Advancing Health Reform by Inclusion:
Engaging Communities of Color in Creating Policy Change

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Acknowledgements

This report was written by Aurelia De La Rosa Aceves, National Urban Fellow, Class of 2012. The National Urban Fellows Organization was founded in 1969 to counter the under-representation of people of color in public sector leadership positions. Today National Urban Fellows and its Public Service Leadership Diversity Initiative are preparing leaders of color for public service leadership positions. Through a mentorship program, where Community Catalyst serves as a mentor organization, National Urban Fellows develops accomplished professionals of all ethnic and racial backgrounds, particularly people of color and women, to be leaders and change agents in the public and non-profit sectors, with a strong commitment to social justice and equity.

As part of Ms. Aceves' fellowship this assessment and report was created to help consumer health advocates, national health advocacy organizations and funders have a better understanding of the strategies used to engage communities of color in creating policy change to advance health reform. This fellowship placement at Community Catalyst would not have been possible without the generous support of the Robert Wood Johnson Foundation.

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Executive Summary

Building a stronger consumer voice in the U.S. health care system is central to the mission of Community Catalyst, a national consumer health advocacy non-profit headquartered in Boston that provides technical assistance to state consumer health advocacy organizations across the country. Since the passage of the Patient Protection and Affordable Care Act (ACA), one of Community Catalyst's critical roles in this effort is identifying and supporting ways that state consumer health advocates can engage the communities most affected in implementing the law.

In 2014, ACA implementation will expand health care access and coverage to millions of people of color[1]. According to a 2011 report by the Healthcare Cost and Utilization Project, communities of color comprise "about one-third of the U.S. population and more than half of the people who are uninsured."[2] The ACA's provisions will directly impact these currently uninsured communities of color by providing them with unprecedented opportunities to access and gain quality, affordable health care coverage.

Since the best change occurs when the communities most affected are involved, this report identifies emerging and effective practices state consumer health advocacy and community-based organizations use to engage communities of color to advance the ACA. The strategies emerged through trial-and-error by advocates across the country, and using these strategies may help organizations begin or improve their own work to engage communities of color in ACA policy implementation. These strategies demonstrate how advocates have been resourceful and created ways to overcome the financial barriers and staff constraints challenging their efforts. However, the demand for this work is increasing at a pace that resourcefulness cannot fully address without fiscal support.

This report used a mixed-methods approach including document review, group conference calls, and one-on-one interviews with leaders from community-based organizations, regional organizations and state consumer health advocacy organizations from the five selected states of focus: Alabama, Michigan, Minnesota, New York and Oregon. In addition, the advocates interviewed came from organizations that are grantees, sub-grantees or coalition members of The Robert Wood Johnson Foundation's Consumer Voices for Coverage 3 Program , a joint initiative with Community Catalyst, and/or Community Catalyst's ACA Implementation Fund, which is a collaboration of a number of foundations including The Atlantic Philanthropies, The California Endowment, The Nathan Cummings Foundation, Ford Foundation, The Jacob and Valeria Langeloth Foundation, and The Rockefeller Foundation

The report found that state and community-based advocates employ the following integrated strategies in this work:

- Build a strong coalition of state consumer health advocacy organizations and community-based organizations
- Tailor ACA education efforts to specific communities of color
- Educate communities of color about the legislative and regulatory processes and demystify these processes
- Organize and conduct meetings in communities of color

When the advocates described these strategies, they described how lack of dedicated staffing and financial resources often constrain their efforts. They also highlighted the critical role of community-based organizations in this work. Many of the efforts made by state advocacy organizations to engage communities of color relied heavily on community-based organizations, but community-based organizations were typically even more understaffed and fiscally under resourced than the state advocacy organizations. State advocates are aware of the challenges community-based organizations face and tried to help the community-based organizations by providing mini-grants to them. Though community-based organizations and state advocates recognized the mini-grants were never enough, it was the most state advocates felt they could do given their own organization's fiscal resources.

For this reason making wise decisions about how to fund this work is critical, and this report makes recommendations to further explore how this can be done effectively. Funders should provide dedicated funding for the purpose of strengthening the voice and capacities of communities of color in implementing the ACA if the ACA is to fulfill its unprecedented promise of promoting racial and ethnic health equity. In addition, the grants should be structured to support the effective practices presented in this report. Community-based organizations, state consumer health advocacy organizations and national organizations all need additional resources to build a network dedicated and able to engage communities of color in ACA policy implementation. There is a specific role for each type of organization to assume in the work, and they will be able to meet the demands of their roles most effectively when resources are there to support their activities to engage communities of color in ACA policy implementation.

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Introduction

Building a stronger consumer voice in the U.S. health care system is central to the mission of Community Catalyst, a national consumer health advocacy non-profit headquartered in Boston that provides technical assistance to state consumer health advocacy organizations across the country. Since the passage of the Affordable Care Act (ACA), one of Community Catalyst's critical roles in this effort is identifying and supporting ways state consumer health advocates can engage the communities most affected in the implementation of the law.

In 2014, implementation of the ACA will expand health care access and coverage to millions of people of color[3]. According to a 2011 report by the Healthcare Cost and Utilization Project, communities of color comprise "about one-third of the U.S. population and more than half of the people who are uninsured."[4] The ACA's provisions will directly impact these currently uninsured communities of color by providing them with unprecedented opportunities to access and gain quality health care coverage.

The following ACA provisions will improve health care access and coverage to uninsured communities of color[5]:

- Expansion of Medicaid eligibility
- Small business (fewer than 25 employees) tax credits
- Expansion of community health centers
- Support for school-based health centers
- The Prevention and Public Health Fund (PPH Fund)
- New community benefits requirements for tax-exempt hospitals
- Increased public health workforce, more primary care providers who accept Medicaid
- Expansion and diversification of the health workforce
- Subsidies for private insurance
- Expansion of National Health Service Corp

The following ACA provisions will improve the quality of health care services provided to insured communities of color[6]:

- Enhanced data collection and reporting requirements
- Cultural Competence Trainings for health care providers and public health workforce
- National Quality Strategy
- Medicaid Quality Standards
- Exchange Standards

The Joint Center for Political and Economic Studies describes the ACA as "the most significant opportunity in at least a generation to reduce disparities in health and health care and improve health equity."[7] Since the best change occurs when the communities most affected are involved,it is imperative that communities of color engage in health advocacy and policy work. The organization's programs reflect this belief. The Robert Wood Johnson Foundation's third iteration of the Consumer Voices for Coverage (CVC3) program, an initiative managed by Community Catalyst, requires state health advocacy organizations participating in the program to engage communities of color in ACA implementation advocacy and policy work. In addition, Community

Catalyst's Affordable Care Act Implementation Fund (ACA Fund) requires its state consumer health advocacy organization grant recipients to engage communities of color in their advocacy and policy work during implementation.

While it is one thing to require that state advocates engage communities of color in their ACA implementation work, it is quite another to figure out *how* state advocates can engage communities of color effectively and support that work. This report aims to address the *how*, by identifying best practices of how to engage communities of color in creating policy change to advance the ACA, and how funders can increase support for engaging communities of color in creating policy change. In addition, it will identify how Community Catalyst can support its state advocates in this work.

This report builds on two assessments. The first, called *A Path Toward Health Equity: Strategies to Strengthen Community Advocacy,* was published by Community Catalyst in July 2010 and focused on community-based and state consumer health advocacy groups working to reduce health disparities in six states: California, Massachusetts, Michigan, Mississippi, New Mexico, and Ohio. The key findings of this report were "most community-based organizations are struggling in isolation from each other, removed from the policy arena" and there is a "widespread interest in building a stronger health equity movement, with larger focus on policy advocacy." The report also found that funders can play a significant role in this work by supporting long-term health equity projects and capacity building of community groups. The second assessment titled *California: Getting to a Healthy State* (unpublished) delves deeper into the opportunities provided by full ACA implementation for communities of color by studying the diverse health advocacy community of California, "one of the most racially and ethnically diverse places in the nation."[8] This assessment of California, a "majority of color" state,[9] is important given the U.S. Census Bureau's projection that our nation will be "majority of color" by 2042.

In addition to the two Community Catalyst assessments, this report draws on a report produced for the Robert Wood Johnson Foundation by Class of 2011 National Urban Fellow Dante T. Mckay. His report highlighted the growing need to engage communities of color in advocacy regarding health care reform, the role of consumer health advocacy in health care reform, and the role of foundations in engaging communities of color in health advocacy. However, this report specifically focuses on engaging communities of color in creating *policy* change to advance the ACA.

What does it mean for communities of color to "engage" in creating policy change to advance the ACA? Community Catalyst defines this type of engagement as participation beyond grassroots organizing and outreach to having a more active role in the process of policy implementation such as helping to shape cultural competence standards for Medicaid and Exchange health plans (plans that will be sold in a state's health insurance marketplace), designing outreach and consumer assistance strategies, working with hospitals to develop and implement hospital community health needs assessments.. The type of "engagement" sought in this report describes how communities of color can help shape the policy agenda of their respective state by having a seat and equal voice at the policy-making table.

Guiding Research Questions

The overarching question of this assessment is: How can communities of color be engaged in creating policy change to advance the ACA?

With an understanding that 1) Community Catalyst primarily works with state-based consumer health advocacy organizations, and 2) community-based organizations typically have the most direct relationship with communities of color, the specific sub-questions are as follows:

- What specific tools and resources do community-based organizations need to interface effectively with state consumer health advocacy organizations?
- What specific tools and resources do state consumer health advocacy organizations need to support and work effectively with community-based organizations addressing health equity issues?
- What specific tools and resources do community-based organizations need to have a seat and equal voice at their state's policy-making table? How can state consumer health advocacy organizations support them?
- What is Community Catalyst's role in giving voice to community-based organizations in ACA advocacy and policy work?

Methodology

This assessment used a mixed-methods approach including document review, group conference calls, and one-on-one interviews with leaders from community-based organizations, regional organizations, and CVC3 and ACA Implementation Fund grantees at state consumer health advocacy organizations.

The initial conference call to discuss the current state-level efforts made to engage communities of color in creating policy change to advance the ACA was held on Wednesday, December 7, 2011 and included fifteen state consumer health advocates from the following nine states: California, Colorado, Illinois, Michigan, Minnesota, New York, Ohio, Oregon, and Washington. After the call, state consumer health advocates were asked to provide contact information for the community-based organizations (CBOs) they partner with to engage communities of color in this conversation. CBO contacts were sent an invitation to join a conference call to discuss engaging communities of color in ACA implementation policy work.

CBO contacts from Michigan, Oregon, Washington, Minnesota and New York participated in the conference call held on Thursday, February 16, 2012.

Next, the following criteria were developed to choose the five states of focus for this report:

<u>Individual state criteria:</u>

1. Must be a CVC3 or ACA Fund grantee
2. State advocates and/or CBOs must be using strategies to engage communities of color in their ACA implementation work

3. State must have participated in Community Catalyst's health equity calls, (i.e., the two conference calls that are part of this project or the health equity conference call series hosted by Community Catalyst over the course of the past year)

<u>As a group criteria:</u>

- Political diversity among all five states of focus:
  1. States that are Pro-ACA
  2. Anti-ACA but pushing forward with reform
  3. Anti-ACA and not doing anything to push forward with reform
- Geographic diversity among the five states
- Broad diversity across communities of color in terms of race and ethnicity represented across the five states selected

Based on the criteria, Alabama, Michigan, Minnesota, New York and Oregon were selected as the report's five states of focus.

Two interview protocols were developed in March 2012 to facilitate one-on-one interviews with staff of state consumer health advocacy and community-based organizations. One-on-one interviews were conducted with staff from the community-based organizations and state consumer health advocacy organizations in the five states of focus. Interviewees were selected based on participation in the two conference calls held in December and February, a referral from the participants on the previous two conference calls, and/or a direct recommendation from field staff at Community Catalyst.

Seventeen interviews were conducted with state consumer health advocates (10) and community-based organization advocates (7) across the five states of focus. This report presents findings from these conference calls and one-on-one interviews. It is clear that this sample of advocates is small and cannot fully describe all efforts to engage communities of color. However, it is relevant to draw findings and recommendations from these advocates' experiences because they provide a real perspective on this work for state and community-based advocates currently engaging communities of color in ACA policy implementation. Though their experiences will not be the experience of every organization, they offer lessons and experience to other community-based and state advocacy organizations, national consumer health organizations, and funders as well.

With that said, the limitations of this study include:

- A narrow sample of advocates, identified by Community Catalyst staff and/or its state advocacy partners, was invited to share their current strategies to engage communities of color.
- One person conducted all the interviews with state and community-based advocates over the course of two months, so the interview schedule was determined by the interviewer rather than the interviewees' schedules. Therefore, the perspectives presented in this report reflect the advocates who were able to meet the interviewer's availability.
- All conference calls and interviews were advertised and conducted in English. This directly limited the community-based organizations that the assessment was able to include in the one-on-one interviews, because some CBO staff members only speak the language of the communities they serve.

Report Findings

Current strategies used by state consumer health advocacy organizations and community-based organizations to effectively engage communities of color in ACA implementation policy work as well as barriers to conducting this work were identified. Not all advocates we spoke with use every strategy presented here, but they employ at least one strategy in their current efforts to engage communities of color in ACA policy implementation.

Strategies to Engage Communities of Color

- **Build a Strong Coalition Of State Consumer Health Advocacy Organizations and Community-Based Organizations**

  A strong coalition of state consumer health advocacy organizations and community-based organizations consist of a group of organizations that possess a shared policy agenda and have the complementary capacities to move the policy agenda forward in their state. Building a strong coalition will not happen overnight. It is a strategic process that goes beyond counting how many member organizations you can assemble. The coalition's strength lies in the complementary capacities and external relationships of coalition members and their ability to work together to move forward shared policy goals.

  In Community Catalyst's work, the coalition is typically led by a state consumer health advocacy organization. State organizations that have successfully developed a shared policy agenda with their coalition have taken the following action steps in developing the agenda:

  1. Invited current and/or potential coalition member organizations to an initial planning meeting.
  2. Facilitated a focused health issue discussion to define health policy priorities important across the groups and organizations.
  3. Used the defined health policy priorities to create a shared policy agenda that encourages future collaboration among the groups and organizations.

  In the context of this report, the shared policy agenda is reducing health disparities and advancing health equity. The key strategy the coalition uses to achieve this agenda is engaging communities of color in ACA policy implementation.

  Creating a coalition that has direct access to both communities of color and policymakers and/or individuals who influence policymakers is a critical component of moving forward the coalition's policy agenda and engaging communities of color in ACA policy implementation. An effective strategy to achieve this type of coalition is engaging and maintaining members from both state consumer health advocacy and community-based organizations for the following two reasons:

  - Community-based organizations have direct, strong and trusted relationships with communities of color and possess intimate knowledge of these communities.
  - State consumer health advocacy organizations typically have direct relationships with state legislators, legislative staff and public officials and possess knowledge of the legislative processes, ACA policy, and the ACA's implementation timeline. (It is

important to note that state advocates said they relied on national advocacy organizations for most of their policy knowledge about the ACA.)

To solidify these roles in the coalition, some state advocates said they had frank conversations with community-based organizations that highlighted the CBOs talents and potential contributions to this work as the direct line of contact with communities of color. Also, the state advocates demonstrated how their organization would complement the CBOs current capacities by offering resources like policy analysis and direct relationships with legislators. This helped them to create mutually-beneficial partnerships where both parties felt valued and knew how to work with one another because each organization understood its role.

When state consumer health advocacy and community-based organizations are under-resourced fiscally and in staff time, their coalition membership should not be more burdensome than attempting this work alone. For this reason, advocates insist that no one organization should be solely responsible for fulfilling a particular role within the coalition. For example, if there were one state organization and twenty community-based organizations working together in a coalition, then all the policy work would likely fall on the shoulders of the state organization. Under these circumstances, coalition membership exhausts the state organization because it would create a workload disproportionate to the organization's capacity.

In another example, it would also be problematic if there were ten consumer health advocacy organizations in the state that wanted to engage the Latino community and only one CBO that served and/or represented the Latino community in a coalition. The CBO would be called upon too frequently and its efforts would be spread too thin. Two of the main factors contributing to this type of environment within a coalition where organization membership tends to overburden state and community-based organizations are 1) a lack of diversity among state consumer health advocacy organization staff, and 2) the gap between state consumer health advocacy and community-based organizations in knowledge, skills, and fiscal power.

State consumer health advocacy organizations are predominately white, which causes these organizations to rely heavily on community-based organizations to carry out much of the work to engage communities of color without providing adequate fiscal support. Many of the state advocates are well-aware that the funds they provide to community-based organizations are not enough, but it's the best the state advocates can do given their own fiscal circumstances. And though the fiscal support may be inadequate, community-based organizations typically are not in a position to turn down funds. This ultimately places community-based organizations in the position to accept a workload they do not have the capacity to fulfill.

- **Tailor ACA Education Efforts to Specific Communities Of Color**

Community-based advocates report that communities of color learn best and want to engage the most in ACA implementation when they receive educational materials and presentations tailored to their specific sub-community within communities of color. For this reason, advocates advise:

1. Breaking down communities of color by geography, sex, age, services needed, etc. whenever possible and appropriate.
2. Identifying the health issues or concerns of specific sub-communities and using them as an entry point into a discussion about the ACA with various communities of color.

Community-based advocates recommend identifying the issue(s) a specific community cares about, avoiding policy jargon, and explaining how a part of the ACA will directly impact the audience's community. It is critical to only explain the part(s) of the ACA that will directly impact the specific community of color's health concerns. Additional information is unnecessary, and may actually prove detrimental to educational efforts, as state advocates have learned through trial-and-error. When some state advocates were working independently from CBOs, they gave presentations to communities of color that included everything the advocates thought was great about the ACA and their audience shut down. Most communities of color have little policy knowledge, so describing an entire law and its provisions is an ineffective approach because the excess information generally overwhelms an audience of individuals of color. For that matter, this approach would overwhelm any audience regardless of their race, ethnicity, class or educational status because the information is not tailored to the audience's specific circumstances. The information is not meaningful unless the audience members can understand how the law will directly impact their lives.

This is why tailoring information about the ACA to communities of color is so important; it helps advocates to clearly communicate the benefits of the ACA and for communities of color to understand what they stand to gain in ACA implementation.

For example, when community-based advocates in New York City speak to a group of low-income, African American mothers they employ the following strategy:

- Begin describing disparities in mother and infant mortality rates—an issue they know this specific community already cares about.
- Use simple statistics to illustrate mother and infant mortality rates relevant to African American women and their children.
- Describe disparities in prenatal care that influence the disproportionate rates of mother and infant mortality.
- Explain how the State Health Insurance Exchange established by the ACA would expand preventive services and prenatal care to address these disparities.

Also, these same community-based advocates in New York City explained how educational materials, i.e. handouts, fact sheets and brochures, must be tailored to specific communities of color as well. Translated materials are necessary, but materials also must be culturally-competent and speak to the issues communities of color care about and struggle with daily. The entry point into a conversation about the ACA with communities of color does not always need to be health-related. For example, advocates in Minnesota structured a conversation about the ACA around employment opportunities when speaking to a community experiencing high unemployment rates. They explained how the ACA would help diversify the workforce as a result of new cultural competency standards that create a demand for culturally competent employees of color. This reinforces why intimate

knowledge of a community plays such a critical role in the development of effective ACA educational efforts.

Finally, state and community-based advocates have found that presentations about the ACA are well received by communities of color when presenters are the same race and age as their audience. These connections with the presenter encourage the audience to trust the information provided, because as one advocate explains "nothing is more off-putting to these communities than folks who don't look like them com[ing] in to lecture them."

Another advocate advises "get someone on your team that speaks the language [of your different audiences], because when you go to various communities with information that is not printed and presented in their language you've already lost."

- **Educate Communities of Color about the Legislative Process and Demystify Their State Legislature**

  Many state and community-based advocates describe how communities of color feel unprepared and/or unwelcome to speak to their state legislators, which are significant barriers to communities of color engaging in ACA policy implementation work. In some states these feelings were heightened among the Latino community as a result of language differences and their state's proposed or passed hostile immigration policies.

  One strategy that helps address this issue is the Leadership Training Institute (LTI) model. The LTI model entails a curriculum designed by state and community-based advocates, jointly and/or individually, to educate communities of color about the legislative process by explaining:

  1. The legislative calendar
  2. Composition of the legislature in terms of party and what that means as it relates to the ACA
  3. How many legislators are individuals of color
  4. The members of the legislature who represent where they live
  5. The roles and responsibilities of the legislative members

  Second, the LTI prepares participants to meet with their state legislators by teaching them:

  - Dress code for meeting with legislators
  - How to greet a legislator
  - Identifying the issues to speak about during a short meeting with a legislator

  The duration of the LTI varies according to a state and/or community-based organizations' resources in terms of finances and staff time. The duration of the institute and on what day and time institute sessions are held rests heavily on the availability of the participants. For this reason, there is no example of a standard LTI; it is flexible to its participants' schedules and existing knowledge of legislative processes. The information presented during an LTI should be tailored to the participants attending the sessions.

Advocacy 101 days have also been an effective strategy where members from communities of color and/or individuals who have gone through an LTI are brought to the state capitol to tour the capitol building, meet with legislators, and attend and sometimes testify at hearings. This event relies on state advocates for their relationships with state legislators and state capitol staff, and the advocates' ability to get state legislators to agree to an Advocacy 101 day. Advocates in Alabama advise organizing transportation to and from the state capitol, because many individuals of color face transportation constraints. This is an additional cost of organizing Advocacy 101 days, especially if an organization decides to rent a bus. However, state advocates have found it possible to rely on coalition members' access to vehicles to provide a low-cost alternative to renting a bus; they choose to reimburse for mileage.

Another strategy to create opportunities for communities of color to weigh in with their legislative members entails having them submit postcards or letters to legislative members. This strategy is relatively inexpensive; the costs include postcard printing or purchasing, postage, and staff time. Some community-based organizations keep postcards addressed to state legislators in their offices and encourage individuals who use their services to fill out a postcard. They may give the individual talking points to use in the postcard, or provide a postcard that already has a message and just requires an individual to sign their name. The postcards can be multi-purpose:

1. Thank a legislator for a particular action they took
2. Encourage a legislator to take a certain action
3. Express disapproval for a legislator's particular action.

The key is to encourage individuals from communities of color to weigh in with their legislators as often as possible, so they become comfortable and confident in voicing their opinion to them over time.

- **Organize and Conduct Meetings in Communities of Color**

Educating communities of color about the ACA and/or their state legislature requires that state and community-based advocates organize and conduct meetings and trainings on these topics. Advocates recommend that these meetings take place within communities of color to encourage:

a. Attendance
b. Local ownership
c. Future local action after the meeting

Communities of color might face transportation and time constraints as a result of working and caring for a family, so advocates have found it helpful to provide a meal and childcare at the meetings.

Advocates recommend two effective ways to advertise these types of educational events:

- **Use church bulletins.** Some churches have a health ministry group that has a section of the church bulletin, and state advocates recommend asking the health ministry group to advertise the educational event in the health ministry section. This is an

effective strategy because many people of color read their church bulletins and trust the information provided by their churches.

- **Go door-to-door to identify informal community leaders.** Community-based advocates recommend walking their communities and asking residents to whom they go for health advice in their neighborhood. This is a great way to identify informal community leaders who have the power to turn out people for a meeting within their community to discuss health. These informal community leaders have hosted meetings at their homes during which community-based advocates were able to make presentations about the ACA and discuss the health issues challenging the community. The staff members who walk the neighborhoods should reflect the demographic of the neighborhood, and ideally advocates would like the staff to be from the neighborhood.

During an ACA education meeting, a focused discussion of the health issues challenging the community should be facilitated to identify the health policy priorities of the community. Once these are identified, a presentation laying out how the ACA can move the community's health policy priorities forward should ensue. The presentations do not need to use a PowerPoint slideshow, but they must employ the strategies discussed in the previous sections to be effective, i.e. tailored information and a presenter who reflects the audience's demographic.

Lastly, the meeting participants must develop next steps to advance their health policy priorities. These next steps have included establishing a neighborhood group to meet monthly and coordinate educational campaigns in their community regarding health issues, organizing an effort to register their neighbors to vote, and signing up individuals who attended the meeting to volunteer with the community-based organization and support its work. Identifying next steps is absolutely critical to encourage local ownership of their community's issues and local action to address them.

Barriers to this Work

- **Limited Staff Capacity to Do This Work**

All of the above strategies require staff time, and this is a particular challenge when state consumer health advocacy and community-based organizations run very lean staffs. It is rare for either state or community-based organizations to dedicate staff members full-time to engaging communities of color in their ACA policy implementation work. Some staff members are hired part-time to do this work, but usually have a full-time staff equivalent workload. These part-time staff members typically have an additional job to support themselves financially and most definitely run the risk of exhaustion on a regular basis. Though this situation was described by both state and community-based advocates, it was more common among community-based advocates.

Other organizations depend completely on volunteers to spearhead their work. A statewide alliance in Minnesota does not have a budget to hire staff, and its few volunteer staff members all have full-time employment outside the alliance. And as mentioned previously, many of the state consumer health advocacy organizations' staff members are predominately

white. This poses a particular challenge when presentations and hardcopy resources need to be tailored to communities of color to do this work effectively, because it encourages the state advocates to rely on community-based organizations to do much of this work.

However, this is problematic when community-based organizations are even more understaffed than the state organizations. In addition, the staff of community-based organizations may not have a background in health policy work or fully comprehend the benefits of the ACA to adequately relay them to communities of color. These staffing constraints reinforce the value of building a strong coalition of state consumer health advocacy and community-based organizations that bring together complementary capacities to effectively do this work. However, even when the organizations come together they still remain understaffed as a whole to meet the increasing demands of this work.

- **Need for Dedicated Resources**

Like staff capacity, the current fiscal resources of state and community-based organizations engaged in this work are inadequate to meet the demands of their work. One advocate expressed her frustrations, **"**It [Engaging communities of color] may be a priority in conversations, but not [in] resourcing it." This sentiment resides commonly among community-based organization staff members who feel that they receive the short end of the stick even when they receive funds to support their work. One advocate describes the unrealistic expectations that accompanies funding, "People put a little pinch of resources behind it [health equity work] and say go transform your community—expecting these large results."

In many cases, funding for this work goes directly to state consumer health advocacy organizations, and some state organizations decide that they want to provide mini-grants to community-based organizations. These community-based organizations could be existing partners in the work, or they could be new partners who went through an application process to receive the mini-grant. A few of the community-based organization staff described how they thought this type of funding structure was inequitable, because the state advocacy organizations were absorbing a majority of the grant and the rest was sub-granted to community groups. State organizations respond that the grants they receive are not large enough to provide adequate fiscal support to both their own organization and partner organizations. They feel the constraints of having to make these decisions about the grant and acknowledge that at times the funds are not sufficient.

State consumer health advocacy and community-based organizations require dedicated financial resources to do this work well, i.e. hiring/paying full-time staff; creating and printing hard copy, tailored documents; arranging transportation for communities of color to attend meetings or visit the state capitol; hosting community convenings that provide a meal and childcare; and, traveling to various communities to provide leadership trainings and ACA educational presentations. Without the funds to meet the growing demand for this work, all the good intentions, motivation and strategies to do this work effectively can only go so far.

Recommendations

The strategies to engage communities of color in ACA policy implementation discussed in this report provide a snapshot of what is currently happening in five states Alabama, Michigan, Minnesota, New York and Oregon. The following recommendations come from the state and community-based advocates who participated in the assessment's two conference calls and in-depth individual interviews and from the themes the author of this report identified while listening to the experiences of those who do this work daily.

State Advocates

State advocates should use the strategies and information presented in this report to:

- Foster relationships with community-based organizations with an awareness of the challenges CBOs face in addition to the skills and capacities they can offer to do this work.
- Identify specific policy issues/opportunities that are a priority for communities of color and work with organizations of color to share responses to the policy issues in a way that is relevant to their interest. Have frank conversations with CBOs that highlight their talents and potential contributions to this work and also demonstrate how the state organization will complement their current capacities. This will help create mutually beneficial partnerships where both parties are valued and each organization's role is clearly communicated and understood.
- Identify funds for:

    1. Providing mini-grants to existing or new CBO partners in this work that combine fiscal support with realistic work expectations
    2. Hiring a full-time staff member dedicated to engaging communities of color in health policy

    Providing mini-grants to CBO partners will increase CBO capacity to devote funds to engaging communities of color in ACA policy implementation, however, this is short-term and immediate support that does not allow CBOs to build the capacity of their organization long-term to do this work. The immediate fiscal support must be accompanied by realistic work expectations, because a disproportionate amount of work relative to fiscal support given to CBOs was the main reason CBOs expressed dissatisfaction with the mini-granting process. To the latter point, hiring a full-time staff member dedicated to this work would help in a few ways:

    - It identifies a full-time point person to coordinate activities with CBOs to engage communities of color in ACA policy implementation.
    - It demonstrates the organization's commitment to this work.
    - It creates staff time solely dedicated to meaningfully engaging communities of color in health policy.

State and community-based advocates do not believe that a part-time staff member can effectively carry out the complex and multiple tasks required to achieve meaningful engagement by communities of color in ACA implementation, as noted in the three points above. Their organizations' willingness to hire a full-time staff member to do this work indicates a commitment and priority given to engaging these communities.

Community Based Organizations

The onus cannot only be on state advocates to engage communities of color in ACA implementation. Community-based organizations have a lot to contribute to policy implementation and this partnership can be strengthened by community based organizations working to:

- Foster relationships with state advocates with an awareness of the challenges faced by many state groups – small staffed, limited resources
- Work with state advocates to identify policy issues/opportunities that are important to communities of color.
- Support state advocacy organizations in the development of culturally appropriate materials and information for community members.
- Conduct frank conversations with state advocates about the CBOs capacity so that a realistic scope of work and deliverables may be identified
- Incorporate themselves in the grant process, by working with state advocacy organizations to ensure full engagement in the proposal writing process

National Advocacy Organizations

National organizations play a critical role in supporting state-based health advocates and their local community-based partners to engage communities of color in ACA policy implementation. National advocacy organizations should:

- Help facilitate meetings of state advocates and CBOs to start the process of building strong Coalitions between state groups and CBOs.
- Create ACA educational materials that state advocates can tailor to specific communities of color.
- Work with state groups to identify specific legislative or regulatory activities to engage CBOs and communities of color.
- Educate state advocates about how to do this work, and develop a learning community around the issue of health equity
- Hire a staff member dedicated to health equity work in the states who would serve as the point person for coordinating efforts to engage communities of color across the nation in ACA policy implementation
- Encourage funders to dedicate funds specifically to this work and adopt new funding approaches proposed in this report that reflect how this work is done effectively.

Since community-based organizations and state advocacy organizations rely so much on national groups for policy and coalition building experience, national consumer health advocacy organizations also should hire a staff member dedicated to health equity and engaging communities of color in ACA policy implementation for these reasons:

- It identifies a point person for state advocates working on the issue.
- It demonstrates the organization's commitment to this work.
- It creates staff time solely dedicated to health equity and meaningfully engaging communities of color.
- It sets a staffing example for state advocates to follow

Funders

Community-based organizations, state consumer health advocacy organizations, and national organizations all need additional fiscal resources to build a network dedicated and able to engage communities of color in ACA policy implementation. As we know, there is a specific role for each of these organizations to assume in this work, and they will be able to meet the demands of their roles most effectively when the fiscal resources are there to support their respective activities to engage communities of color in ACA policy implementation.

The advocates named limited staff time and fiscal resources as the two greatest barriers to their work. The two are intertwined because the underlying factor of constrained staff time is limited fiscal resources. Therefore recommending that state advocacy organizations hire a staff member dedicated to health equity and engaging communities of color in ACA policy implementation is a lofty request unless there is funder support.

If communities of color stand to benefit most from ACA policy implementation, then funders need to establish a fund solely dedicated to:

1. Building the network infrastructure of community-based organizations, state consumer health advocacy organizations, and national health advocacy organizations necessary to engage communities of color in ACA policy implementation
2. Supporting the work of this network to engage communities of color in ACA policy implementation using the strategies identified in this report. In addition, it is critical to have a funding structure that supports the effective practices to engage communities of color presented in this report.

For this reason, two new funding approaches are proposed. In the first approach, state consumer health advocacy organizations would be the recipients of grant awards, serve as the primary grant contact and be held responsible for the overall execution of the grant activities, but state advocates and their community-based organization partners would be required to work together to develop their grant. The proposal would need to provide a detailed explanation describing how they plan to engage communities of color and the roles and responsibilities of each organization. .

This funding approach would help in three ways:

- It would serve as a smooth transition from the current funding structure, because state advocacy organizations would maintain their leadership role in their fiscal relationship with CBOs.
- It would directly support the partnerships necessary to do this work calling on the skills, knowledge, expertise and relationships.
- It would address the CBOs' concern about sub-granting practices, because the application process would require CBOs be involved in formal discussions pertaining to the grant funds they would receive relative to the work expected of them.

The second, new funding approach proposes making grants to community-based organizations directly. In this scenario, CBOs would receive fiscal resources to hire staff and build a sustainable infrastructure to engage in ACA implementation at the state and local level as opposed to receiving funds to support for a sole project or one-time partnership bound by time with a state advocacy organization. Community-based organizations would serve as the primary grant contact and be held

responsible for all grant activities, and they would be encouraged to work in close partnership with state advocacy organizations or other community-based organizations to develop their proposal.

The grant applicants would need to provide a detailed explanation describing how their organizations plan to engage communities of color and the roles and responsibilities of each organization. Unlike the previously proposed new funding structure, this structure places fiscal power directly in the hands of CBOs that work most closely with communities of color and possess the intimate knowledge of communities of color that is absolutely critical to all efforts to engage communities of color in ACA policy implementation.

Both of the proposed funding models require further exploration to address potential challenges that a new model may create, however it is critical that we examine new ways of doing this work in order for communities of color to fully engage in ensuring the health and well- being of their own communities.

Conclusion

The U.S. population is growing more diverse and the number of individuals who are uninsured or underinsured disproportionately come from communities of color. There is an urgency to engage communities of color in ACA policy implementation, because these communities stand to lose and gain the most during implementation. While the ACA affords many opportunities to advance health equity, it will have the greatest impact if the unique needs of communities of color are voiced, made a priority and used to shape ACA implementation.

The strategies provided here were identified through trial-and-error by advocates across the country. Using these strategies may help organizations begin or improve their own work to engage communities of color in ACA policy implementation.

The strategies presented in this report demonstrate how advocates have been resourceful and created ways to overcome some financial barriers and staff constraints, but the demand for this work is increasing at a pace that resourcefulness cannot fully address without fiscal support. Making wise decisions about how to fund this work is critical. First, strategies used to do this work effectively must be examined, as this report has begun to do. Second, a funding structure that supports these strategies must be developed. Without fiscal support, the efforts of national, state and community-based organizations to engage communities of color in ACA policy implementation are very limited despite the need for this work being so widespread and urgent.

Appendix

Interview Protocol—Regional and Local Community-Based Organization Staff

Date:

State:

Regional/local location within state:

Staff/ Organization:

State Political Response to ACA:

Major racial and ethnic groups in state:

The purpose of this interview is to identify best practices, opportunities, and challenges in the way that community-based consumer health advocacy organizations are engaging communities of color in the policy process of Affordable Care Act implementation within [state]. Themes from the interviews will be collected and shared in a written report. We will follow-up with you to request permission to use any direct quotes if needed.

I. **Priority Population**
   a. Can you identify the key organizations that represent the perspectives of communities of color in [state]?
   b. Which racial and ethnic groups does your organization engage in its ACA policy implementation work?

II. **State Political Climate**
   a. Briefly, can you describe [state's] political reaction to the ACA (Pro-ACA, Anti-ACA but pushing forward with reform, and/or Anti-ACA and not doing anything to push forward reform)?
      i. How has this influenced your organization's approach to its ACA policy work?
   b. Have the state-level policy discussions about ACA implementation in [state] included implications for communities of color? (If yes, how?) (If no, why not?)
      i. How has this impacted your organization's effort to engage communities of color in ACA policy implementation?

III. **Health Policy Priorities of Communities of Color**
   a. What is your understanding of the of the health policy priorities of communities of color in [state]?
   b. Which of these health policy priorities of communities of color does your organization work to address?
   c. How did your organization decide to address these specific health policy priorities of communities of color?

IV. **Relationship between State and Regional/community-based organizations**

a. Can you name the top 3 state consumer health advocacy organizations you partner with to engage communities of color in [state]'s ACA policy implementation and describe your relationship with each of them?
b. Can you describe the strengths/benefits of working with state consumer health advocacy organizations to engage communities of color in ACA policy implementation? Please be specific.
c. Can you describe the challenges of working with state consumer health advocacy organizations to engage communities of color in ACA policy implementation? Please be specific.

V. Strategies and Approaches to engage Communities of Color in creating policy change

a. When engaging communities of color in your work is it easier to engage them in one advocacy capacity (organizing, coalition building, policy) over another?
    i. Why do you think this is the case?
b. What are the particular tools and/or strategies your organization uses to engage communities of color in the health policy priorities you identified earlier? (The interviewer will have to probe to see if strategies are different from one issue to the next.)
c. What are the issues and/or messages that resonate with communities of color regarding these health policy issues?
    i. How did your organization identify these issues and/or messages?
d. Do people from communities of color come to your organization to ask questions about their health care—either regarding coverage or how to navigate the system?
        1. How often?
        2. Is your organization best positioned to answer their questions about health care (coverage or system navigation) and assist them?
            a. If not, who is?

VI. Outcomes so far

a. What have been the outcomes of your efforts to engage communities of color in [state's] ACA policy implementation? (i.e. the use of culturally competent navigators in the exchange)
b. Do you think these outcomes would have been accomplished without the engagement of COCs?

VII. Next Steps & Community Catalyst's Role

a. How do you plan to engage communities of color in [state's] ACA policy implementation in the next 6 months?
b. What specific resources and tools do you need to continue partnering effectively with state consumer health advocacy organizations in engaging communities of color in ACA policy implementation?
c. How do/will you measure the success of your efforts to engage communities of color in creating policy change to advance the ACA?
d. How can a national consumer health advocacy organization support your partnerships with state consumer health advocacy organizations in engaging communities of color in ACA policy implementation?

Is there anything you would like to add that we were unable to discuss today?
Thank you for your time.

Interview Protocol—State Advocacy Organization Staff

Date:

State:

Staff/ Organization:

State Political Response to ACA:

Major racial and ethnic groups in state:

The purpose of this interview is to identify best practices, opportunities, and challenges in the way that state consumer health advocacy organizations are engaging communities of color in the policy process of Affordable Care Act implementation within [state]. Themes from the interviews will be collected and shared in a written report. We will follow-up with you to request permission to use any direct quotes if needed.

I. **Priority Population**
   a. Can you identify the key organizations that represent the perspectives of communities of color in [state]?
   b. Which racial and ethnic groups does your organization engage in its ACA policy implementation work?

II. **State Political Climate**
   a. Briefly, can you describe your state's political reaction to the ACA (Pro-ACA, Anti-ACA but pushing forward with reform, and/or Anti-ACA and not doing anything to push forward reform)?
      i. How has this influenced your organization's approach to its ACA policy work?
   b. Have the state-level policy discussions about ACA implementation in [state] included implications for communities of color? (If yes, how?) (If no, why not?)
      i. How has this impacted your organization's effort to engage communities of color in ACA policy implementation?

III. **Health Policy Priorities of Communities of Color**
   a. What is your understanding of the of the health policy priorities of communities of color in [state]?
   b. Which of these health policy priorities of communities of color does your organization work to address?
   c. How did your organization decide to address these specific health policy priorities of communities of color?
   d. When your organization addresses these health policy priorities of communities of color, is the work framed as policy work important to a demographic or important to your organization's existing policy activities?

IV. Relationship between State and Regional/Local community-based organizations

a. Can you name the top 3 regional and community-based organizations you partner with to engage communities of color in [state's] ACA policy implementation and describe your relationship with each of them?
b. Can you describe the strengths/benefits of working with these regional and/or community-based organizations to engage communities of color in ACA policy implementation? Please be specific.
c. Can you describe the challenges of working with these regional and/or community-based organizations to engage communities of color? Please be specific.

V. Strategies and Approaches to engage Communities of Color in creating policy change

a. When engaging communities of color in your work is it easier to engage them in one advocacy capacity (organizing, coalition building, policy) over another?
    i. Why do you think this is the case?
b. What are the particular tools and/or strategies your organization uses to engage communities of color in the health policy priorities you identified earlier? (The interviewer will have to probe to see if strategies are different from one issue to the next.)
c. What are the issues and/or messages that resonate with communities of color regarding these health policy issues?
    i. How did your organization identify these issues and/or messages?
d. Aside from your work, are there other efforts to engage Communities of Color on these issues in local communities?
    i. Who is spearheading those efforts?

VI. Outcomes so far

a. What have been the outcomes of your efforts to engage communities of color in [state's] ACA policy implementation? (i.e. the use of culturally competent navigators in the exchange)
b. Do you think these outcomes would have been accomplished without the engagement of COCs?

VII. Next Steps & Community Catalyst's Role

a. How do you plan to engage communities of color in [state's] ACA policy implementation in the next 6 months?
b. What specific resources and tools do you need to continue supporting and partnering effectively with regional and local community-based organizations in engaging communities of color in ACA policy implementation?
c. How do/will you measure the success of your efforts to engage communities of color in creating policy change to advance the ACA?
d. How can a national consumer health advocacy organization support your partnerships with community-based organizations to engage communities of color in ACA policy implementation?

Is there anything you would like to add that we were unable to discuss today?
Thank you for your time.

End Notes

[1] Community Catalyst. 2010. *A Path Toward Health Equity: Strategies to Strengthen Community Advocacy.* http://www.communitycatalyst.org/doc_store/publications/A_Path_Toward_Health_Equity_July_2010.pdf

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[3] Community Catalyst. 2010. *A Path Toward Health Equity: Strategies to Strengthen Community Advocacy.* http://www.communitycatalyst.org/doc_store/publications/A_Path_Toward_Health_Equity_July_2010.pdf

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[5] Community Catalyst. 2011. *California: Getting to a Healthy State, p. 5-6.* (unpublished)

[6] Community Catalyst. 2011. *California: Getting to a Healthy State, p. 5.* (unpublished)

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[8] Community Catalyst. 2011. *California: Getting to a Healthy State, p. 2.* (unpublished)

[9] Community Catalyst. 2011. *California: Getting to a Healthy State, p. 2.* (unpublished)

