State Policy-Makers' Views on the Role of Consumer Advocates in Health Policy Discussions

Consumer Voices for Coverage Evaluation

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EXECUTIVE SUMMARY

To promote health care policies that achieve meaningful increases in health coverage at the state or federal level, and enhance the role that consumer advocates play in shaping health coverage policy, the Robert Wood Johnson Foundation (RWJF) created the Consumer Voices for Coverage (CVC) program, which provided grants to consumer advocacy organizations and their partners in 12 states. The grants were designed to strengthen state-based consumer health advocacy networks, elevate the consumer voice in health care reform debates and advance policies to expand health coverage. RWJF engaged Mathematica Policy Research to evaluate the program.

As part of the evaluation, Mathematica interviewed key policy-makers in the 12 CVC states in mid-2010 to assess changes in the involvement, influence and effectiveness of consumer advocacy groups in shaping state health coverage policy over the period of the CVC grant program (2008 to 2010). Major findings from these interviews, conducted between July and September 2010, include the following:

- Most policy-makers believe consumer advocacy groups in their state have become more involved in the development of health coverage policies in the past three years, through greater interaction and communication with policy-makers. A majority (63 percent) of respondents indicated that consumer advocacy groups were moderately or significantly more involved than they had been in 2007.
- The majority (62 percent) of respondents believe consumer advocacy groups increased their influence on state health coverage policy by a great deal or to a moderate degree over the past few years. Relative to other interest groups, such as health care insurers, providers and employers, 55 percent of respondents say consumer groups' ability to shape the outcome of state health coverage policies increased in the past three years.
- The majority (57 percent) of policy-makers said that they were very or moderately familiar with the consumer advocacy networks supported by the CVC grants, and policy-makers frequently cited CVC grantees or members of their leadership teams as most involved (60 percent of all responses) or most influential (58 percent of all responses) among all consumer advocacy groups in the state on issues relating to health coverage policy. In addition, 64 percent of respondents said consumer advocates were usually "at the table" when key health policy issues were discussed or debated. However, 29 percent of policy-makers were not at all familiar with the CVC network name, and in 6 of the 12 states, at least half of respondents were more familiar with individual organizations than with the network. The CVC network was cited infrequently (8 percent of all responses) as the consumer group most involved or influential in health policy debates.
- Respondents rated the level of involvement of consumer advocates on key health policy during 2009-2010 as highest on three issues: (1) opposing cuts to health program budgets, or attempting to minimize the impact of cuts on consumers (73 percent); (2) federal health reform adoption or state decisions regarding implementation of federal reform (68 percent); and (3) Medicaid or Children's Health Insurance Program (CHIP) eligibility issues (62 percent).

- On the issues policy-makers thought consumer advocates were most involved in during the past year, 39 percent believed the consumer advocacy groups made a big difference or changed the outcome, 32 percent believed they made a moderate difference and 8 percent said they made a small difference. Only 5 percent of respondents believed that consumer advocates made no difference in the outcome (the remaining 15 percent did not know or did not respond to this question).
- When asked what consumer advocacy groups could do to make the greatest contribution to health policy debates in the future, most policy-makers suggested they could increase their influence in the policy-making process through greater willingness to compromise and, in the immediate future, should focus on educating the public about the value and options for state implementation of federal health reform that can help increase health insurance coverage.

In sum, RWJF created and funded the CVC program to strengthen consumer advocates' voices in state health policy-making, and our interviews with policy-makers indicate that consumer advocacy groups in general, and those involved in CVC-funded networks in particular, were more involved in shaping health policy than they were three years before. Moreover, a majority of interviewees believed that consumer advocates made a significant or moderate impact on the health policy issues on which they focused in the past year or two.

Yet, this positive assessment comes with important qualifications. First, many forces and political dynamics affect the nature and outcome of policy debates on health coverage expansion, so the results do not mean that consumer advocates alone determined the outcomes. Additionally, half of all respondents believed that the political environment itself in this period (with many Democratic-led legislatures and governors in office) was an important contributor to consumer advocates' increased involvement or influence. The outcome of the 2010 elections, in which Republican elected officials gained control of many legislative houses and governors' offices, will test the ability of consumer advocates to engage policy-makers across parties and viewpoints. As the political environment changes in some CVC states, consumer groups will have to engage newly elected policy-makers, reach across party lines and build relationships with new leaders to continue having a voice in health policy within their states and a role in shaping the states' response to federal health reform.

I. INTRODUCTION

In 2007, the Robert Wood Johnson Foundation (RWJF) launched the Consumer Voices for Coverage (CVC) program in order to strengthen state-based consumer health advocacy networks, elevate the consumer voice in health care reform debates and advance policies that expand health coverage. The CVC grants were designed to help consumer organizations become more effective in shaping state health policy by building integrated health care advocacy networks consisting of a lead organization, leadership team partners and other allies.[1] The program also provided technical assistance to grantees to strengthen their capacity to carry out six core advocacy activities, which the national program office, Community Catalyst, had identified as important to consumer advocates' success (Community Catalyst, 2006).

At the beginning of 2008, RWJF awarded three-year CVC grants in 12 states that were regarded as having a good chance of adopting or implementing policies that would substantially increase health insurance coverage for their residents.[2] The grants were flexible in that they allowed the consumer networks to pursue a broad range of policy campaigns and shift their focus as needed, depending on political "windows of opportunity" in the state and the health policy issues on which they believed they could make progress. The 12 states that received CVC grants include: California, Colorado, Illinois, Maine, Maryland, Minnesota, New Jersey, New York, Ohio, Oregon, Pennsylvania and Washington (Table I.1).

RWJF contracted with Mathematica Policy Research to evaluate the CVC grant program. 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) whether and how they influenced state health coverage policy.

This report focuses on the third question. It examines changes in CVC consumer advocate networks' involvement and influence on state health coverage policy from the perspective of policy-makers themselves. The theory of change behind the CVC program design was that consumer advocacy networks, supported by grant funds and technical assistance resources, would strengthen their capacities to undertake advocacy activities focused on gaining access to and influencing relevant agenda-setters and policy-makers. If political windows of opportunity were available at the state or federal level, consumer advocates could effectively engage in the policy process and help shape and advance health coverage expansion proposals.

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1 RWJF strictly prohibits use of its grant funds for lobbying activities. All CVC grantees had non-RWJF funds available to conduct any direct or grassroots lobbying activities related to furthering their health policy goals. Some of the examples of CVC grantees' impact on state health policies discussed in this report may describe these non-RWJF funded activities.

2 In October 2010, RWJF announced that it would provide an additional year of funding for the 12 original CVC grantees to carry out campaigns on specific policy issues related to achieving substantial coverage gains through implementing provisions of the Patient Protection and Affordable Care Act (PPACA), which passed in March 2010. In its announcement, RWJF stated that "As states make plans for using PPACA to expand health coverage, it will be important for consumer advocacy groups, along with other key stakeholders, to represent their interests in state-level discussions regarding PPACA implementation. *Consumer Voices for Coverage* grantees are well-positioned to play a constructive role as states move ahead with the implementation of PPACA."

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

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 Consumer Voices 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

Consequently, Mathematica sought to interview key policy-makers and leaders in the 12 CVC grantee states to obtain their views about (1) changes in the involvement and influence of consumer advocacy groups in shaping state health coverage policy, (2) how they affected the nature or outcome of specific health policy debates and (3) the effectiveness of their advocacy over the CVC grant period, from 2008 to 2010. We also compared the 2010 responses with those given for similar questions asked of a smaller group of state policy-makers in baseline interviews conducted in 2008.

A. Interview Respondents

We sought to interview a maximum of 96 individuals in the 12 CVC grantee states (8 per state) who held key policy-making roles in the executive and legislative branches of state government or who were informed and experienced observers of state health policy development, such as leaders of health policy institutes and local health foundations.

To identify potential respondents who held these roles (all of whom are referred to as "policy-makers" in this report), we requested suggestions from CVC grantees and Community Catalyst, the national program office for the RWJF grant program, which monitors grantee progress and provides technical assistance and field-building support. In addition, we sought nominations from the following four RWJF-funded programs involved in state health coverage policy: (1) AcademyHealth's State Coverage Initiative, (2) National Academy for State Health Policy, (3) Center for Health Care Strategies and (4) State Health Access Reform Evaluation program at the University of Minnesota. In a few states, no individuals were nominated in some categories, so we conducted web searches to identify appropriate people in these positions.

From the lists of individuals nominated or identified, we selected a mix of people in each state who held policy-related positions in six categories (see Table I.2), giving preference to those who: (1) were most frequently identified by nominating organizations, (2) had been in a policy-making role for at least 18 months and (3) represented the political party in control of the administration or legislature.

We held interviews with 73 policy-makers, a response rate of 76 percent or an average of 6 per state, ranging from 4 to 8 in the 12 states. Despite efforts to schedule interviews with at least one person in each of the six policy-maker categories in each state, in two states (New Jersey and Pennsylvania) we were unable to schedule interviews with legislators or legislative staff. Consequently, results from these two states do not represent the legislative perspective.

Table I.2. Types of Policy- Makers Interviewed

Respondent Type	Number	Percentage
Executive agency leaders (health, insurance, Medicaid, commissions)	21	29
Legislators and legislative staff	15	20
Governors' health advisors	9	12
Health policy research institutes	9	12
Other key stakeholders (hospital or medical associations, labor unions, insurance plan leaders)	9	12
Private health foundations	10	14
Total	**73**	**100**

Mathematica conducted interviews using a semi-structured interview guide (Appendix B), which covered the following topics: (1) change in consumer advocates' involvement in state health policy debates; (2) change in consumer advocates' influence in state health policy debates, and change in influence relative to other major interest groups; (3) familiarity with the CVC network, its member organizations and its goals or positions on major health policy issues; (4) perception of the CVC organizations' involvement in, and influence on, key health coverage issues in the past year; (5) perception of CVC organizations' effectiveness in six core advocacy activities; and (6) suggestions on how consumer organizations could be more effective or make a greater contribution to health policy in the future.

B. Organization of the Report

This report summarizes the views of 73 policy-maker respondents in the CVC states about changes in consumer advocates' involvement and influence on state health coverage policies from 2007 to the present. Following this introduction, Chapter II discusses policy-makers' views about changes in the involvement and influence of consumer advocates generally in state policy debates. Chapter III discusses policy-makers' familiarity with and perception of the CVC grantee organization and CVC network specifically. Chapter IV describes the health policy issues on which policy-makers believed consumer advocates had the greatest impact. Chapter V discusses policy-makers' views on important roles that consumer advocates can play in upcoming state health policy

debates, and recommendations on how they can increase their effectiveness. Chapter VI concludes with a discussion of the implications of the findings for consumer advocates' ability to shape state health policy debates in the future.

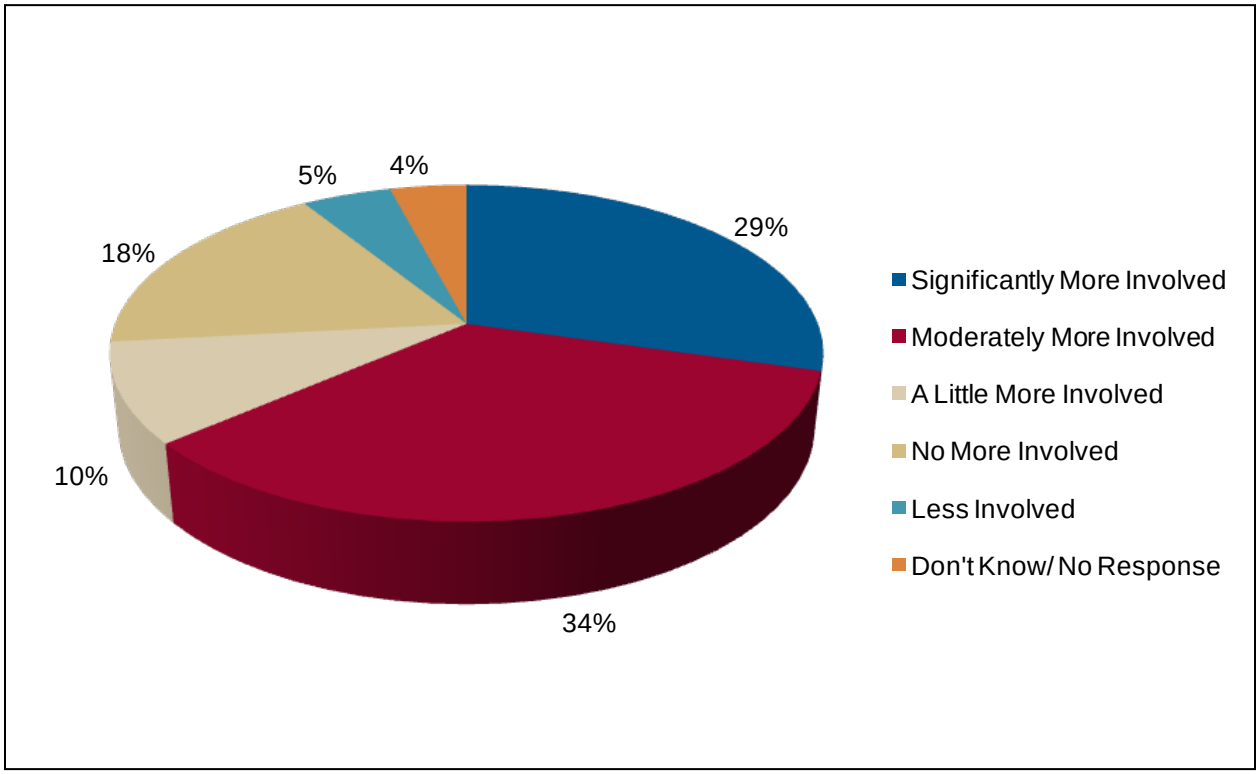
II. CHANGES IN CONSUMER ADVOCATES' INFLUENCE AND INVOLVEMENT IN STATE HEALTH POLICY DEBATES

To achieve their policy goals, consumer advocates need access to policy-makers and the policy process, as well as influence. For the interviews, we defined "involvement" as having interaction and communication with policy-makers who make or influence policy decisions. We defined "influence" as the ability to not only gain access to policy-makers, but also ultimately shape policy debates or outcomes.

A. Consumer Advocates' Involvement and Influence in State Policy Debates Increased Over the Last Three Years

Most policy-makers believed that consumer advocacy groups in their state increased their involvement in state health policy debates over the past three years. A majority (63 percent) said consumer advocacy groups increased their involvement by a moderate or significant amount (Figure II.1). Just 10 percent said consumer advocates were a little more involved, 18 percent reported that they were no more involved and 5 percent said they were less involved in state health policy debates. More detail about consumer advocates' level of involvement and influence in each of the 12 CVC states is available in Appendix A.

Figure II.1. Change in Level of Involvement of Consumer Advocacy Groups in State Health Policy Debates

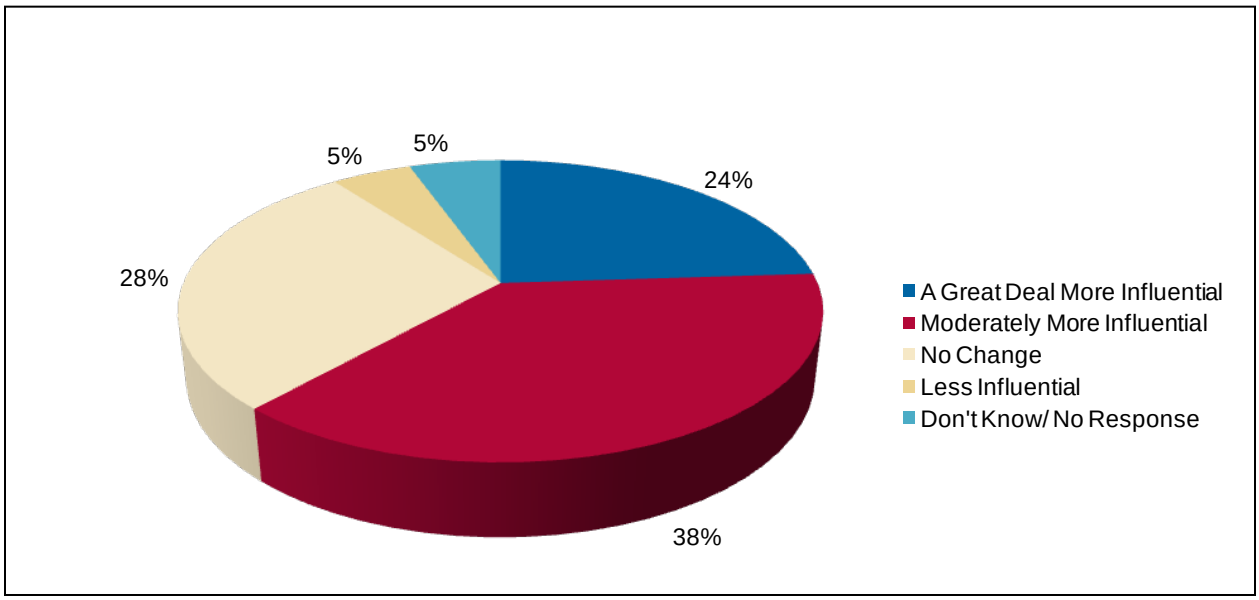


Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

Most policy-makers (approximately 62 percent) interviewed also believed that consumer advocates increased their ability to influence state health coverage policies by a great deal or moderately so over the past three years (Figure II.2). Almost a quarter (24 percent) of respondents said that consumer groups had become a great deal more influential, 38 percent said they became moderately more influential, 28 percent said that there was no change, 5 percent said groups were less influential and 5 percent did not know or had no response.

Figure II.2. Change in Level of Influence of Consumer Advocacy Groups on State Health Policy Debates



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

B. Political Windows of Opportunity Explained Consumer Advocates' Greater Involvement and Influence Slightly More Than Advocacy Effectiveness

A slight majority of policy-makers (55 percent) thought that changes in the political environment explained the change in consumer advocates' involvement in health policy development, compared to 45 percent who attributed greater involvement to changes in consumer advocates' effectiveness.

Some policy-makers credited consumer advocacy groups' increased level of participation to the 2008 national election, which brought health reform to the top of the federal political agenda and gave consumer advocates avenues to participate more extensively in health care debates at both the state and national levels. One policy-maker, for example, said of the increase in consumer advocacy, "It was somewhat galvanized by the federal debates as well as other factors that pushed the agenda forward at the state and federal level." According to another policy-maker, "The federal impetus has given consumer advocates more ability to make headway on [health care]. Because of federal reform, everyone was looking to the advocates to understand what is happening at the grassroots level." Some respondents said efforts to reform health care at the federal level presented consumer advocates with unprecedented opportunities to inform policy at the state level as well. One policy-

maker commented that federal reform gave state consumer advocates more media attention. "To me it says that those groups are considered an influential enough force to talk to."

Several policy-makers also said that changes in states' political leadership allowed consumer advocates to increase their involvement or influence. The 2006 election produced a change in political leadership (see Table II.1). In seven CVC states, voters elected Democratic governors or legislators who were committed to expanded health coverage, a factor that RWJF took into consideration in making the CVC grant awards.

Table II.1. Political Control Within CVC States, 2006- 2010

State	Governor			Senate			House		
	2006	2008	2010	2006	2008	2010	2006	2008	2010
California	R	R	R to D	D	D	D	D	D	D
Colorado	R to D	D	D	D	D	D	D	D	D to R
Illinois	D	D	D	D	D	D	D	D	D
Maine	D	D	D to R	D	D	D to R	D	D	D to R
Maryland	R to D	D	D	D	D	D	D	D	D
Minnesota	R	R	R to D	D	D	D to R	R to D	D	D to R
New Jersey	D	D	D to R[a]	D	D	D	D	D	D
New York	R to D	D	D	R to D[b]	D	R	D	D	D
Ohio	R to D	D	D to R	R	R	R	R to D	D	D to R
Oregon	D	D	D	D	D	D	R to D	D	(Split)
Pennsylvania	D	D	D to R	R	R	R	R to D	D	D to R
Washington	D	D	D	D	D	D	D	D	D

Source: National Governor's Association 2006. New York Times 2011. U.S. Census Bureau 2007.

[a]In New Jersey, the Republican governor was elected in November 2009 and took office in January 2010 (the other data presented in the 2010 column reflect the outcomes of the November 2010 elections).

[b]The Republican party reclaimed control of the New York State Senate temporarily in June 2009 when two Democrats broke from their party and agreed to vote with Republicans until key changes were made in the Senate leadership. When concessions were made by Democratic leaders in July 2009, the two former members rejoined the party, restoring Democratic control.

According to one respondent, the newly elected Democratic governor in one state appointed members of consumer advocacy groups to task forces in an effort to "engage a broader range of stakeholders more formally in the decision-making process." Policy-makers in another state noted that members of the newly Democrat-controlled legislature granted consumer groups increased access to the legislative process by requesting their attendance at meetings and inviting them to participate in other deliberations. According to one respondent, "The political climate has opened up for [consumer groups]. The stars are aligned right now: we have a Democratic governor, house,

and senate here, and many of our legislators are open to hearing what consumer advocates have to say." Conversely, a few policy-makers reported that consumer advocates may have lost influence in those states that elected Republicans to governorships and key positions within state legislatures.

Approximately one-quarter (28 percent) of policy-makers stated that the involvement of consumer advocates in state health policy debates was about the same or less than three years ago, mostly because consumer advocates had shifted their attention to federal reform in 2009 and 2010. In other cases, respondents said consumer advocates had been more involved several years ago during previous state reform efforts, but were less involved in 2010 simply because the state did not consider major reform this year. One policy-maker explained, "Consumer groups were much more involved in 2007 than in 2010. This year all we can do is federal conformity (that is, comply with the federal health reform law)."

Other policy-makers said that consumer advocates' involvement had not increased because they began from a relatively high baseline three years ago and their involvement remained high. As one respondent explained, consumer groups "were already a strong voice, so they started from a strong position. They already had my ear and had a big part in [shaping] my policy decisions as Chair of the Health Committee." According to another policy-maker, "We had pretty active consumer advocacy groups [three years ago]. The [CVC] grant provided funding for them to continue their work, but there has not been a dramatic shift in involvement. It started off pretty high."

The distribution of responses to change in consumers' involvement is similar to that for change in consumers' influence (Figures II.1 and II.2). This correspondence may reflect a strong relationship between involvement in the political process, including access to and communication with policy-makers, and the ability to shape policy outcomes. This relationship is illustrated by similar explanations for the two sets of ratings offered by policy-makers. For example, among those who said consumer advocates' influence had increased, a slim majority of policy-makers (54 percent) attributed the change to new political windows of opportunity at the state and federal level, compared to 46 percent who attributed it to consumer advocates' greater effectiveness in engaging in policy development processes.

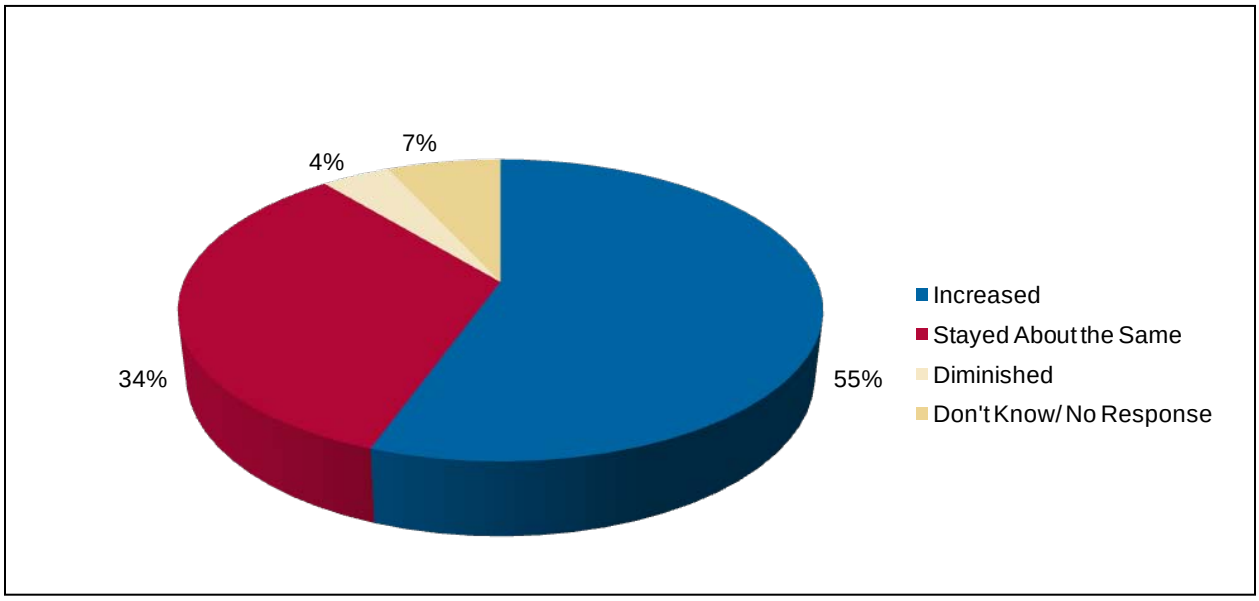
Some policy-makers noted that, while political changes were important in determining the influence of consumer advocates, the degree to which groups effectively carried out advocacy efforts also determined their level of influence in shaping policy debates.[3] They attributed consumer advocacy groups' ability to exert significant influence on policy to: (1) representing cohesive or diverse coalitions, (2) engaging policy-makers across parties and viewpoints, (3) charismatic leadership and (4) presenting unified messages to policy-makers and media outlets. For example, one respondent said, "[Consumer groups] are coming with greater numbers behind them, which increases influence. They are also coming with better coordinated information."

[3] We asked interviewees a series of questions about consumer advocates' effectiveness in six core advocacy capacities, and whether their effectiveness improved, worsened, or stayed the same over the past three years. Results from these responses will be presented in Mathematica's final CVC evaluation report to be produced in 2011.

C. Consumer Advocates Gained a Slight Edge in Influence Compared to Other Interest Groups

When asked whether the influence of consumer groups had changed relative to other interest groups, such as health care insurers, state and medical hospital associations, employers and other provider groups, 55 percent of policy-makers said consumer groups' influence had increased relative to these groups in the past three years (Figure II.3). About a third (34 percent) of policy-makers indicated that the influence of consumer groups was about the same as other interest groups over this time period, while only 4 percent of respondents said that their influence had decreased relative to other interest groups in the time period.

Figure II.3. Change in Level of Influence of Consumer Advocacy Groups in State Health Coverage Policy Debates Compared to Other Key Interest Groups



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

Many policy-makers attributed the rising relative influence of consumer advocacy groups to more effective strategies, including improved communication with key decision-makers and the presentation of timely and effective policy alternatives to policy-makers. For example, in one state, where four of five policy-makers said that the influence of consumer advocates increased, an elected official explained, "The coalitions are more sophisticated in the ways they work together and they've learned to prioritize issues." In another state, however, six of eight policy-makers reported that consumer influence remained the same as that of other groups. To some policy-makers in the state, this reflected an imbalance of financial resources necessary to influence policy decision-making. Said one, "They don't have any money. The biggest way to have influence in the political process is with money. Provider groups and insurers get influence and access as a result of having more money."

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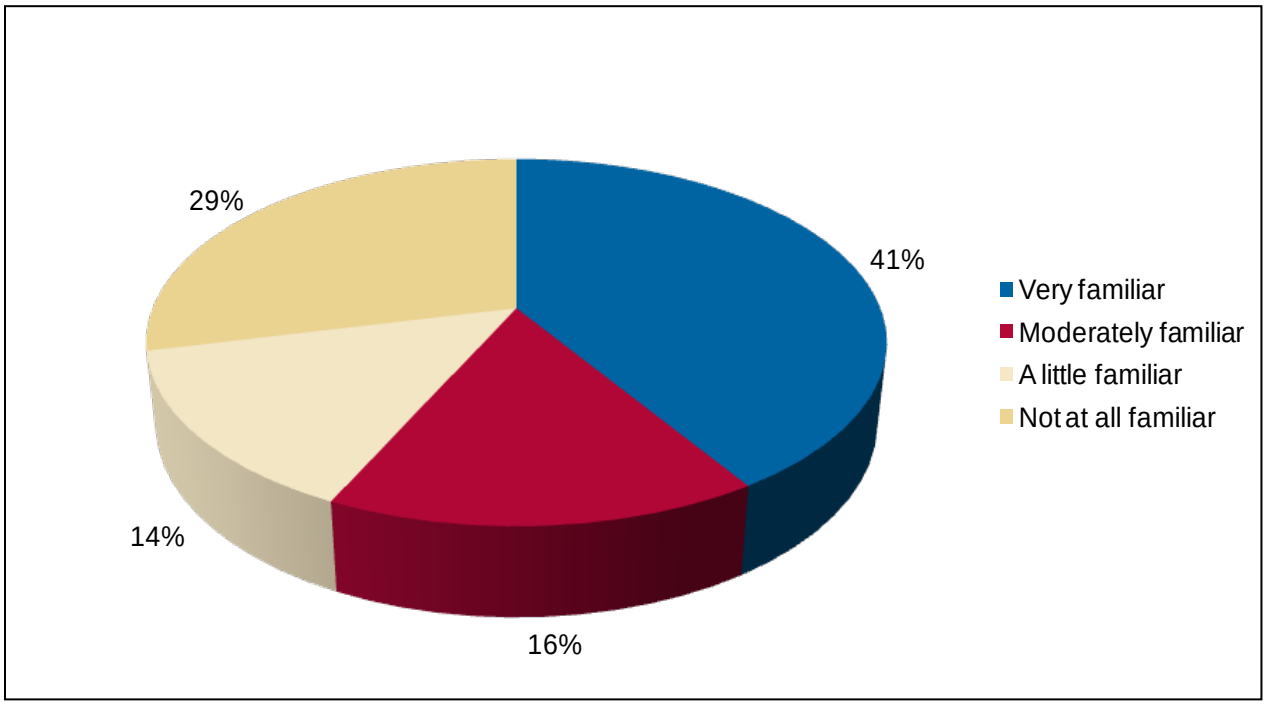
III. POLICY- MAKERS' FAMILIARITY WITH AND PERCEPTIONS OF CVC NETWORKS

The majority of policy-makers were familiar with CVC networks, but most were *more* familiar with individual member organizations than with the larger network. In addition, policy-makers often cited CVC grantees or leadership team members as the most involved or influential consumer advocacy groups on health policy issues, but rarely named the CVC network, which suggests policy-makers did not always connect grantees and leadership team members with the network.

Just over half (57 percent) of policy-makers said that they were very or moderately familiar with the consumer advocacy networks formed and supported by RWJF's CVC grants (Figure III.1), though nearly a third (29 percent) of policy-makers did not associate the consumer advocacy grantee or leadership team organizations with the CVC network name. In 6 of the 12 states, at least half of respondents were more familiar with individual consumer advocacy organizations than with the CVC network.

Figure III.1. Policy- Makers' Familiarity with CVC Networks

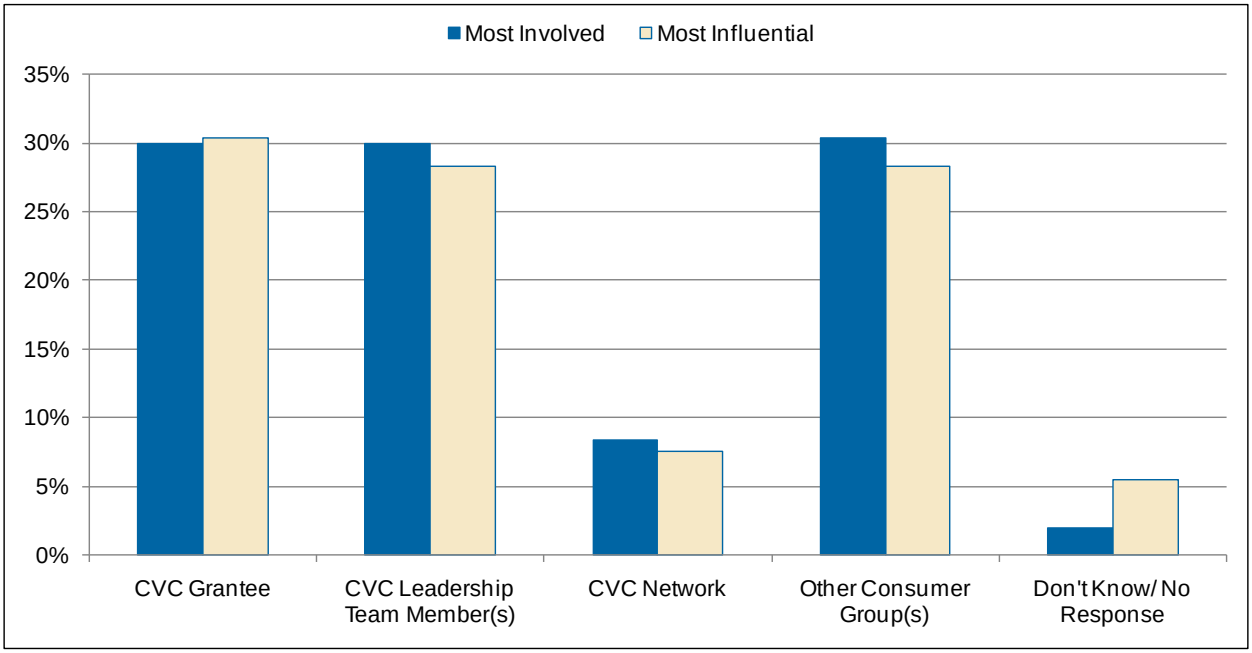


Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

Policy-makers from nearly all of the 12 states said that CVC grantees were the most visible organizations within the networks. When asked which consumer advocacy organizations were most involved or influential, policy-makers frequently cited CVC grantees or members of their leadership teams as the most involved (60 percent of all responses) or most influential (58 percent of all responses) on issues relating to health coverage policy (Figure III.2). The CVC network itself was cited infrequently (8 percent of all responses) as one of the consumer groups most involved or influential in health policy debates.

Figure III.2. Most Involved and Influential Consumer Advocacy Groups, by Type of Group



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

In addition to CVC grantees, CVC leadership team organizations and the CVC network, policy-makers often cited other consumer groups that were not members of the CVC leadership team in that state as most involved (30 percent) or most influential (28 percent). These organizations included children's health advocacy groups, legal aid organizations, state AARP chapters or other groups representing seniors, labor unions, disability advocates, disease-specific groups, faith groups and others.[4] Many policy-makers explained that the groups they regarded as most involved or influential depended on the issue. If a state's policy agenda addressed coverage for specific population groups, rather than expanded health coverage in general, other advocacy organizations tended to stand out. For example, "covering kids" groups were cited as having the greatest involvement and influence on children's health issues, seniors and disability groups on long-term care issues, and legal aid advocates on changes to Medicaid eligibility.

Policy-makers often found it difficult to distinguish the goals and activities of CVC grantees from those of the CVC networks, suggesting that, in most of the 12 CVC states, the network formed under CVC auspices did not have a separate identity among key decision-makers. The inability of policy-makers to differentiate the CVC networks from the grantees may be due partly to the fact that the CVC grantee in many states is itself a coalition or network of organizations, such as Health Access (California), Colorado Consumer Health Initiative, Maryland Health Care for All! and the Campaign for Better Health Care (Illinois). As one respondent said, "I am less familiar with the

[4] Each CVC leadership team and network is composed of different organizations, so for example, the state AARP chapter or a legal aid organization may be on the CVC leadership team in some states but not in others.

goals of the coalition. There is a blurring of [the grantee] and coalition goals." As a result, when responding to questions concerning advocacy by the larger CVC network, many policy-makers referred just to the CVC grantee or individual consumer advocacy groups.

In at least four states, policy-makers frequently referred to consumer advocacy efforts by citing the individual grantee leader. A number of policy-makers viewed strong leadership within CVC networks positively, stating that highly visible grantee leaders were able to serve as strong spokespeople for the network and have effective relationships with top policy-makers and other stakeholders. But several respondents said that some leaders tended to dominate the stage and obscure the views and participation of other member organizations.

Because of significant variation in the way in which respondents referred to consumer organizations involved in the CVC grants, and the difficulty respondents had in distinguishing the role of CVC grantees, leadership team members, the CVC network, or other consumer groups, we use the term "consumer advocates" in the rest of the report to describe the role or impact of consumer advocacy groups involved in CVC grants, unless a respondent specifically cited one organization or the network.

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IV. CONSUMER ADVOCATES' INVOLVEMENT AND IMPACT ON SPECIFIC HEALTH COVERAGE POLICY ISSUES

In a previous report for the CVC evaluation (Strong et al., 2010), we described the state-level health policy issues in which CVC networks engaged in 2008 and 2009 as reported by the grantees and leadership team members for each state. However, we could not attribute the outcomes of these policy debates to the work of CVC-affiliated organizations.[5] The interviews conducted for this survey help fill that gap by presenting the views of state decision-makers. The results suggest that consumer advocates were not only active in health policy debates over the 2009-2010 period, but in many cases they also had a significant influence on the results.

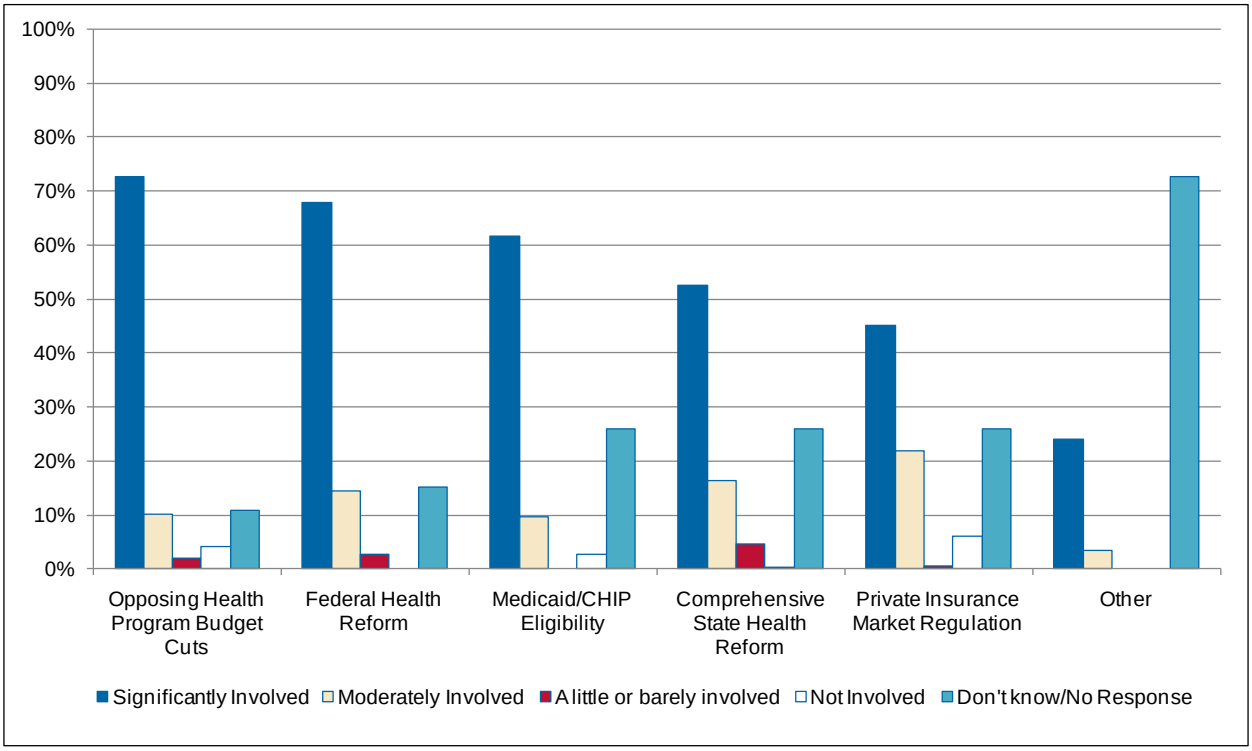
A. Policy- Makers Believed Consumer Advocates Were Most Involved in Opposing Budget Cuts, Federal Health Reform and Medicaid/CHIP

Policy-makers perceived consumer advocates as being significantly or moderately involved in many of the important health coverage policy debates in their state in the past year, and the issues on which consumers were seen as most involved are largely consistent with those reported by CVC grantees. When asked to rate consumer advocacy groups' level of involvement in debates on six major health policy issues during 2009-2010, a majority of policy-makers cited consumer advocates' involvement as significant on three policy issues: (1) opposing cuts to health program budgets, or attempts to minimize the impact of cuts on consumers (73 percent); (2) federal health reform adoption or state decisions regarding implementation of federal reform (68 percent); and (3) Medicaid or CHIP eligibility issues (62 percent) (Figure IV.1).

About half of policy-makers said consumer advocates also were significantly involved in private insurance market reforms (45 percent) and comprehensive state health reform initiatives that addressed cost, quality and access (53 percent). Very small percentages (7 percent or less) of policy-makers thought consumer advocates were only a little, or not at all involved in any of these issues. But sizable percentages of respondents (10 to 26 percent, depending on the issue) did not respond or know enough to rate consumers' involvement in these issues, or said the issues were not on the state's agenda in the past year or two, usually because of the focus on federal health care reform.

[5] In a previous report (Strong et al., 2010), we used information from four primary data sources: (1) status reports filed by grantees in 2008 and 2009; (2) semi-structured 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) semi-structured group interviews with leadership team members in November 2009.

Figure IV.1. Consumer Advocates' Degree of Involvement in Major Health Policy Issues, by Percentage of Total Responses



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73.

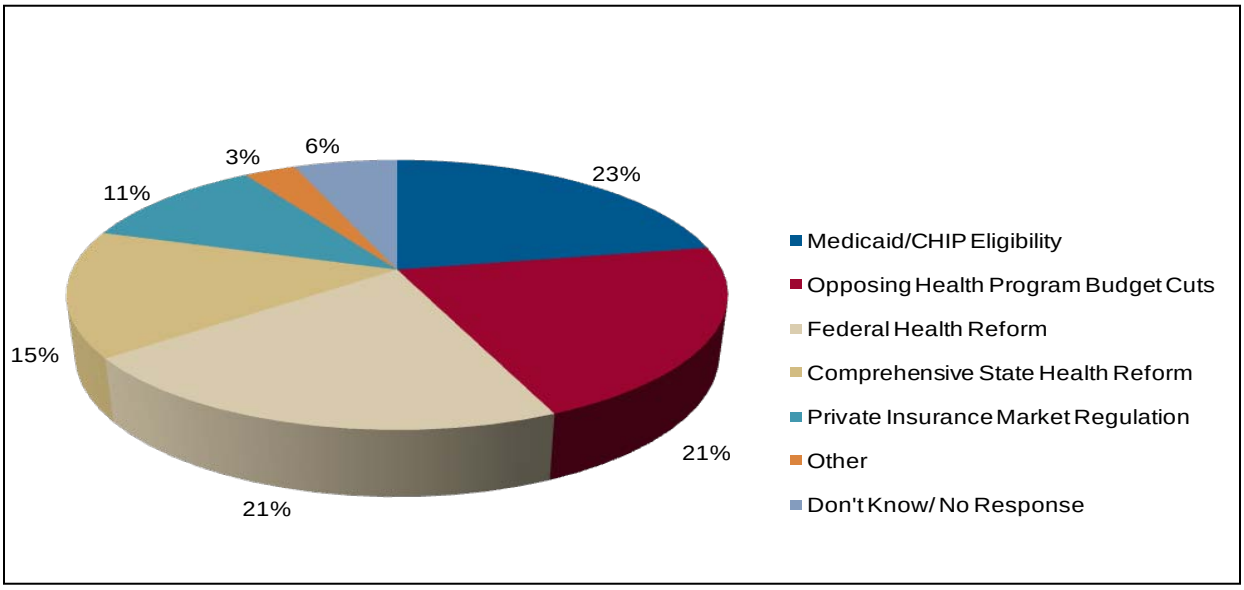
We also asked policy-makers to specify one health policy issue that received the most attention from consumer groups in their state. (Figure IV.2). Policy-makers most often identified Medicaid/CHIP eligibility (23 percent), opposing budget cuts (21 percent) and federal health reform (21 percent) as the issues in which consumer advocates had been most involved. Policy-makers' ratings of consumer advocates' priority issues are largely consistent with those reported by CVC grantees. A previous report conducted for this evaluation (Strong et al., 2010) found that from 2008 to 2009 grantees were most involved in private insurance reform (in all 12 CVC states), expansion to public insurance programs (9 CVC states) and opposition to cutbacks in public insurance programs (7 CVC states). That report did not assess grantee activities related to federal reform, but subsequent grantee reports indicate that CVC networks were very involved in it in late 2009 and early 2010.

The most notable difference in the priority issues identified by policy-makers and grantees was in the area of private insurance regulatory reform. Grantees in every state said this was one of their top priorities, but just 11 percent of policy-makers identified it as consumers' top priority. However, this discrepancy may be due to the different time frames; the previous report focused primarily on 2008 and 2009, while the policy-makers focused mainly on the first half of 2010 when federal reform and state budget cuts were at the center of health policy debates.

In another indicator of policy-makers' and policy observers' generally high rating of consumer advocates' level of involvement, 64 percent of policy-makers said consumer advocates were usually "at the table" when key health policy issues were discussed or debated; 15 percent said they were sometimes at the table, 12 percent said they were rarely or never at the table, and 8 percent did not

know (results not shown). Although we did not define "at the table" for respondents, the responses given by policy-makers largely reflect their understanding of the term as playing a key role in policy decision-making processes.

Figure IV.2. Policy- Makers' Views of Consumer Advocates' Priority Issues, 2009- 2010



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

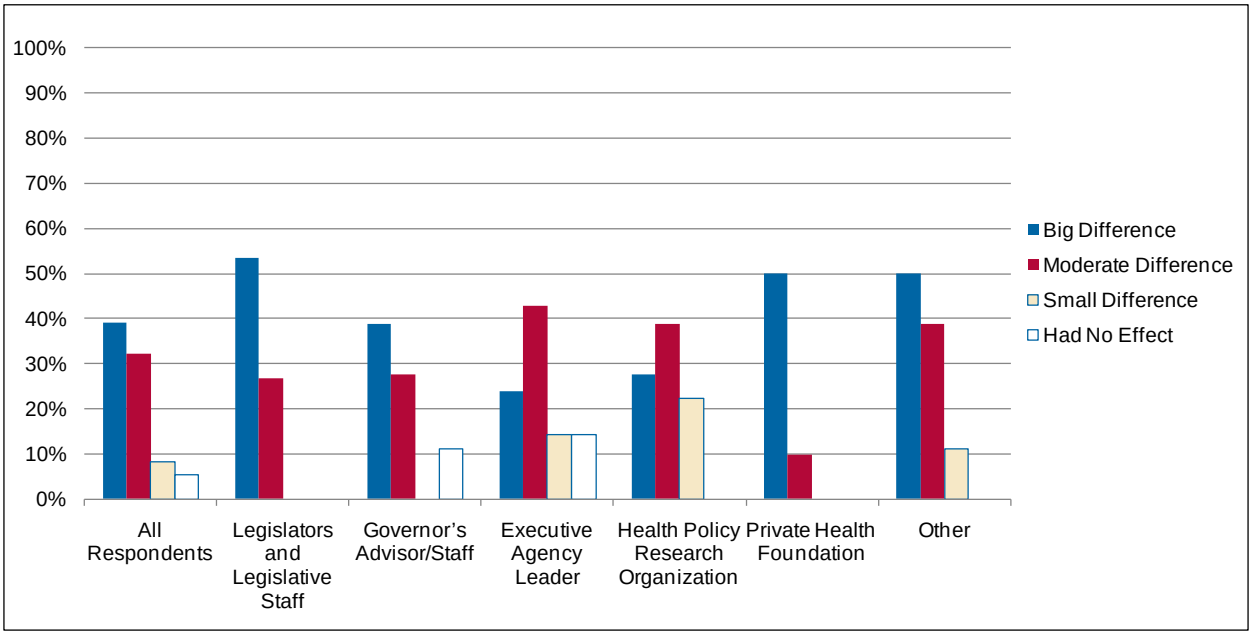
Note: N = 73.

B. Most Policy- Makers Believed Consumer Advocates Had a Large or Moderate Impact on State Health Policy

Policy-makers rated consumer advocates' influence on key state health policy issues as high; about 7 in 10 policy-makers said consumers made a large or moderate impact on state health policy debates or the outcomes. On the issues in which policy-makers said consumer advocates were most involved, 39 percent believed the consumer advocacy groups made a big difference or changed the outcome, 32 percent believed they made a moderate difference, 8 percent said they made a small difference and only 6 percent did not believe consumer advocates made any difference in the outcome; the remaining 15 percent of respondents did not know or did not respond to this question (Figure IV.3; see "All Respondents" column).[6]

[6] These findings suggest that consumer advocates' influence on state health policy debates in 2010 may have increased since the start of the CVC program in 2008. In the baseline interviews conducted in 2008, 19 of the 32 policy-makers interviewed (59 percent) believed that consumer advocates had major or significant influence in shaping state health coverage policies. However, because of differences in question wording, the findings are not directly comparable. In the 2008 interviews, some respondents interpreted "influence" as consumer advocates' connections to political leaders, some as their contribution to specific policies and some as their influence relative to other groups. Therefore, we changed the wording of these questions in the 2010 survey in order to elicit the policy-makers' beliefs specifically in regard to consumer advocates' influence on specific policy outcomes..

Figure IV.3. Degree of Consumer Advocates' Influence on State Health Policy Debates, by Respondent Type



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 73. If respondents rated consumer advocates' influence in more than one category, their response was divided into two (0.5 in each category).

Consumer advocates influenced the debate or outcome on four of the most prominent health policy issues considered in 2010: (1) opposing state budget cuts to public health insurance programs; (2) supporting federal health care reform; (3) supporting private insurance regulation and reform at the state level; and (4) supporting Medicaid or CHIP eligibility expansions. Appendix A describes policy-makers' views on how consumer advocates influenced these debates in all 12 states, but a few examples are provided here:

- **Opposing cuts to health program budgets**. One state legislator said consumer advocates were "very involved in the committee stage and really made a hard pitch for [opposing] particular cuts. They were the go-to people for where you can make cuts and where you can't. It would be much less effective [if they were not involved]… .We were able to protect more services through their advocacy." In another state, a policy-maker said that the CVC made a big difference in opposing budget cuts to a state-funded program for low-income adults not eligible for Medicaid by "working very hard to get articles and stories in the news about people who need the program, to keep the issue in front of the public. They organized letter writing campaigns from both Democratic and Republican districts, and organized groups of [program beneficiaries to speak on its importance to them], who had never come to lobby for benefits or anything else previously."
- **Federal health reform.** One respondent said of the CVC network's influence, "Although it was a federal issue, CVC did make a difference…legislators are sensitive to their constituents' views, and the CVC network triggered a lot of debate at the local level, so their impact was significant in that regard. I think they definitely helped to get

federal reform passed. There were rallies and stories of those affected locally, which made the need for federal reform 'real' to a lot of people, including elected officials."

- **Insurance reform.** One state legislator said the CVC network was responsible for adoption of insurance regulatory changes: "I don't know if we would have done anything at all without their involvement. There would have been no change to the [insurance] premium structure without their involvement. They really did their homework, everything was developed, even the data from the actuaries."

When we examined responses regarding level of influence by respondent type, we found that legislators and legislative staff rated consumer advocates' influence much higher (53 percent) than executive agency leaders did (24 percent) (Figure IV.3). In addition, executive agency leaders and governors' health advisors were the only two of the six policy-maker types to say consumer advocates had no effect (14 percent and 11 percent, respectively). This may be a result of consumers focusing their advocacy more on legislatures than on executive agencies, or it could be that policy-makers in these two groups believe that only those holding policy-making positions are responsible for the ultimate result.

Despite the overall high ratings of consumer advocates' influence on health policy debates or their outcomes, there was often a wide range of opinions among policy-makers within a state regarding the level of consumer advocates' impact on the outcomes, or how they influenced them. These differences sometimes appeared to reflect the policy-maker's position, political affiliation, or familiarity with consumer advocates' efforts.[7]

[7] The examples in Appendix A also illustrate the variety of opinions policy-makers held about consumers' influence on policies in each of the 12 CVC states.

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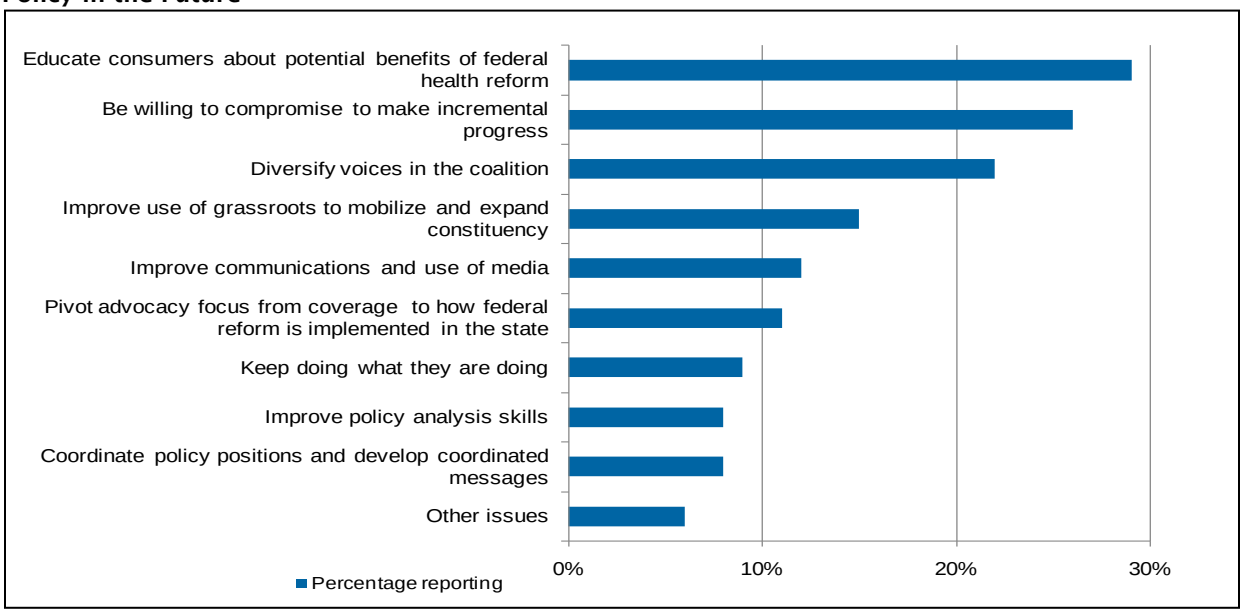
V. POLICY- MAKERS' RECOMMENDATIONS ON CONSUMER ADVOCATES' ROLE IN FUTURE STATE HEALTH POLICY DEVELOPMENT

When asked about important activities or roles that consumer advocates could play in upcoming state health policy debates, a majority of policy-makers interviewed indicated that consumer advocates could contribute most by educating the public about the value to the state, and state options related to, implementing recently passed federal health reform legislation. They also said that, in the long-term, advocates could improve their effectiveness in the policy-making process by showing a willingness to compromise in order to make incremental progress toward long-term goals.

A. Policy- Makers Encourage Consumer Advocates to Educate the Public About the Benefits of State Implementation of Federal Health Reform

Sixty-five of the 73 respondents offered recommendations regarding what consumer advocates could do to help shape health coverage policy in the near term. Among this group, 29 percent (including at least one respondent in 9 of the 12 states) said that the most important role consumer advocates could play would be to inform the public about the potential benefits and value to the state of implementing federal health reform (Figure V.1). As one respondent put it, "We don't have a public relations arm here in the Governor's office, but [the advocates] could be part of that….to get beyond the negative and incorrect press reports [on federal health reform]. Consumer advocates' job could be to help make the public understand [why we should] implement it; right now, the advocates are telling people how to implement something they do not want. We need them to help the public understand [how they could benefit from reform]."

Figure V.1. Policy- Makers' Suggestions on Ways CVC Networks Could Contribute to State Health Policy in the Future



Source: Mathematica CVC Interviews with State Health Policy-Makers, 2010.

Note: N = 65. Respondents could give more than one response to this question; percentages do not total 100.

Several policy-makers noted that consumer advocates could capitalize on one of their strengths—storytelling—to make a compelling argument for state implementation of federal health reform. "Consumer advocates need to be able to 'tell the story' about how state and federal health care reform can help individuals and families, how it could make a difference in people's lives," said one respondent. Another respondent noted that a critical part of advocates' role as educators about federal reform will be to craft messages that strike a balance between the moral and economic arguments for reform: "They need to continue to find the right balance between the human interest—the message that, 'This is the right thing to do'—with the message that, 'It's good for the economy and here's why, for example people with insurance have low absenteeism at work.' They need to balance the message so people don't roll their eyes at the sob stories."

Most policy-makers thought consumer groups could help educate the public about the value to state residents of implementing federal reform but they also need to help states evaluate options for implementing specific health reform provisions, such as health insurance exchanges. Eleven percent of policy-makers said consumer advocates should shift from focusing on expanding insurance coverage—which federal reform should achieve—to recommending options to the state for implementing federal reform. Several stakeholders (at least one in each of six states) suggested the need for these groups to become the "go-to" organizations concerning options for implementation of reforms.

B. Policy- Makers Suggest Other Ways Consumer Advocates Can Increase Their Long- Term Effectiveness

Many policy-makers also identified ways consumer advocates could improve their effectiveness in the political and policy-making process in the long term. Just over a quarter of policy-makers said that consumer advocates could improve their ability to shape state health policy by showing that they would be willing to compromise in order to make incremental gains, and that doing so would improve their partnerships with state officials. For example, some policy-makers suggested consumer advocates should not present state officials with "all or nothing" requests. Policy-makers said consumer advocacy groups would be more welcome at policy-making tables if they presented solutions to help policy-makers sort through difficult challenges. As one official summarized it, "We have to cut one billion dollars from the [state] health care budget this year, and we asked the consumer network, what would you cut? They said, that's not what we do, we oppose all of the cuts. [We need them to] help us rank priorities. They need to learn compromise, and by doing so they can help make difficult choices easier." While policy-makers' recommendations regarding the need to "give-and-take" do not translate into firm rules or guidelines on how much consumers should compromise to increase their effectiveness in the policy-making process, they indicate the importance of an ability to make some concessions to be viewed as astute political partners.

Other common recommendations made by policy-makers regarding how consumer advocates could improve their effectiveness or make a contribution to state health policy debates included the following:

- ***Diversifying voices in the network.*** Twenty-two percent of policy-makers said consumer advocates could make a greater contribution to policy-making by diversifying the voices in the network, both by bringing more consumer voices to the table and including nontraditional partners such as providers and business (which some states did). This was mentioned by at least one respondent in 8 of the 12 states.

- ***Improving the use of grassroots participants to mobilize and expand the network.*** Fifteen percent of policy-makers said consumer advocates could improve their grassroots mobilization; many of these respondents noted a particular need for expansion into rural areas of the state. This was mentioned by at least one respondent in 7 of the 12 states.
- ***Improve communications and the use of media.*** Twelve percent of policy-makers said consumer advocates in their states could be more effective by improving the way they communicate. This was mentioned by at least one respondent in 6 of the 12 states.

C. Changes from 2008 to 2010 in Policy- Makers' Recommendations to Consumer Advocates

When we compared recommendations to consumer advocates in 2010 to those suggested in the 2008 baseline interviews with policy-makers, there were some notable similarities. For example, about 28 percent of policy-makers in 2008 said that CVC networks should educate the public about health reform with a focus on the need to make trade-offs between cost and coverage. In 2010, a similar share of policy-makers (29 percent) said that consumer advocates should focus on educating the public, but this time the focus was on state implementation of federal health reform options. Other findings suggest consumer groups are still grappling with some of the challenges they faced in 2008; about 28 percent of 2008 respondents suggested a willingness to compromise as an important way in which consumer advocates could become more effective; in 2010, almost the same share of suggestions (26 percent) cited compromise as an area in which consumer advocates could improve in the future.

There were also important differences in responses across the two time periods. In 2008, the second most frequent recommendation, made by about a third of policy-makers interviewed, was that consumer groups needed to unify their policy positions and coordinate their policy messages. In 2010, out of 65 respondents who offered suggestions for improvement, only 5 (less than 10 percent of those who answered this question) mentioned these as areas in which consumer advocates could improve. This may indicate that consumer groups have made progress in these areas or that policy-makers' priorities have changed. In 2008, 18 of the 32 policy-makers, and at least one respondent in 11 of the 12 states, said that CVC networks should create political urgency to expand health coverage. After federal health reform passed in 2010, policy-makers' perception of the need for this had abated.

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VI. DISCUSSION

RWJF created and funded the CVC program to strengthen consumer advocates' voices in state health policy-making. We interviewed key policy-makers directly involved in, or well-informed about, recent state health policy decisions in the 12 states that received CVC grant awards. Based on these interviews, consumer advocacy groups in general, and those involved in CVC-funded networks in particular, were more involved in shaping health policy than they were three years before. Moreover, a majority of interviewees believed that consumer advocates made a significant or moderate impact on the health policy issues on which they focused in the past year or two.

Yet, this positive assessment comes with an important qualification. Many forces and political dynamics affect the nature and outcome of policy debates on health coverage expansion, so the results do not mean that consumer advocates alone determined the outcomes. As one policy-maker stated, speaking of consumer advocates' involvement in the state budget debate, "Anyone who takes credit [for any outcome] in the face of such complex fiscal constraints is not being totally straightforward. No consumer groups could [by themselves] affect the issues when the problems are so big, so difficult, and the magnitude of the deficit so significant."

In addition, the reasons given by policy-makers for the increase in consumer advocates' involvement and influence in a broad range of state health policy issues have important implications. On the one hand, 46 percent of respondents believe consumer advocates' influence was attributable to effective advocacy activities—mobilizing grassroots groups, building coalitions in support of policies among a broad range of organizations, analyzing the potential impact of policy options and proposals on consumers, communicating directly with policy-makers and using the media to educate the public or key constituencies. This suggests that, to maintain their influence in health policy development, consumer advocates need to sustain and, in some cases, strengthen their capacity and improve their effectiveness in these areas.

Yet, 54 percent of respondents believed that changes in the political environment itself were an important contributor to consumer advocates' increased involvement or influence. Many said the switch from a Republican to Democratic governor or from Republican to Democratic control of a state legislative chamber in the 2006 election cycle opened the door to consumer advocates' involvement or influence. Republican respondents, whether elected or appointed by an elected Republican, in general had a less positive view of consumer advocates' influence. Although Republicans do not necessarily disagree with consumer advocates on all health policy issues, they tend to have different views about how to solve health insurance coverage and affordability problems than the consumer advocacy groups funded by the CVC program.

On November 2, 2010, momentous political shifts took place in a number of CVC grantee states (Table II.1). In five states, Republican elected officials gained control of one or both legislative houses, and in three states, a Republican governor replaced a Democratic governor. These changes will test the ability of consumer advocates to engage policy-makers across parties and viewpoints, a skill on which policy-makers rated consumer advocates as "moderately effective" or "weak" more often than on the other core advocacy skills. As the political environment changes in some CVC states, consumer groups will have to engage newly elected policy-makers, reach across party lines and build relationships with new leaders to continue having a voice in health policy within their states and a role in shaping the states' response to federal health reform.

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STATE POLICY- MAKERS' VIEWS ON THE ROLE OF CONSUMER ADVOCATES IN HEALTH POLICY DISCUSSIONS

APPENDIX A

EXAMPLES OF CONSUMER ADVOCATES' INFLUENCE ON STATE HEALTH POLICY DEBATES

According to policy-makers interviewed in the 12 CVC states, consumer advocates were often significantly or moderately involved in many of the important health coverage policy debates in their state in the last year. Consumer advocates influenced the debate or outcome on four of the most prominent health policy issues considered in 2010: (1) opposing state budget cuts to public health insurance programs; (2) supporting federal health care reform; (3) supporting private insurance regulation and reform at the state level; and (4) supporting Medicaid or CHIP eligibility expansions.

This appendix contains examples of the activities that CVC networks took to influence these policy issues in their states and policy-makers' views on their level of influence on the outcome. The examples illustrate consumer advocates' involvement and influence, but they do not reflect the multiplicity of forces and political dynamics that may also have affected the nature and outcome of these policy debates.

RWJF strictly prohibits use of its grant funds for lobbying activities. All CVC grantees had non-RWJF funds available to conduct any direct or grassroots lobbying activities related to furthering their health policy goals. Some of the examples of CVC grantees' impact on state health policies provided below may describe these non-RWJF funded activities.

State Budget Cuts

To address the budget shortfalls caused by the economic recession, governors and state legislators faced difficult decisions regarding program cutbacks. In response to proposed cuts to Medicaid and other state-supported health insurance programs, policy-makers cited the efforts by consumer advocates in several states as having had an important influence on minimizing the impact of budget cuts on consumers.

For example, in **Minnesota** the governor proposed eliminating the General Assistance Medical Care program, a state-funded program for low-income adults not eligible for Medicaid. Several respondents said consumer advocates made a big difference by keeping public attention focused on the issue and crafting an alternative to maintain some coverage. According to one respondent, "They worked very hard to get articles and stories in the news about people who need the program, to keep the issue in front of the public; they organized letter writing campaigns from both Democratic and Republican districts. They also organized groups of homeless veterans [to speak on the importance of the program] who had never come to lobby for benefits or anything else previously." Another respondent said, "They helped raise awareness that counties could not compensate for the impact of state budget cuts. They helped the Governor and legislature come to an alternative as opposed to just cutting it off. I think the outcome would have been different if they had not been involved." At least one policy-maker, however, disagreed that consumers made much difference. "The deficit

played a bigger part than any stakeholder in the issue, so the outcome probably would have been about the same had the [consumer advocates] not been involved."

In **Maine,** a state that had to plug an $849 million budget shortfall in fiscal year 2010 (about 28 percent of the state budget), several policy-makers credited consumer advocates as having averted more drastic cuts to Medicaid. According to one policy-maker, the consumer groups in that state "are strong advocacy organizations with very skilled folks who work with the legislature and know the state budget and Medicaid program very well. So they can suggest options to the legislature which the Department of Health may not think of." Another respondent agreed, "The outcome could have been different [without their involvement]. If you talk to [Republicans] who are concerned about state budget, they would say, 'we know the advocates are going to come to the legislature.' So, the network plays an important defensive role in the debate over the state budget. Consumer advocates played a role in preventing significant Medicaid cuts. In the absence of pressure at the local level there would have been more cuts." And another summed up consumers' influence by saying, "When dealing with budget issues, having folks working with people on both sides of the aisle, it makes a huge difference. We were able to protect more services through their advocacy."

New Jersey also struggled to balance its 2009-2010 budget, which had a deficit of about $2 billion in February 2010; the deficit was forecast to be as high as $11 billion in 2010-2011, almost 40 percent of the total state budget (McNichol et al., 2010). One policy observer in the state believed that by opposing budget cuts, consumer advocates had a moderate influence in "preserving funding for major services that were high priority. If the CVC network was not involved, there would be deeper cuts to certain health services." As one example, in 2009, the state eliminated Medicaid premiums for children in families earning less than 200 percent of the federal poverty level (FPL).

In **Washington,** consumer advocates became heavily involved in opposing a bill that would have ended the long-standing Basic Health Plan, a subsidized program that helps make health insurance more affordable for working families. Their work on the issue was widely recognized. According to one policy-maker, "The consumer advocates lobbied, testified, had meetings with us and with the general public, issued press releases, went knocking on doors, and generally got information out on the issue. They did a lot of information sharing with many different groups, helping to explain why we were trying to preserve the program."

But there were mixed views among the respondents in Washington State about how much consumer advocates influenced the outcome. One policy-maker from the state believed, "The coalition made a big difference because they kept the pressure on the Governor to maintain funding for [the program]. Without pressure from these groups, the legislature might have decided that the funding was a low priority compared to other issues that were debated in this session." Another respondent from Washington State disagreed: "I'd say they probably only made a small difference because [of legislative support for the program], we would have ended up in the same place, with the same decisions made." A third respondent in Washington State held both views: "Consumer advocates were able to put pressure on state legislators to authorize funding that will keep these programs in place until 2014 when full federal funding is available under federal health care reform. In times like this you have to set priorities; because they've learned to speak with one voice, they are more difficult to ignore. Their strength is in the broader coalition that they have built. At the same time, I'd say they only made a moderate difference in this issue because a number of legislators were willing to 'fall on their swords' to keep these state programs alive."

Federal Health Reform

The intense focus on federal health reform in fall 2009 and winter 2010 gave consumer advocates many opportunities to inform federal policy-makers and to educate the public about the potential effect of different choices on consumers. In **Illinois**, for example, consumer advocates participated in the national debate by presenting information to federal legislators about the potential impact of health reform on the state, and then pushing for the creation of a statewide task force to advise the state on implementation issues. Said one policy-maker, "What stood out was their work on creating a 'large table' for making state decisions on implementing federal health care reform. They supported the bill that creates a large task force. It's a vehicle for them and other advocates to be heard, and it promotes public participation, and more opportunity for public comment."

Consumer advocates in **Pennsylvania** also made a big difference in educating and persuading the state's Congressional delegation to support federal health reform. Said one policy-maker in the state, "Legislators are sensitive to their constituents' views, and the [CVC network] triggered a lot of debate at the local level, so their impact was significant in that regard. They may have gotten legislators to change their minds. There were rallies, stories of those affected, which made the need for federal reform more real to a lot of people, including elected officials." Another policy-maker agreed: "[The CVC network] did make a difference in getting federal healthcare reform passed. I think in particular they made a difference in some very conservative areas where they were able to have a pretty strong influence. They rallied consumers, informed them about the issues, held events in the state capital, and invited legislators to come out and talk to people. I think their influence on the swing votes in the House and Senate was pretty strong."

After the Patient Protection and Affordable Health Care Act was signed into law in March 2010, consumer advocates shifted their focus back to the state level, where responsibility lies for implementing numerous aspects of the legislation. CVC grantees or networks in Colorado, Illinois and New York have been named to advisory groups formed to provide input to state policy-makers on options for implementing federal health reform. The degree to which consumer advocates will influence state implementation decisions remains unclear, since it was too soon to tell when these interviews were conducted. An **Illinois** policy-maker said of consumer advocates: "They've been involved in statewide hearings and helped to get the bill passed [to establish a federal health reform implementation task force], but I don't know about [how much] influence [they have had] because there has been no outcome at the state level." Another policy-maker in the state said consumer advocates have had little impact so far. "The consumer advocates asked for early adoption [of federal reform options for expanding Medicaid eligibility], but that's ludicrous because of our budget deficit . . . we have done all the expansion we will do for now." A policy-maker in **Maryland** agreed: There has been little debate so far [about expansion of Medicaid coverage for low-income adults before 2014] because it's a budget matter. We aren't able to pay for it. Consumer advocates manage to bring it up in every forum possible and keep it on the minds of policy-makers and there is value to that, but does that mean that the policy-makers will do something about it? No."

Private Insurance Regulation and Market Reforms

Before the federal health care reform debate came to the forefront of the national political agenda, state governments tried to take steps to make private health insurance more affordable or accessible. Consumer advocates in all 12 states that received CVC grants reported working on these issues at the state level in the first two years of the CVC grant program—2008 and 2009—and their efforts were recognized as influential in passing state legislation in this arena. Some consumer advocates were also cited as having had significant influence on state-level debates concerning state health insurance exchanges, to be established under the federal health reform law that passed in 2010.

Advocates in **New York** have made private insurance regulation a major issue. This past session, they were credited with (1) a major victory in restoring the authority of the Insurance Commissioner to not only review but also approve health insurance premium hikes, and (2) enacting other private market reforms. According to one policy-maker, "They made a big difference. . . The group shaped legislative proposals; they drafted opinions, did research and provided factual data for arguments. I don't think we would have done anything at all without their involvement." Another policy-maker said, "They helped shape the contours of the final statute. And their support was crucial in helping get this through the Senate, [where the bill] faced very vigorous opposition from the insurance and business community. [CVC leadership team members] were involved in almost everything." On changes to the employer buy-in portion of the Family Health Plus program, a legislator said, "There would have been no change to the employer buy-in premium structure without their involvement. They really did their homework, including [producing] actuarial data." Another agreed that consumer advocates, "…were very creative and effective in changing the position of [a senior state health official] regarding the Family Health Plus Employer Buy in Program; he was skeptical of their approach but they brought everyone along."

Ohio legislators also considered a package of insurance market reforms in 2009, which consumer advocates actively supported and were enacted that year as part of the state's annual budget. The provisions, which would make health insurance available to nearly 100,000 people according to some estimates, set a rate-cap for people with pre-existing conditions enrolled in private insurance through the state-mandated Open Enrollment Program, allowed dependents up to age 28 on their parent's employment-based policy and required small businesses to offer cafeteria plans to uninsured workers so they could buy coverage with pre-tax dollars. Said one policy-maker of consumer advocates, "They were involved in building coalitions around the initiatives . . . and they marshaled a lot of support. They also conducted policy analysis." Consumer groups in Ohio were also cited as being very involved in an initiative to reform the health care delivery system, and are leading a committee that is developing an enhanced primary care home model. They have also begun to exert some influence on state choices under federal health reform. One policy-maker thought consumers already "may have had an impact at the state level regarding implementation of high risk pools. The [CVC leadership team] is also advocating for how the Insurance Department is going to implement rate reviews, and they have been very active at the table in those particular discussions."

After federal health reform was enacted in 2010, many bills were introduced in the **California** legislature to authorize state implementation. In 2010, California became the first state to pass a law to set up a state health insurance exchange through which consumers can compare and purchase health coverage, and authorized state officials to negotiate with insurers on price. According to one

policy-maker, consumer advocates "played a crucial role in trying to develop the exchanges. They met with staff drafting legislation and with legislators and suggested amendments, sat on panels that promoted these bills, and they used their website and email contact lists to notify everyone about the various bills they supported. If the network were not there, the issues would be on the table but they might not be structured in the manner that they currently are. They raised the importance of setting minimum standard benefits for everyone, and the need to ensure transparency and accountability in healthcare." Another policy-maker said consumer advocates made a moderate impact on the debates concerning state options related to federal health care reform, but "without them, I think the outcome would have been the same."

Medicaid/CHIP Eligibility Changes

While there was little state-level debate on Medicaid or CHIP eligibility expansion in 2009-2010 due to state budget pressures, the American Recovery and Reinvestment Act of 2009 prohibited states from cutting Medicaid eligibility as a condition of receiving additional federal matching funds. However, some states did expand eligibility for children after the federal government re-authorized CHIP in early 2009. The Patient Protection and Affordable Care Act (federal health reform law) also gave states the option of expanding Medicaid eligibility to childless adults with incomes below 133 percent of FPL as of April 2010.

In 2009, **Colorado** lawmakers expanded CHIP eligibility to children and pregnant women with family incomes up to 250 percent of FPL and to parents with income up to 100 percent of FPL. They also enacted a provider fee, which helped to raise funds for these and other CHIP and Medicaid eligibility expansions. According to one policy-maker in the state, consumer groups had pushed for continuous eligibility for Medicaid beneficiaries (requiring less frequent re-determination of eligibility). While the Colorado CVC network also devoted significant efforts advocating for stronger regulation of private insurance plans offering small group and individual policies from 2008 to 2010, the policy-makers we interviewed were most familiar with their involvement in 2009 Medicaid and CHIP expansion policy debates. Although state policy-makers ultimately decided to expand eligibility to children and pregnant women first, consumer advocates "were heavily engaged [in trying to] change our mind, and continuous eligibility is in there as a long-term goal." (It will take effect in January 2012.) As one policy observer said, "Consumer advocates helped to pass the law that authorizes provider fees and we have a lot more people on Medicaid because of that."

In 2009, **Oregon** also expanded coverage to an estimated 80,000 children under age 19 in families with incomes up to 200 percent of FPL. One policy-maker believed that consumer advocates played an important role, "in a difficult budget time to get the coverage expansion through the legislature. They [were] part of the coalition that campaigned and worked with grassroots folks to influence legislators and get the final votes."

Maryland had enacted legislation in 2007 expanding Medicaid to childless adults earning less than 116 percent of FPL, but maintaining support for the expansion in tough budget times has been a challenge. Maryland's consumer advocates won high praise from many respondents for their highly visible publicity and outreach campaign, which has helped boost Medicaid enrollment among those newly eligible. According to one policy-maker, due to their efforts, "thousands more people enrolled in Medicaid, many of whom were eligible but didn't know it. That would not have happened without their media and other [outreach] efforts. They were definitely the leadership group in this arena." Another policy-maker agreed that consumers' involvement in "Medicaid outreach has been very helpful; their experience doing grass-roots outreach really made a difference."

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STATE POLICY- MAKERS' VIEWS ON THE ROLE OF CONSUMER ADVOCATES IN HEALTH POLICY DISCUSSIONS

APPENDIX B

INTERVIEW PROTOCOL

State: _____
Respondent Name: _____
Respondent Title: _____
Respondent e-mail and/or phone number:_____

Type of Respondent
___Governor's health advisor/staff
___Elected official/legislator
___Legislative staff
___Commission/board member or staff
___State agency director or staff (Insurance, Health, Medicaid)
___Health policy research organization:
___Private health foundation
___Business representative
___Other interest group representative, specify:_____
___Other, describe: _____

Respondent was also interviewed in 2008: ___Yes ___No

Date and Time of Call: _____
Interviewer Names: _____

Other Information *Use this section to indicate: (1) whether interview was cut short for any reason; (2) respondent substituted for original respondent (e.g., legislative staffer instead of legislator); (3) other information about the interview.*

Introduction
Thank you for making time to speak with us. This is _____ and _____from Mathematica Policy Research, a nonpartisan independent research firm. The Robert Wood Johnson Foundation has contracted with Mathematica to evaluate one of its grant programs called Consumer Voices for Coverage, which has supported consumer advocacy networks in 12 states, including yours, for the last three years.

The purpose of this interview is to elicit your opinion, as a key policy-maker or observer of health policy in [identify state], on changes over the past three years in consumer advocacy groups' involvement in, and influence on, state policy debates concerning health insurance coverage. We define consumer advocacy groups as those representing people who use health care services and purchase health insurance for themselves or families; it does not include groups of health care providers, health insurers, or employers.

Your responses will be kept completely confidential. We will not list your name as a respondent, and we will not identify you if we include any of your comments to illustrate a general point in our report to the foundation.
Do you have any questions before we begin?

A. Involvement of Consumer Advocates in Health Policy Debates
My first few questions are about the *involvement* of all consumer advocacy groups in your state in health policy debates.
A1. To what extent have consumer advocacy groups become more involved in state health coverage policy debates over the past three years? Would you say they are (*read all except "don't know"*):

__ Significantly more involved
__ Moderately more involved
__ A little more involved
__ No more involved
__ Less involved (*response option added)*
__ Don't know

For this question (and question B1), if respondents say "it depends," that is, some consumer groups were more involved than others, and start to provide detail about different groups, try to steer them towards a more general response by asking them to "think about ***all*** *consumer advocacy groups in your state" and "we'll ask about specific consumer advocacy groups later in the discussion."*

Comments:

A2. Which consumer advocacy groups have been **most involved** in state health coverage policy debates this year (or in the last legislative session)? [Open-ended response]:

B. Influence of Consumer Advocates on Health Policy Debates
Now I have a few questions about how *influential* consumer advocates in general are on the health policy debates in your state.

B1. To what extent have consumer advocacy groups become more **influential** in state health coverage policy debates over the past three years? Would you say they are *(read all except "don't know"*):

__ A great deal more influential
__ Moderately more influential
__ No change
__ Less influential
__ Don't know

B2. Why would you say they are (repeat answer given to B.1): (Open-ended)

B3. Compared to other key interest groups such as health insurers, health care providers, and large or small employers, has consumer advocacy groups' ability to shape or influence state health coverage policies changed in the past three years? Has their influence: [*read all except "don't know"*)]:

___ Increased relative to other key interest groups
___ Stayed about the same as other key interest groups
___ Diminished relative to other key interest groups
___ Don't know (Go to B.5) *If respondent says "don't know",* ***ask why****: e.g., not in the state, not in a position to judge 3 years ago)*

B4. Why would you say their influence has (repeat answer given to B3): (Open-ended)

B5. Which consumer advocacy groups have been **most influential** in state health coverage policy debates this year (or in the last legislative session)? [Open-ended response]:

C. **Knowledge and Perception of CVC Network (or Grantee)**
Now I have some questions specifically about [name CVC network] in your state.

C1. How familiar are you with [CVC network]? In other words, how well do you know which groups are members, their goals and positions on major health coverage policy issues? Would you say you are [*read all]:*

__Very familiar
__Moderately familiar
__A little familiar
__Not at all familiar*

Comments:

** If interviewee is not at all familiar with CVC network, identify CVC grantee and list the LT members of the CVC network - have these names/lists in hand before the call! If the leadership team has more than 10 members, list just four or five of the more prominent organizations. Then ask:*
C.1a. How familiar are you with the [CVC grantee] and these LT members' goals and positions on major health coverage policy issues?

__Very familiar
__Moderately familiar
__A little familiar
__Not at all familiar

C2. I am going to read you a list of major health policy issues, and for each one I would like your opinion on **how involved** [CVC network name] was this year (2010), or in the last legislative session, in state policy debates on these issues. Please tell me if you think they were: significantly involved, moderately involved, barely involved, or not at all involved (*Don't mention "don't know;" just check below if respondent volunteers that response)*

Issues	**Significantly involved**	**Moderately involved**	**Barely involved**	**Not at all involved**	**Don't know**
a. State Medicaid/CHIP expansions					
b. Opposing or trying to minimize proposed cuts to state health program budgets					
c. Private insurance market reform/regulation by the state					
d. Federal health reform (adoption or state implementation)					
e. Comprehensive state health reform addressing coverage, cost and quality					
f. Other, describe:					

Comments:

C.3. On which one of the following state health policy issues was [CVC network name] **most involved** in 2010, or in the last legislative session? I'll list them again (*read all except "don't know"*):

___State Medicaid/CHIP expansions
___Opposing or trying to minimize proposed cuts to state health program budgets
___Private insurance market reform/regulation by the state
___Federal health reform (adoption or state implementation)
___Comprehensive state reforms addressing coverage, cost and quality
___Other, describe:
___Don't know

Comments:

(*If respondent cites a specific bill, proposal, referendum, etc. suggest that it be placed in one of the above categories and ask respondent to verify that the category is appropriate. For Questions C6 and C7, cite the "shorthand" bill, proposal, referendum, or commission report.)*

C.4. **To what extent** did [CVC network name] change or affect the outcome of the debate on this issue (identified in C5)? Did they (*read all except "don't know"*):

___ Make a big difference
___ Make a moderate difference
___ Make a small difference
(**Go to C.7 if respondent cites any of the above)**

___ Did not affect the outcome at all [*if this response is checked,* ***ask why*** *[CVC network name] did not affect the outcome of this issue*? **Then go to C3**

___ Don't know [go to C3]

C5. *For respondents that answered big/moderate/small difference in C6, ask:* **How** did [CVC network name] change or affect the outcome of the debate on this issue? [open-ended; **if the outcome is not clear, ask respondent to explain it briefly]**

Probes:
a. For legislation or budget actions: Did their support help to pass, or their opposition help to defeat, the proposal?
b. How did their support or opposition to particular provisions change the final legislation, rules, Commission recommendations or budget actions?
c. What might have happened had [CVC network name] not been involved or tried to influence the debate? Do you think the outcome would be different or the same?

C.6. Next, I'm going to list six advocacy activities and ask you to tell me how effective [CVC network name] is **now** in carrying out these activities. Were they very effective, moderately effective, or weak/not effective? [*Don't mention "don't know"; check if respondent says it]*

	Very effective*	**Moderately effective**	**Weak/not effective**	**Don't know**
1. Building coalitions or alliances with other key interest groups				
2. Grassroots organizing or building strong grassroots support				
3. Policy analysis to determine likely impacts of policy choices, or develop policies				
4. Conducting campaigns that engage policy-makers across parties and viewpoints				
5. Media relations and communications				
6. Fundraising/generating resources to support advocacy campaigns				

C7a. * *For any activities that get a "very effective" response, ask*: Why are they so effective? (e.g., grassroots coalition is large/active in all districts, or small but dedicated and active)

C7b. * *For any activities that get a "weak or not effective" response, ask*: Why are they so ineffective? (e.g., grassroots is small/not in many districts, don't engage across party lines)

C8. *If you think you may be pressed for time, this question is optional:*
Compared to three years ago, how would you rate [CVC network name]'s ability to perform these advocacy activities? I'll list each advocacy activity again, and for each one, tell me if you think [CVC network name]'s ability has improved, stayed about the same, or worsened in the last 3 years.
(*Check "don't know" if respondent says don't know enough or not able to assess changes)*

	Improved	**About the same**	**Worsened**	**Don't know**
1. Building coalitions or alliances with other key interest groups				
2. Grassroots organizing or building strong grassroots support				
3. Policy analysis (to determine likely impacts of policy choices or to develop policies)				
4. Conducting campaigns that engage policy-makers across parties and viewpoints				
5. Media relations and communications				
6. Fundraising/generating resources to support advocacy campaigns				

Comments:

C9. When you consider all of the major state health coverage policy debates that took place in 2010, or in the last legislative session, was [CVC network name] usually "at the table" when key decisions were made? Were they usually, sometimes, or rarely an active participant in meetings when key decisions were made?

__ Yes, usually
___Sometimes
__ Rarely
__ Don't know (go to C9)

C10a. Why was the CVC network [usually, sometimes, or rarely] invited to the table when key decisions were made? *(8b and 8c cover this question)*

C10b. If usually or sometimes, were they invited because of their influence or because their opinion matters, or did they "push their way in"? If invited to the table, what did the group have to offer, why was it important to have them there?

C10c. If rarely, why were they not invited?

C11. When you consider all the things the [CVC network/coalition] has done over the past year or two, are there any particular activities, events, campaigns, or messages that stand out as especially influential—positive or negative—on state health policy debates?

D. Consumer Involvement in Future Health Policy and Last Thoughts
Only ask these 3 questions if any time remaining. I have just a few more questions.

D1. What do you think the CVC network needs to do to make a greater contribution to policies or policy debates on health coverage expansion in your state in the future? What could they do better or differently?

(Open-ended response):

(If useful, can use these as probes and check if responses fit into the following categories:
___Create political urgency to address health coverage
___Unify positions on coverage policies
___Develop coordinated messages
___Educate the public
___Be willing to compromise to make incremental progress
___Develop alliances with nontraditional partners

D2. The CVC grant will end this year. What do you expect would happen if [CVC network name] was no longer able to marshal the resources and coordinate the positions and advocacy activities of its consumer organization members?

D3. Is there anything else you would like to say about the role, involvement or influence of consumer advocacy groups in your state's health coverage policy debates, or RWJF's grant to the CVC network?