
All for One and One for All: *Promising Practices for Consumer Health Advocacy Collaboration*



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Introduction and Summary

Since the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, consumer advocates have redoubled their efforts to ensure that the implementation of the new health law maximizes coverage and care. Expectations are high for consumer health organizations to be part of implementation decisions. As the watchdog, the expert, the organizer, and the advocate in legislative and regulatory decision making at both the state and federal levels, today's environment necessitates consumer advocates work collaboratively toward common goals.

Community Catalyst's philosophy for building a "system of advocacy" is based on the understanding that no one organization has all the capacity or the expertise for effective and sustained consumer health advocacy on its own. Central to a working system of advocacy is the ability to link together the complementary skills and voices of a diverse collection of consumer organizations through a coalition, network or other alliance.

Generally, the objectives for consumer advocacy collaboration are twofold: to create a comprehensive system of advocacy with connections to stakeholder organizations in order to increase consumer power and visibility to achieve the health care policy goals deemed necessary and appropriate *and* to create a space where health care advocates can be strategic, honest, and successful together.

Community Catalyst has fostered the development of statewide coalitions from Florida to Oregon and seen the results of successful collaboration in state consumer health advocacy through its work in more than 40 states. An initial in-depth study of 16 states conducted by Community Catalyst in 2006 demonstrated the positive correlation between advocacy capacity and policy change impact through the effective use of a system of advocacy.¹

A recent evaluation of the Consumer Voices for Coverage program, funded by the Robert Wood Johnson Foundation (RWJF) and managed by Community Catalyst, revealed conclusions reaffirming those in the 2006 report: state advocacy organizations that worked in coalition together saw a number of mutually beneficial results. As documented by Mathematica Policy Research (MPR) in a *Health Affairs* article last year, state consumer health advocacy networks overall increased and strengthened relationships among groups, had greater visibility for the consumer in health care policy debates, had more interactions with policymakers than before, and had bolstered their influence on health coverage policy.²

Over the past two years, consumer advocates across the country have been met with new challenges and new opportunities to make the consumer voice heard in ACA implementation decisions. Federal impetus for organizations to weigh in on health insurance Exchange regulations or to protect the state Medicaid program as the foundation for increased health coverage in 2014, for example, provides common goals for many consumer advocates to work toward together. But how is it done?

About This Report

In working closely with state-based advocates that are building or maintaining consumer health coalitions, Community Catalyst identified some important lessons and promising practices for others who are developing their own collaborations. Additionally, we interviewed five representative state consumer advocacy organizations specifically to gather additional details about how allies and partners work together in Georgia, Kansas, Ohio, New York, and Texas. Community Catalyst found four common factors that influence the successful establishment and maintenance of statewide health advocacy networks or coalitions.

1. Work together with purpose: find a structure that works for your state environment and allow it to evolve as needed
2. Make it operational: establish understandings about membership, form operating agreements and promote regular communications
3. Foster leadership and shared capacity building
4. Find the funding to support and sustain collaboration

1. Find a structure that works for your state environment and don't be afraid to change it when needed

The health advocacy community at large is not very big. At the state level, advocates see each other regularly at the same meetings or congregate outside chambers at the capitol building during legislative session. Often times, advocates work together on important issues again and again over many years. Organizational relationships develop and pockets of communication evolve.

However, when advocacy collaborations become more formalized, advocates also become more effective. Working in more coordinated arrangements with other health advocates has historically been a significant factor in successful statewide health advocacy initiatives. Collaboration makes it possible to leverage strengths of varied organizations and their leaders, be it organizing or policy analysis or communications. But when the topic of “working with partners” comes up, one of the most common questions is about how to organize the way groups work together. Is it called a coalition or a network? Or does it matter? The simplest answer is it depends. While evidence from the MPR evaluation suggests that formalizing the consumer health advocacy coalition had a marked impact on achieving policy objectives and increasing advocacy capacity, every network did not look the same.

Community Catalyst's view across the country reveals that in almost every experience, the arrangement that is the most successful is the one that works for a specific state environment and the health advocacy partners in that environment. A scan of state-based consumer groups shows many different models of working with allies and partners.

Assess the needs of your advocacy community and identify your goals and purpose

While one size does not necessarily fit all when it comes to coalition or collaboration, it is evident that advocates are most effective when they work together, with purpose, toward common goals.

Some groups find their unity in information sharing, recognizing that regular communication among the advocates inspires stronger relationships and advocacy across the community. Others coordinate activities and take action together on a common advocacy agenda or on multiple issue campaigns. State advocates must first assess what is already happening on the ground, what is needed to create a stronger collective voice for health care consumers, and determine what is the best way to begin.

In Texas, the Center for Public Policy Priorities (CPPP), started their coalition as an information-sharing network during the federal debate around national health reform. Called Texas Voice for Health Reform, it was a way for groups who had an interest in state and federal health policy issues to share information and coordinate when possible. It also provided a more comfortable structure at the time when many groups were not willing politically to be seen as advocating for health reform.

While the original purpose was to allow groups to communicate more regularly, their current, more formal coalition formed out of it. Renamed Cover Texas Now, the Texas coalition now works collaboratively on a common legislative and regulatory agenda around ACA implementation. Cover Texas Now focuses primarily on private insurance issues and works in coordination with the Texas CHIP Coalition that prioritizes Medicaid and the health of parents and children.

Kansas' coalition is another example of an issue-based collaboration. There, the Kansas Health Consumer Coalition (KHCC) leads two alliances: one on health reform and another on Medicaid. While there is crossover with organizations participating in both alliances, different groups emerge

as leaders within each alliance as a result of expertise. Anna Lambertson, executive director of KHCC, emphasized their objective in forming the issue alliances was to establish more collaboration among the health advocacy community, and she said KHCC is considered the anchor organization across each of the alliances.

Be flexible: allow your collaboration style to evolve with the changes in environment, new relationships, and shifting purpose

Establishing structure is important, but don't be afraid to change things when an opportunity or a challenge presents itself. For some, having more structure in the beginning provides clarity about roles, responsibilities, and expectations that can create a sense of comfort. For others, building working relationships in a more informal way can provide the openness needed to inspire collaboration.

Either way, it's important to be adaptable. Consider the constantly changing political environment within which health advocates work. Prominent issues ebb and flow, creating new opportunities, as do organizational capacity and leadership. Relationships and leadership among groups change, and finding new ways of working together can mean success or failure. What works now in your state advocacy community might not be as effective in six months or two years. Allow your collaboration style or structure to evolve, but maintain a sense of direction and purpose for working together.

Until last year, the Ohio Consumers for Health Coverage (OCHC) coalition, led by UHCAN Ohio, had one level of membership, which required agreeing to the guiding coalition principles. However, they recently adjusted their membership structure to accommodate a few groups that wanted to participate in the advocacy campaigns and were supportive of the coalition's principles, but either couldn't sign-on as an official member or did not have capacity to serve on the coalition.

Recognizing the benefit of having a larger collective voice for their advocacy agenda, OCHC members decided to change the coalition membership structure. Now they have two tiers of membership: leadership team members and leadership team partners. Partners are organizations who support the principles and the priorities of OCHC, who participate in the activities of the coalition, but who are not listed publicly as members and cannot vote in the formal decision making process (however most decisions are made by consensus; see more about OCHC decision making below). This tiered membership allows flexibility for groups who have common interests to participate, even when organizational constraints might prevent them from listing their name as part of membership.

2. Establish understandings about who's in and who's out, form operating agreements, and promote regular communications

Making the collaboration work is a combination of several important elements, including staffing and leadership, membership expectations, decision making, principles or common points of agreement, and regular communication. If members of your alliance, or network are on board with each of these operating assumptions, then being able to identify common strategy and coordinate complementary activities should follow. Not that it's ever easy, but having an agreed-upon foundation for how your coalition operates can help alleviate potential anxieties about rules and power so consumer advocates can focus on the policy change goals they are working toward together.

Establish understandings about membership

Defining who is welcome to join your coalition or network or alliance can be politically and strategically challenging. The purpose of establishing a framework for collaboration in the first place is to foster greater capacity and coordinate strategy to build power and visibility for consumer interests. But if there are groups around your table with whom everyone is not comfortable, it can cause hesitancy and unwillingness to share critical information.

Overall, the decisions about membership criteria are also driven largely by the state advocacy environment. However, in most cases, consumer advocacy coalitions tend to define their membership by striving to make it as representative as possible of the "consumer voice" or of organizations working in the best interest of health care consumers, rather than organizations that may represent other interest groups, such as providers and insurers.

In Kansas and Ohio, consumer advocacy leaders say they are very intentional about reaching out to a broad array of organizations. "We want to authentically say that we're representing organizations that work with all different kinds of consumers," said Lambertson from KHCC. "We generally invite any statewide or community organization that does health work." Most state advocates say they don't define their coalition or network membership criteria formally, but determine it on a case-by-case basis. "It's more like you know it when you see it," said Kathleen Gmeiner, project director from UHCAN Ohio which is a leader organization in OCHC.

While Ohio's coalition has an informal membership recruitment process, OCHC has a more traditional coalition structure, with a separate coalition name, a leadership team of voting individuals and organizations who make decisions for the coalition, decision-making agreements, and membership requirements to support coalition principles.

Similarly in New York, membership to the statewide Health Care For All New York (HCFANY) coalition is open to anyone who wants to sign-on to their 10 standards for quality affordable health care. Membership organizations are primarily consumer groups, but it's not designated as criteria for HCFANY membership. Elisabeth Benjamin, vice president of health initiatives at Community Service Society (CSS) and leader in the HCFANY coalition, uses Small Business Majority as an example. She said that while they're not a consumer group, Small Business Majority worked with HCFANY for so many years as a close ally, that it made sense for them to be part of their coalition; they're now a member of the Steering Committee.

About Stakeholders

The groups referred to here as consumer health advocates are primarily those that represent the interests of people who use the health care system, including the uninsured and underinsured and people enrolled in public programs such as Medicaid. Generally, consumer health advocacy organizations and coalitions seek to ensure that quality, affordable health care is available to as many people as possible. Consumer advocates bring together consumers, those that don't have an industry speaking for them, to represent their interests in the policy debates that affect access to quality, affordable health care.

Other interests, such as those of hospitals, insurers, physicians, business, etc. are health care stakeholders. Stakeholders are usually well-organized and have the money and the means to influence policy decisions that affect their interests in health care.

Consumer advocates tend to use their coalition, or network structure to identify opportunities to work with stakeholders rather than to invite these groups to join. In fact, in many states, consumer coalitions formally coordinate advocacy efforts with other stakeholders on specific issue campaigns where there is shared interest. By doing so, consumer advocates broaden support for a particular health policy change to more effectively counter opposing interests.

In Kansas, their consumer alliances have found a middle ground. They include safety-net clinics and mental health centers because the groups have identified common issues and advocacy goals. Lambertson at KHCC said they have been cautious about partnering with the hospitals or medical associations, but the consumer alliances do reach out to these stakeholders on specific topics when it makes sense.

In New York, HCFANY has a wide diversity of stakeholders who participate in coalition activities. Some groups like religious organizations, other coalitions, providers, and individual insurance brokers have signed on as official HCFANY stakeholders, but they do not participate in meetings of the membership committees.

In Ohio, UHCAN Ohio executive director Cathy Levine said they don't attempt to involve stakeholder groups in the OCHC coalition. "We have active relationships with many of the health care stakeholders; relationships that have been built over many years," she said. "We seek input as needed with stakeholders, try to always make sure that opportunities exist for multi-stakeholder input, and build alliances as we can on key issues." Prior to OCHC's development, some of the same organizations had built and still maintain the Ohio Family Coverage Coalition, which includes hospitals, managed care plans, safety-net providers, and consumer advocates and works on coverage issues of common interest.

Georgia advocates meet regularly under the umbrella of "health advocate meetings," and keep it purposefully informal, but consistent. "We had a lot of cohesion when we started asking groups if they wanted to participate in these regular meetings," said Cindy Zeldin, executive director of Georgians for a Healthy Future (GHF). "It didn't feel like it was beneficial to say who's in and who's out."

Zeldin went on to reiterate the common theme that they "know it when they see it" regarding membership. "Right now we tell new groups interested in joining our meetings that there are some expectations: they need to understand that we know not everyone is going to agree on every issue, but everyone gets some benefit from participating, and we ask everyone to act respectfully toward one another and to respect confidentiality."

In Texas, however, they explicitly limit membership in the Cover Texas Now coalition to consumer and public interest organizations. Anne Dunkelberg, associate director at CPPP and a leader in the Cover Texas Now coalition, said they sometimes invite a particular provider group to join a meeting if there's a relevant issue being discussed, but they don't generally open up formal membership. She gave the

examples of social workers, mental health providers, and community health centers as examples of allies who frequently join their coalition conversations. Even the Texas Medical Association and the Texas Hospital Association often collaborate. “But it’s going to be an evolving issue about how we deal with providers and other stakeholders in the coalition membership,” Dunkelberg said.

Set expectations about principles and decision making

Overall, advocates tend to respond to the needs of their partners, but having some understanding about decision making and expectations can help gain the most buy-in and participation in the long term. Principles or similar common points of agreement are an operating procedure that many coalitions or alliances use, but such principles are not always developed or used for the same purposes.

For example, in Kansas, the Medicaid and health reform alliances each establish individual issue-specific principles and promote those principles under the KHCC umbrella with alliance members listed as supporters. Lambertson said branding under KHCC’s name has not posed any leadership or visibility competition among members because they develop the principles through thoughtful consensus building to represent everyone’s constituency and to find a shared message that every member can take ownership over. They use the principles regularly for decision making. Lambertson said having the principles helps the alliance members stay focused in conversation and when reacting to outside circumstances. “It’s been really helpful to keep us moving forward,” she said. “Literally in my mind, I will picture the principles and remind myself to stop and think about what we’re trying to accomplish.”

In Texas, Dunkelberg described both their Medicaid coalition and their broader consumer health coalition to underscore the different ways of using principles. Their Medicaid coalition comes up with new principles for a legislative agenda every session. For this coalition, their principles change to reflect the common goals of the legislative session. Cover Texas Now has overarching principles that each participating organization signs on to support. They develop legislative priorities under those existing principles through an iterative process of discussion until everyone is comfortable and everyone signs on to the legislative agenda too.

Role of Stakeholders and Others in Your System of Advocacy

Your system of advocacy is bigger than your coalition: Understanding that the network, alliance or coalition of consumer advocates is not where partnership stops is also an important lesson. Most of the time a consumer coalition is a collection of consumer interests working together to create a stronger, unified, consumer voice. But to be truly effective, consumer advocates should identify stakeholders, other activists, business organizations, etc., who have overlapping interests issue-by-issue and build relationships to create a broader system of advocacy to support common consumer-driven health policy outcomes.

Levine, in Ohio, gives the example of how OCHC and Progress Ohio work together. OCHC interacts closely with the administration, legislators, and other stakeholders on complex implementation issues. Progress Ohio, a close ally, coordinates Ohio’s Health Care for America Now (HCAN) coalition, which tends to be more edgy and polarizing in its messaging. Progress Ohio is an active member of the OCHC coalition, but maintains a separate voice alone and as part of HCAN. Instead of this being a deficit of the coalition, it works to their advantage. The groups can coordinate individual responses to be complementary, but not the same; they can tag-team different types of activities so that one group does the heavy hitting on an issue while the other comments on the issue from a policy perspective.

Dunkelberg notes that this process presents challenges when an issue comes up during part of the year the legislature is not in session; in those cases, it becomes more ad-hoc for which groups participate along the way. Getting involved in the Medical Loss Ratio (MLR) debate at the federal level was one of those times. The Cover Texas Now coalition had not identified a position or an agenda around the state being exempted from the MLR requirement under the ACA, so when it came up, a subset of coalition members took it on and coordinated efforts as a workgroup, not representing the full Cover Texas Now coalition.

In Ohio, their coalition's decision-making model is referred to as modified consensus building. Members come to agreement using consensus, but if a member feels they can't support a particular action however doesn't want to stand in the way of the coalition moving forward, they will let the minutes reflect that the member abstained. Overall, the OCHC coalition decisions are guided by broad health reform principles that all members signed on to and by the agenda developed through regular planning retreats.

With a 120-member coalition, New York's HCFANY campaign coalition designates its decision making to members of the Steering Committee. Decisions are made through consensus, however Benjamin from CSS emphasized that no one group has individual veto power. However, if enough partners are hesitant about a decision, there's usually agreement to step back by the full Steering Committee. New York's coalition employs a systematic committee structure, including committees on policy, organizing, and health equity, each operating with separate leadership under the Steering Committee.

While consumer advocates employ a variety of different models and levels of formality with regard to decision making and principles, one theme emerges across each collaboration structure that helps make them work more successfully: consistency.

Create consistency to encourage more collaboration

Consistent communication stands out as a critical factor for making any coalition, or network effective. Whether it's a formal agreement for working together or not, just creating a consistent space for sharing information and acting together with one or more partners creates more trust and effective collaborative advocacy.

Zeldin from GHF said advocates in Georgia have been meeting at least once per month for two years, and more often during legislative session. She noted that regular meetings among the advocates have resulted in other important kinds of collaborations, such as sign-on letters in support of the Medical Loss Ratio, co-releasing issue reports, leveraging and sharing contacts, and being able to identify and bring broader groups of advocates into meetings with officials from state and federal agencies.

In Kansas, Lambertson said she views regular meetings as vital to the success of their health care alliances. With advocacy groups typically operating in individual silos, the regular meeting times allowed groups to get to know each other better and have opened up more willingness to see where there's alignment with one another.

With multiple committees, HCFANY in New York has a fairly formalized meeting structure. The Policy and Steering Committees meet bimonthly and other committees meet on varied schedules. One challenge to consider with meeting schedules though, is to be flexible. Slow down the regular

schedule when less is happening and pick it back up again later or be aware of how multiple committee meeting schedules affect members who participate in many capacities. Also, consider augmenting meetings with other communications mechanisms like a Google Group (an email list serve). For example, Georgia advocates use a Google Group to share quick updates from a legislative meeting or to initiate rapid response to a press story.

3. Foster leadership and shared learning

Leadership can bring advocates together toward a common vision the same way the lack thereof can leave groups suspended in inaction. The importance of strong and trusted leadership for successful health advocacy cannot be overlooked.

Coalition leaders offer more than policy expertise. In the MPR evaluation findings, Community Catalyst identified leadership as an additional core capacity for effective health advocacy, defining a leader as someone who's enthusiastic, a good communicator, and who has the ability to motivate and inspire others.³

Observations of multiple coalitions across the country have also revealed that partner organizations feel more at ease and protected when they trust that the leader is a skillful listener and understands the nuance of different organizational positions. The role of relationship builder is also central to leadership. Many times, coalition dynamics are influenced by the work that a good leader does behind the scenes to build understanding among groups to find agreement.

Lambertson at KHCC highlighted a turning point in consumer advocacy in Kansas. She noted the statewide convening that KHCC hosted with Community Catalyst specifically focused on implementation planning for the Affordable Care Act. She said that setting presented the right opportunity for KHCC to emerge as a coalition leader and they continued to build on it. Now others look to them for information and for continued leadership in bringing the advocates together.

Establish models for shared leadership and learning

A network or coalition is as strong as its members. That means leadership, expertise, decision making, and public confidence should be cultivated and shared among participants. Three shared leadership strategies stand out among successful health advocacy coalitions: 1) develop the knowledge and skills of every member; 2) ensure decision making is participatory and collaborative, and 3) provide opportunities for all members to be the public face of the coalition or network.

This kind of attention to individual coalition members helps make the collaboration as a whole more powerful since others will not only see one organization as the face of the movement, but will see the dynamic fusing of skills and leadership on prominent health advocacy priorities.

In New York, they attribute part of their success to having several really strong leaders to guide day-to-day strategy and decision making. With a truly shared leadership model, different coalition members take on committee chair roles and lead with their expertise. As the coalition convener, Benjamin emphasized that recognizing the expertise others have and giving them the opportunity to share it makes partners really feel valued and makes the collaboration work.

In Georgia, the health advocacy community doesn't work together under a set of principles and doesn't take positions together as a group. Their purpose is primarily information-sharing, but sometimes they identify two to three groups that an issue is most important for and those groups work together to raise the profile of that topic more publicly. The subset of advocates will co-brand any position, sign-on letter, or press on the issue. Zeldin from GHF said this way of working helps build shared leadership because different organizations take ownership depending on the issue. By doing this, they are able to highlight the expertise of a variety of groups and individuals and promote the public leadership of many organizations on important health care topics.

Advocates in Kansas and Texas also approach their coalition efforts with an eye toward shared leadership and learning. In Kansas, Lambertson said a core tenet among members of their Medicaid and health reform campaigns is to always work together to find similarities among each organization's positions on an issue; that way each group delivers a unified message that draws on common threads from their partners' messages. This communication among the group creates a lot of opportunities for education about different perspectives on an issue and in the end builds a bigger base of advocates who can deliver a well-rounded message on their priority health care campaigns.

In Texas, Dunkelberg highlighted the important role that each member of their coalition plays in educating and developing advocacy skills of other members. For example, the groups that are known as policy experts take the lead on getting partners up to speed on the issues and policy developments; organizing leaders can help not only turn out for events, but can provide tools such as online petitions or alerts that smaller organizational partners can use to mobilize their own constituencies.

Finally, in Ohio, Levine emphasized the importance of building a coalition with a common understanding that there's something in it for everyone. For example, she said that over the years, they've refined the way they do outreach to new members for the OCHC coalition, particularly as they've focused more on engaging others that are interested in addressing health equity issues in the state. "We don't just invite someone to sit at *our* table," Levine explained. "We gather together to talk about their goals too and the ways that working together can drive us all to the outcomes we're looking for. We've also become more attuned to the special issues of advocates for people with disabilities and advocates on mental health issues, both of whom are part of our coalition."

4. Find the funding to support collaboration and staffing

The ability for any group to build, lead, or participate in any health advocacy collaboration is often influenced by the level of funding support available. Funding all the critical work that needs to be done is hard for every consumer advocacy organization. But in most cases, taking on coalition leadership often means also taking on the burden of funding—and fundraising—for the work of the group as well.

Consumer advocacy coalitions and alliances have started under different funding scenarios. For example, in New York, Ohio, and Texas, collaborations began as a result of a grant deliverable. OCHC in Ohio and the HCFANY coalition in New York were formed as a result of the RWJF Consumer Voices for Coverage program, which required the formal development of a statewide consumer health network with common objectives, policy priorities, and coordinated advocacy campaigns.

In Texas, CPPP was a grantee under phase two of the RWJF Consumer Voices for Coverage program, a project more targeted at supporting state-based organizations that were well positioned to educate policymakers and the public about the importance of reforming our national health care system than building capacity.

Determine how or if resources will be shared among partners or members

Depending on the health advocacy community and the circumstances surrounding funding opportunities, different coalitions or networks decide to distribute funds in various ways.

In Texas, Dunkelberg explained that grant money in the state was used to support CPPP's role in building, planning, organizing, staffing, and leading the coalition's efforts. CPPP also took on a fundraising role to bring in additional grants from local foundations to support the growing coalition. Funds were not distributed to other partners for participation in the Cover Texas Now coalition.

Similarly in Ohio, coalition partners are not funded to participate, and the initial grant primarily supported UHCAN Ohio as the convening organization in building and staffing the coalition. Levine from UHCAN Ohio, explained that the arrangement was a reflection of the Ohio advocacy community. Most of the original OCHC members were either large organizations who didn't need the grant funding, but who wanted someone else to staff the effort, or small groups without the capacity to take on a substantial piece of the work.

UHCAN Ohio does subcontract some of their grant funding out to selected partners, in part, to diversify the coalition, but Levine emphasized that they subcontract for more than just participation or deliverables. "We pick the groups we subcontract with carefully to make sure they have the capacity to do what's needed and to go beyond deliverables to be outcome driven," she said. "By investing in groups who want to see the same outcomes as we do, we are doing more than checking off numerical deliverables—we are building capacity within the coalition to achieve our common goals."

New York is perhaps one of a few outliers among advocacy coalitions with regard to re-granting dollars. The HCFANY coalition subgrants between 60 percent and 70 percent of its grant funds, with CSS keeping a percentage for administration of the grant. This is possible, in part, because

CSS is a large, well-established organization with dedicated and diversified funding sources. Benjamin at CSS said that grant funds are open to anyone from the Steering Committee. Members submit proposals to fund the work agreed upon in the coalition's annual workplan development. CSS and another non-bidding member review proposals, make grant awards, and then the workplan is updated with details about who is responsible for each area of work. This ensures transparency and that everyone sees who is funded to do what.

"Groups are not funded just to do activities or deliverables," Benjamin from CSS said. "They are funded to do the work that is required to be part of the coalition." For example, chairing a committee is something an organization can be funded to do as part of their funded coalition responsibilities. She explains that this practice keeps all the funding issues transparent, so no one worries why one group got more money than another. It also helps partners feel more invested. They're not just a member coming to meetings; they're accountable for making the coalition successful too. Benjamin noted that this way of sharing funds also works to help diffuse leadership among partners so it's not seen as too heavily focused on CSS as the administrator of the grant.

"We have an incredibly aggressive and robust advocacy environment," Benjamin explains. "People like each other and want to work together and because there are resources, it works. The money is important. We fund our partners and they feel respected."

Diversify to sustain the funding support

Sustaining consumer advocacy collaborations in states poses a challenge across the board, no matter, it seems, how similar or different the initial financial support is. In Ohio, now that the initial grant supporting the coalition has ended, UHCAN Ohio worked to diversify its own organization's funding base to support the continued staffing of the coalition. In Texas, the Cover Texas Now coalition is planning a meeting to plan how to raise money together to support the coalition. Dunkelberg said they will likely try to find ways to seek joint grant funding to help strengthen buy-in and unity among the groups. In New York, they've also sought additional grant funding to continue the work of the coalition.

Levine in Ohio said they sometimes engage coalition members in fundraising on a small scale by seeking support among the membership for specific coalition activities, like a retreat or an event. Gmeiner in Ohio also mentioned that the coalition considers the time and leadership that partners put in as in-kind support of the coalition's work. By doing this, UHCAN is able to recognize the investment of time and resources that other groups are donating to the coalition efforts instead of requesting a financial investment.

Consumer alliances in Kansas and Georgia began with support from the convening organization's core operating funds only; there was no grant or funding stream dedicated to developing an alliance or network to work on consumer advocacy issues. For both KHCC and GHF, building a coalition around common health policy priorities is seen as part of their organizational missions. However, while KHCC and GHF currently continue to support coalition efforts with their own core operating funds, both Lambertson and Zeldin emphasize that it's becoming critically important to identify more diverse funding sources to sustain the coalition building capacity and to support the growing work of their consumer alliances.

In Kansas, where their structure is an informal network that they've built from the ground up, Lambertson said the biggest challenge they have encountered for funding is that a funder wants

something more concrete, with a name attached to it. She said it's been difficult to articulate what they're accomplishing together informally and to help a funder understand that the groups working collaboratively is a huge success compared to where health advocacy groups were before.

Zeldin in Georgia echoed those sentiments. She said their health advocate meetings are working well for them now and have been extremely effective. The groups participating are not ready for a formal change in the way they work together. However, she noted, a more formalized structure down the line might help make the relationships more sustainable.

In all coalitions, including more informal collaborations or networks, it is critical for advocates to clearly articulate what they have and will accomplish together that they couldn't have done otherwise. It's also important to identify the contributions of the participating members in ways that can be shared by everyone. Even without guiding principles or operating agreements that bind a group of advocates together, it's still possible, and essential, to develop an agenda that helps make it clear for funders what the advocacy community is doing together. Both issue-specific successes and process- and relationship-building goals should be articulated and claimed when accomplished.

Outcomes: What Consumer Advocates Accomplished Together

Consumer advocacy collaborations not only produce more policy wins, but also result in increased capacity to be effective and credible consumer advocates in state and federal health policy debates. Below is a snapshot of outcomes that some of the state collaborations highlighted as significant success factors in their work with partners.

Demonstrated expertise and credibility: In Kansas, the health reform alliance meant consumer interests were heard in the development of the state health insurance Exchange recommendations. Advocates successfully secured a recommendation from the insurance agency that the Exchange governing board should have a majority membership of consumers. Subsequently, advocates further broke new ground by securing monthly meetings with insurance department staff, creating a first-time ongoing conversation between the state insurance agency and consumer advocates.

Rapid Response: Health advocates in New York have been able to maximize their rapid response through the HCFANY coalition, particularly on policy issues, and add a consumer voice where one is needed. In an example from last spring, a CSS client wanted to challenge their proposed insurance rates, but couldn't find the information they needed about their rates. After reaching out to the state department of insurance, the insurance company got involved and created opposition to releasing the rate information. HCFANY's leadership Steering Committee acted swiftly to put out press statements, organize outreach to the state agency and make sure the interest of the individual were heard over the insurance company.

Increased capacity to implement a multi-faceted campaign: In Texas and Georgia, advocates pulled out all the stops in each state's Medical Loss Ratio (MLR) fight. Cover Texas Now responded to the state's request for an exemption to the ACA's MLR requirement by garnering close to 6,000 individual signatures to support the MLR requirement. They also successfully placed opinion editorials in three major daily newspapers, briefed lawmakers about the issue and secured a letter to the Secretary of Health and Human Services from state Democratic lawmakers and members of the Texas Congressional delegation, and finally submitted comments to HHS during the formal comment period on the regulation exemption. By weaving together the strengths of

different partners, the coalition was able to quickly put into action all the needed campaign components at the state and federal levels to accomplish an important policy win for Texas consumers.

Georgia advocates had similar success, using their statewide health advocates meetings to identify a workgroup of organizations to strategically advocate against their state's MLR exemption request. Advocates identified key reporters and kept them briefed and updated regularly, which helped secure statewide press when they filed comments during the formal comment period. They also developed and released an issue brief that 17 organizations had signed-on to, creating more press opportunities. The visible campaign strengthened the relationship between advocates and the state department of insurance and helped to establish a precedent for effective collaboration among advocates in the future.

Elevating a united consumer voice: In Ohio, the OCHC coalition has elevated the consumer voice in health care debates by identifying strong joint policy positions and leveraging the expertise of each group sitting at their table. OCHC emphasized the coalition's commitment to speaking as a united voice so that the consumer perspective is not overlooked. By strengthening their united front and putting the policy, grassroots, and increased communications expertise to work, OCHC has become the go to consumer voice around matters of health care in Ohio. Their voice and credibility is now an established part of health policy discussions, which has been particularly valuable through political changes in the administration.

Conclusion

In the months since the Affordable Care Act was signed into law, the political environment in states and nationally has become more volatile. At the same time, consumer health advocates across the country are actively engaged in both federal and state-level health policy debates. The movement toward reform has bolstered the confidence of those who want to see the health care system improved and provided the stage to amplify the consumer voice.

From private insurance reforms and the creation of state health insurance Exchanges, to coordinated care pilot programs and Medicaid expansion to cover more individuals and families, the array of health policy issues to be implemented is both exciting and overwhelming. But it is also a great opportunity. Health care consumers have so much to gain if implementation efforts are done right. The ACA also sets out to significantly change the ways we deliver care to patients. With all of this before us, truly patient-centered care can be achieved if consumer representatives are visibly, boldly, and permanently part of the next frontier of health policy change.

State-based consumer advocates now more than ever need to look around them and consider what they can do with an organized, coordinated, expert group of allies around them to boost the consumer voice within the intensifying number of health policy debates.

¹ Community Catalyst. *Consumer Health Advocacy: a View from 16 States*. October 2006.

² D. Strong, D. Lipson, T. Honeycutt, and J. Kim. *Foundation's Consumer Advocacy Health Reform Initiative Strengthened Groups' Effectiveness*. *Health Affairs*, 30, No. 9 (2011): 1799-1803.

³ *ibid.*