the consumer's perspective. First, they brought real-life consumer stories to the forefront. Second, they gave talks or presentations to groups on both sides of the issues. Third, they communicated directly to policy-makers through multiple channels. These efforts intensified when federal reform debates moved to the states in 2009.

Grantees used people's stories to highlight their message. An important campaign tool to humanize the complex health care debate and to counter the emotional appeal of arguments opposing expanded coverage was storybanking-collecting personal, real-life stories that illustrate the effects of poor health care or coverage, or the difficulties of navigating the private insurance market. Most CVC grantees solicited such stories in the course of other activities, such as operating helplines, to find people who could tell compelling stories to the media or in public hearings or other venues. With a storybank, grantees could select interviewees or stories tailored to specific issues or requests. New Jersey Citizen Action published a booklet of such stories to garner support for reform. The Washington Community Action Network also collected stories from people of color about the financial, geographic and language barriers they encountered to accessing medical care. One member of the Network, who lost his mother due to the lack of health insurance coverage told his story at a rally organized by the Washington Community Action Network. Federal legislators and the media heard this story at the rally and disseminated it widely. President Obama referenced the story on television at a bi-partisan Health Care Summit held by the Obama administration in February 2010 and invited him to the signing of the Patient Protection and Affordable Care Act at the White House on March 23, 2010. Health Care for All New York invited visitors to its Web site to "share your story" by filling out an online story form (operated via Survey Monkey, free online survey software) indicating (1) the types of issues involved, such as delaying or not receiving medical care due to a lack of insurance; and (2) whether Health Care for All New York could use the story for various audiences and circumstances. The Washington Community Action Network's "Web Action Center" (at http://www.washingtoncan.org/action/) allowed Web site visitors to share a health care story, as well as write letters to the editor or send e-mails to lawmakers addressing current policy issues.

Networks presented consumer perspectives to multiple audiences. The Maine grantee set up a speakers' bureau and trained members to use common ideas and language to discuss health reform. Grantees and other network members in Colorado, Maryland, Minnesota, New Jersey, New York, Ohio, Oregon, Pennsylvania and Washington gave presentations and briefings or held forums on affordability, language access, or other health care issues. Network members in these and other CVC states gave presentations to chambers of commerce, labor groups, faith-based groups and other associations, and served on panels addressing issues facing working families or other topics. CVC supporters attended meetings sponsored by organizations representing traditional or potential consumer allies, such as faith-based, ethnic and immigrant or civil rights organizations. They also took advantage of opportunities to join meetings with health care industry groups or other interest groups.

Campaigns included direct contacts with policy-makers. Grantees and other CVC participants, including grassroots activists, attended or testified at budget or legislative hearings.

Grantees sent issue alerts or "blast e-mails" to their allies and grassroots members and volunteers when action was needed on specific issues. These alerts generated phone calls, e-mails, letters, postcards, and other contacts with policy-makers. Network leaders and key members met with policy-makers to present information and participate in discussions. At the state level, they often met with legislators, and sometimes with governors, their staff members, or insurance commissioners. As health care reform moved through Congress, CVC grantees and others became engaged with their congressional representatives, especially with staff members who were focused on health reform. They provided information, discussed positions taken by consumer organizations and responded to requests from staff soliciting feedback or information on specific topics. When federal legislators returned to their states in the summer of 2009 to hear from their constituents about health care, CVC networks helped turn out organization members and grassroots participants at town hall meetings to support reform.

**CVC grantees and networks became involved in federal health care reform.** When health care and coverage moved to the forefront of the policy agendas of the Obama administration and Congress in early 2009, it was natural for CVC participants to become involved. As described in Chapter II (see Figure II.1, for instance), a goal of CVC had been to stimulate or support federal reforms through state-level work. In addition, CVC participants were well placed to link federal issues and constituencies to state ones. To help them assume this role, Community Catalyst coordinated training for grantees on working with Congress members, and helped grantees identify and meet members and their staff who were focused on the reform legislation in the House and Senate. Finally, networks used the communications and grassroots infrastructures they had built to engage people and organizations in outreach to legislators and participation in town hall meetings or other events organized around health care reform. In some cases, as established advocacy organizations, CVC grantees and leadership team organizations also became involved in the Health Care for America Now! Coalition (HCAN) or related groups and coalitions supporting reform. While a full discussion of their activities related to federal reform is beyond the scope of this report, data show that CVC networks were heavily focused on this issue throughout 2009.

## **V. EFFECTS OF CVC ON GRANTEES AND THEIR NETWORKS**

CVC provided generous funding for health coverage advocacy. CVC grantees received \$250,000 per year for three years, a larger and more stable source of funding than they typically received from other sources to support advocacy. Grantees also received technical assistance and guidance on communications and policy analysis from Community Catalyst and other consultants. Community Catalyst also assisted grantees in other areas of their work, such as identifying appropriate partners and constituents, developing an overall strategy for advocacy, and managing relationships with other interest groups. They brought in fundraising experts to stimulate grantees to focus on sustainability after CVC funds ended. Funding and technical assistance were supplemented by regular networking opportunities with their fellow grantees through annual conferences, training sessions, conference calls and CVC newsletters organized and produced by Community Catalyst.

RWJF hoped these resources and activities would help establish ongoing consumer advocacy networks with strengthened capacities to address health coverage and health care issues in the future—as well as support policy changes to expand health coverage during the life of the grant. After the first two years of the grant, is there evidence that the CVC initiative has led or will lead to these intended outcomes?

We asked grantees and leadership team members how CVC influenced their capacities, activities and plans for the future. These respondents felt that CVC positively affected their advocacy networks in several important ways. First, the grant boosted credibility for the consumer advocacy networks, increasing their visibility and facilitating their health advocacy efforts with key stakeholders and decision-makers. Second, they reported that the initiative enhanced their advocacy capacities—especially in communications, grassroots organizing and policy development and analysis. CVC also set the stage for their involvement in federal health care reform in 2009. However, respondents were still uncertain about what the future holds for their health advocacy networks once CVC funding ends.

## A. Funding from RWJF Boosted Credibility

For consumer voices to carry weight, organizations advocating for increased coverage and for health reforms needed credibility with key stakeholders and decision-makers in health policy. Grantees reported that sponsorship by RWJF, a large, influential and respected foundation, brought their work to the forefront and highlighted their role in health policy debates, markedly increasing the credibility of the grantees and the CVC networks. As one respondent put it, "RWJF does not fund nobodies—so if they funded us, we must be somebody important."

The enhanced credibility opened doors, allowing CVC grantees to build relationships and their networks during the first two years of the grant. Having the RWJF reputation behind the grantees helped them approach partners to work on issues or participate in the coalition. "It facilitated conversations," one grantee said. With the backing of the Foundation, the networks were able to draw in partners, expand their advocacy activities and develop a more visible presence.

Increased visibility was helpful, especially for newly formed networks. Colorado Voices for Coverage's research and analysis on affordability led to numerous media presentations and

hearings with state and federal lawmakers. Representatives from TakeAction Minnesota, an organization for whom health advocacy represented a new focus, felt that in the two years since the project began they had evolved from a virtually unknown entity to "the" organization to go to for information on health reform in the state—in large part because CVC gave them the resources to do so. "TakeAction Minnesota is now a leader on healthcare and our work is now noticeable. Last year...we had to tell people who we were. [Now], on the general assistance medical care issue, people were calling us, asking us if we would lead the fight, what we would do and when they could come to our meetings. That's been a real change for us." As evidence for their emergence as a voice in their state, TakeAction Minnesota was selected as their state's lead agency for a national advocacy effort supporting federal health care reform.<sup>17</sup>

## B. CVC Expanded Communications and Grassroots Capacity

Participants reported that CVC strengthened grantee and network advocacy capacity, most notably for communications and grassroots organizing.

New staff and added skills strengthened grantees' communications capacity. Grantees ramped up their internal and external communications largely by hiring staff with the requisite skills and experience to oversee and manage their media and develop and direct an overall communications strategy. Grantees also received technical assistance to improve their communications skill and knowledge. One firm advised grantees on Web site design, and most started, expanded, or updated Web sites to better use them as educational and outreach tools for consumers as well as policy-makers. For example, to collect anecdotal experiences of real consumers, Illinois, New York and Pennsylvania put storybanks and "letter to the editor builder" tools on their Web sites, aimed at connecting the consumer perspective with specific issues being debated by decision-makers and legislators. The Community Service Society in New York reported that state officials and the media used their Health Care for All New York blog as an informational resource on current legislation and specific reform issues at hand.

Participants had more difficulty taking advantage of technical assistance on communications strategy provided by a national firm through CVC. While Illinois, New Jersey and Ohio grantees felt that advice received from the consultants was helpful in developing press releases and messaging, others (such as California, Colorado, Minnesota and New York) felt that the guidance lacked local context. Instead, these grantees used CVC funds to retain local communications firms and obtain tailored consultation, or relied on network members or allies with specialized communications skills to advise the group.

**CVC** resources enhanced grassroots infrastructure. In addition to effective communications, CVC participants considered statewide grassroots mobilization efforts vital for ensuring that the consumer voice was heard by state and federal legislators and policy-makers. Networks used CVC funds to enhance their grassroots capacity by hiring organizers or setting up

 $<sup>^{17}</sup>$  As mentioned below, several other CVC grantees and network members were engaged in this Health Care for America Now! initiative.

operations in hard-to-reach parts of the state, revamping existing grassroots strategies or developing organizing infrastructure from the ground up. TakeAction Minnesota hired organizers to create volunteer citizen teams in specific congressional districts, tasked with educating and questioning their legislators on particular issues relevant to health care reform. Grassroots organizers hired by Illinois' Health Care Justice Campaign developed local congressional district committees to recruit activists and build leaders from the ground up. Secure Health Care for Washington expanded its existing organizing infrastructure and also built a small business coalition with some 2,000 members.

# C. Participants Valued Policy Analysis Advice

Guidance on policy development and analysis was another resource available through the CVC initiative, and the networks took advantage of it. While funds and technical assistance enabled CVC networks to add communications staff and hone their grassroots organizing, assistance with policy analysis was mainly focused on providing technical knowledge and advice on issues as they arose. Grantees noted that this targeted assistance on policy was essential, especially when the policy environment was fluid and CVC networks needed to be responsive and agile in a short time frame.

The New Jersey grantee, for example, received guidance and expertise from Community Catalyst on issues regarding the proposed conversion of Horizon Blue Cross Blue Shield from a nonprofit organization to a for-profit company. Similarly, the Oregon Health Action Campaign reported that the research and background information they received on affordability helped them develop their own strategy around the issue. Ohio Consumers for Health Coverage relied on Community Catalyst's policy guidance to help understand how to apply the lessons of health coverage expansion in Massachusetts to Ohio. "We did not know a lot about the insurance market; they also educated us on cost containment."

However, representatives from one grantee organization said that, although the policy advice was helpful, they sometimes struggled to reconcile their policy agenda with that of Community Catalyst. Specifically, this grantee reported that it had difficulty negotiating the line between policy activities and lobbying, due to perceived pressure to engage in activities that could be construed as lobbying.<sup>18</sup>

## D. CVC Set the Stage for Engaging in Federal Reform Debates

Participants felt strongly that their CVC experiences formed a useful foundation for engagement in the federal health care reform debates in 2009. Having built relationships with both state- and national-level organizations as part of their state advocacy efforts, CVC networks had opportunities and access to information and to key stakeholders in the debates over federal health care reform. In Illinois, local grassroots groups were able to actively participate in the national debate while remaining cognizant of state concerns. "[The local committees] can keep both state and federal issues on their plates at the same time. We see some integration between federal and state

<sup>&</sup>lt;sup>18</sup> Most CVC grantee organizations had separate arms that were able to conduct lobbying activities supported through non-Foundation funds.

issues. We use the energy around the federal reform discussion to bring people in and show them how it relates to the state." Leadership team members in Illinois, New Jersey and Washington served on statewide health care roundtables and held discussions with their federal legislators about health reform bills, for example. Leadership teams also met with congressional staff in Washington, DC, and wrote letters to their congressional delegates. These contacts were bolstered by timely guidance provided by RWJF through training to help grantees build or enhance relationships with members of Congress and other federal policy-makers. As the movement for federal health care reform was gathering momentum, representatives from nine of the CVC networks attended the training in Washington, DC, in March 2009. Participants cited the importance of this training for developing crucial linkages with congressional representatives and their staff members.

While all of the networks have been able to leverage their CVC state experience to further federal reform efforts, CVC participants were positioned to benefit from federal reform debates as well. Consumer advocacy groups at the federal level, such as Organizing for America and Health Care for America Now! (HCAN), worked with state and local activists including CVC grantees in Maine, Minnesota, New Jersey, Pennsylvania and Washington. These groups shared information, communication tools and databases, and coordinated events and meetings together to raise awareness about key issues. Some grantees were also the lead organizations for HCAN in their state, which gave them access to additional communications and technical assistance resources that benefited both their state- and federal-level work.

However, in at least one case, the changing of priorities from state policy work to federal reform proved problematic. In Colorado, the leadership team experienced some challenges due to the increased spotlight on federal reform legislation. Participants said "it was hard to achieve balance" given the lack of certainty around the national health care debate. Primarily due to state budgetary cuts as well as organizational fiscal constraints, the advocacy work around federal reform felt like "an unfunded program area" that stretched their resources thin. Additionally, the shift caused some changes in the leadership team dynamics when one organization decided to leave in order to focus entirely on national reform work.

## E. Replacing CVC Resources Remains a Challenge

The CVC funding stream gave grantees and their broader networks freedom and support to assess needs, plan targeted advocacy initiatives and then devise strategies to put them into practice. Grantees expressed appreciation for a grant that gave them time to build strong working relationships with key stakeholders and develop trust among coalition partners.

The level and length of CVC funding influenced the grant's effect on consumer advocacy efforts. For example, in Maine, the three-year grant created an opportunity for organizations to work together coherently. Members of their leadership team reported, "We learned about each other's operating methods, and how we approach work, and that will benefit us moving forward even if we don't have [future] funding to do the same kind of work collaboratively." In Minnesota, the availability of ample funding and time to create the coalition has made it possible for the grantee to develop and make progress on several policy campaigns, such as the Cover All Kids legislation and the Minnesota Health Security Act. According to the leadership team members, "...part of what was really effective about the CVC grant was its scope, size, and length. We had a year to create the [coalition], invest in the relationships, work out the negotiations, then move forward on a significant campaign as well as spin-off campaigns—it was the three years with \$250,000 [each year] that made all of that possible."

After two years, most CVC networks had not yet developed future funding strategies. CVC participants felt they had built working relationships, partnerships and alliances through CVC and some were optimistic that these relationships would continue. Although many grantees reported approaching potential funders for support during 2008 and 2009, as of fall 2009, none had yet secured funding sources to support their future work together. At the September 2009 annual CVC conference in Philadelphia, most participants said they had not yet been involved in formal conversations or plans for supporting their networks after the CVC grant ends. Participants felt that, given the fiscal constraints most organizations, including grantmakers, were facing due to the economic downturn, it was unlikely they would be able to continue CVC-related operations at their current pace.

With less funding, participants felt they might not be able to be as proactive as they were under CVC. As one participant said, "... a bunch of small groups could work together to leverage our power and our resources, but it will be hard to get those multiplied effects without some funding to support it." A leadership team member pointed out, without other funding, "...it will be difficult to maintain the singularity of focus and drive and effort."

Besides CVC, current sources of funding for grantee and leadership team organizations include membership dues, private donations, small grants through private foundations and fundraising drives and events. In order to continue their health reform advocacy work, organizations that receive funding from these other sources could help sustain some limited activities on a pared-down or partial scale. However, a number of coalitions that collect dues have noticed a recent decline in renewals or lack of sufficient new subscriptions, making this a somewhat unpredictable source for sustained funding. Grantees might also tap into state funds for Medicaid enrollment and implementation activities. For instance, organizations in Maryland may have access to state support since they have been actively working to increase enrollment in their Medicaid program through consumer hotlines.

Participants suggested some specific ways RWJF could support sustainability. To broaden their funding options and increase their chances of continuing the work they began with CVC, participants suggested three steps that RWJF could take. First, the Foundation could provide additional technical assistance on sustainability through workshops, meetings and networking opportunities. For example, participants asked whether a consultant who had provided workshops on sustainability at CVC conferences could help each grantee develop a sustainability plan for its network. Second, the Foundation could use its reputation and resources to highlight the importance of state-level advocacy in the fight for health reform and expanded coverage. RWJF might be able to help open doors to other national funders or to decision-makers who could support state-level advocates. Finally, they suggested the Foundation could develop and disseminate reports or brochures documenting the contributions of the CVC grantees and networks and highlighting their achievements. CVC participants could use these reports for outreach to potential funders.

Even though participants acknowledged the challenges in sustaining their consumer network operations, all of them emphasized that it would be crucial for consumer advocates to continue their work on health reform at the state level to bring about meaningful long-term policy changes, especially as federal reform is implemented.

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